The Development and Feasibility of a Novel Breast Cancer Awareness Intervention for Young Women with Neurofibromatosis Type 1, and their Associates.

C.M. Plunkett

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The Development and Feasibility of a Novel Breast Cancer Awareness Intervention for Young Women with Neurofibromatosis Type 1, and their Associates.

Caitríona Muireann Plunkett

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Abstract

This research presents the development and feasibility of a novel breast cancer awareness (BCA) intervention for young women with neurofibromatosis type 1 (NF1) and their associates. Given the increased risk of breast cancer in this cohort, the study provides a preliminary evaluation of BCA including symptom, screening eligibility, breast checking frequency and risk knowledge, and medical consultation promptness. Patient and Public involvement was integral to intervention development and included the supervisory team, and the Childhood Tumour Trust charity, with online Padlet contributions garnering further insights from young women with NF1 (N = 2), associates (N ≈ 13), and healthcare professionals (N = 5).

Systematic review: With the absence of NF1-specific interventions, BCA intervention efficacy was assessed among young women aged 18–50 years. Five studies met inclusion criteria highlighting the effectiveness of BCA interventions. However, measurement tools inconsistencies, and a lack of comprehensive application of behaviour change theory underscored the need for tailored systematic interventions and standardised measures.

Study 1: Pre-post questionnaires measured NF1 BCA changes following exposure to a novel NF1 BCA animation. Adapted from the Breast-CAM, the Breast-CAM-NF1 measured changes including NF1-specific risk and screening recommendations. Data from 24 participants (N=13 young women with NF1; N=11 associates) were analysed using Wilcoxon signed rank and McNemar's tests suggesting significant improvements of increased confidence in noticing a breast change (p = .020), a reduction in reasons for putting off going to a doctor (p = .036), and improved breast screening knowledge (p = .006).

Study 2: Reflexive thematic analysis (RTA) explored researcher positionality on data interpretation, providing transparency and credibility in qualitative findings. Three positionalities were established of a woman who has had breast cancer and realises BCA importance, an 'accidental' researcher having never previously considered this path, and as a mother.

Study 3: Feasibility was explored through interviews with young women with NF1 (N = 11) and associates (N = 8). RTA highlighted increased empowerment, persistent healthcare barriers, and the suitability of animation as a learning tool.

Preliminary evaluation tentatively indicates intervention feasibility. It is recommended that future research explores long-term efficacy with wider involvement including healthcare professionals for NF1 BCA knowledge acquisition. Consideration of more accessible participant information sheets or employing other formats such as video is also recommended. A high drop-out rate (65%) was noted at the point of providing these, with one possible explanation being the length (7-pages) which may negatively affect comprehension.

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Chapter One

An overview of the thesis

1.1 Background and motivation to the research decision

Neurofibromatosis type 1 (NF1) is a complex genetic disorder that affects 1 in 2,500 to 3,000 individuals worldwide (Cieza Rivera et al., 2024). Its manifestations include, but not exhaustively, neurological, cardiovascular, and musculoskeletal (Yap et al., 2014). Psychological and cognitive issues, including learning difficulties, are also prevalent (Vogel et al., 2017). It also predisposes individuals to both benign and malignant type tumours (Tamura, 2021), with women with the condition found to have an increased risk of developing breast cancer at a younger age, compared to the general population (Maani et al., 2019). This association has only been established and accepted principally within the last fifteen years, with research specifically finding that those aged <50 years (Walker et al., 2006; Sharif et al., 2007; Evans et al., 2012; Madanikia et al., 2012; Da Silva et al., 2015; Seminog and Goldacre, 2015; Uusitalo et al., 2017; Maani et al., 2019; Evans et al., 2020) have an up to five-fold increased risk (Maani et al., 2019; Hovinga and Temel, 2020; Viskochil, 2021). Cases have been found to predominantly present in women with NF1 that are aged 34 to 44 years (Suarez-Kelly et al., 2019).

This thesis has been developed from previous research findings within my MSc Health Psychology where the beliefs, screening attitudes, and breast cancer awareness (BCA) of young women with NF1 were explored. Young women with NF1 aged 18-40 years were recruited through the Childhood Tumour Trust. This is a charity based in the United Kingdom that offers support to those diagnosed with NF1, and their families. This age group was specifically targeted as screening within this cohort is recommended from an earlier age of 40 years, and it was recognised that women with NF1 over the age of 40 years may already be attending screening and subsequently have increased BCA knowledge pertinent to their condition. This classification of ‘young women with NF1’ as aged 18-40 years as previously applied is retained within this thesis. Semi-structured interviews, with questions based on the health belief model (Rosenstock, 1974) explored the research aim. Findings highlighted a lack of awareness surrounding the associated breast cancer risk, with participants communicating a lack of awareness about the condition amongst attended healthcare professionals (HPs). Subthemes communicated the impacts of this information deficit including a battle to be taken seriously with perceived challenging attitudes among HPs, and information barriers to be breast cancer aware with NF1 due to a confusion surrounding screening age eligibility and the associated statistical breast cancer risk. Clinical recommendations included establishing accurate and accessible NF1 BCA information, the implementation of a BCA intervention for young women with NF1, and an NF1 BCA intervention for HPs. This PhD, sponsored by the Childhood Tumour Trust, began with the intention of directly acting on these recommendations. However, due to the difficulty in gaining involvement from HPs early in the research, only the first two recommendations were actioned. The effects of the COVID-19 pandemic continued to be experienced in 2021 when the research began, with HPs experiencing stress, increased workload, mental health issues, and general embargos on partaking in research projects making it difficult to recruit these individuals (Bratan et al., 2021). However, HPs have not been entirely omitted from this research. As demonstrated within future chapters, they have helped shape the design of the NF1 BCA intervention within PPI.

Considering involvement, it is important to be transparent of my position within this research. I am a woman who has had breast cancer, having gone through treatment for an aggressive grade 3 breast cancer subtype. Despite cancer being staged as early invasive ductal carcinoma due to being breast cancer aware, a considerable amount of dose-dense chemotherapy was required with a mastectomy. I had a pathological complete response, whereby no evidence of disease remains after completion of neoadjuvant chemotherapy (Sasanpour et al., 2018). Awareness is important. To be blunt, it saved my life and allows me to continue to be here as a mum, a wife, a friend, and a researcher. My motivation for this research was to raise BCA particularly in cohorts that may not have this awareness such as young women with NF1 and their associates.

The following sections (1.2 and 1.3) consider the necessity of a novel NF1 BCA intervention before communicating the research aim (1.4). The latter part of this chapter will provide a succinct overview of the objectives of the remaining chapters.

1.2 Considering the necessity of a novel NF1 breast cancer awareness intervention

For women with NF1 within the United Kingdom (UK) and the Republic of Ireland (ROI), the National Institute for Health and Care Excellence's guidance (NICE; 2023) is followed, placing women with NF1 at moderate cancer risk, with earlier annual mammograms from

40 years of age recommended. The MSc findings highlighted that information pertaining to risk and screening were not widely known by the women interviewed, or by HPs as communicated by these participants. This aligns with previous research, reporting a lack of knowledge amongst those with NF1 about the association of NF1 and increased risks including breast cancer (Oates et al., 2013; Bicudo et al., 2016; Karwacki, 2020).

The lack of earlier screening awareness is a notable finding as the aim of breast screening is to decrease mortality rates caused by cancers, by detecting any potential changes that may be of concern (Kolak et al., 2017). From a geographical perspective, both the ROI and UK present within the top ten of European cancer incidence rates and cancer mortality rates (Global Cancer Observatory, 2020a). For breast cancer (females), the UK and ROI rank highly in incidence and mortality rates among their European counterparts, with ROI ranking as 7th and the UK ranking as 10th (Global Cancer Observatory, 2020b). Breast cancer is the most common type of cancer among females, and a leading cause of death worldwide within this population (Global Cancer Observatory, 2020c; Global Cancer Observatory, 2020d). It is the most common type of cancer in the UK, and the second most common in Ireland (Global Cancer Observatory, 2020e; Global Cancer Observatory, 2020f). BCA symptom, and screening eligibility knowledge are particularly pertinent to young women with NF1, with breast cancer tumours within this cohort predominantly presenting as aggressive grade 3 types (Yap et al., 2018) often resulting in a diagnosis of a later staged cancer with increased tumour size compared to non-NF1 breast cancers (Uusitalo et al., 2017).

By increasing BCA, including self-efficacy to know what changes to be aware of and the increased risk, it may encourage earlier presentations, resulting in earlier diagnoses and treatment for an improved survival rate from breast cancer (Linsell et al., 2010; Ruddy et al., 2014; O’Mahony et al., 2017). Self-efficacy is defined as one’s perceived confidence in capability, or self-mastery to perform a specific behaviour (Bandura, 1977; Prestwich et al., 2018). In this regard, it is behaviours associated with BCA within an NF1 context. However, no participant interviewed within the MSc research was aware that the increased risk was up to five-fold. This thesis recognises that whilst increasing knowledge and having access to information aid in improving prevention and cancer awareness (Smith et al., 2013; Hovick et al., 2014), a dearth of considerations about information avoidance remains, acting as a barrier to these (Link and Baumann, 2022). The avoidance of cancer information is a purposeful decision, often involving a lack of desire or the experience of a fear to learn about information that is perceived as emotionally distressing, and threatening (Sweeny et al., 2010; van't Riet and Ruiter, 2013). A negative perception of cancer has been shown to have a damaging effect on screening attendance and subsequently the stage of which a cancer is diagnosed (O'Mahony, 2011). The research considers terror management theory (TMT; Greenberg et al., 1986) as constructive in providing an understanding of fatalistic behaviour, and how it might be mitigated for adaptive responses (Courtney and Goldenberg, 2021) among young women with NF1 towards BCA behaviours and attitudes.

Objectification theory (Fredrickson and Roberts, 1997) is also considered, recognising that women's bodies, compared to those of men's bodies, have a higher tendency to be viewed more on external appearance or as objects (including sexual objectification), or as a body rather than as a human being. This is often tied to the woman's physical form, presentational appeal, and body esteem (Courtney and Goldberg, 2021) which are important to consider within women's health and cancer awareness interventions due to their ability to both hinder and help positive health behaviours. From a TMT perspective, the physical body by virtue of its 'creatureliness' serves as a reminder of death's inevitability (Goldenberg et al., 2000; Courtney and Goldenberg, 2021). Performing breast self-examinations has been argued to make cognitions of death more accessible (Goldenberg et al., 2008) due to the direct placement of awareness by the woman on the physical form of their own breasts. However, self-objectification may be beneficial in creating better BCA amongst women (Courtney and Goldenberg, 2021). Considering TMT, self-objectification may reduce the perceived threat of mortality, as if a woman utilises this perception, it may also aid in distancing from the potentially threatening association of creatureliness and therefore death (Goldenberg and Roberts 2011; Morris et al., 2018), providing health-promoting responses including attending screening, checking their breasts with reduced fear, and increased BCA self-efficacy behaviours (Arndt and Goldenberg, 2017). This is particularly pertinent to women who are at an increased breast cancer risk, arguably including women with NF1, who often unknowingly engage in objectification detachment strategies to reduce this threat perception (Courtney and Goldenberg, 2021).

Health literacy is also considered, with low levels associated with poor health outcomes (Bergström et al., 2014) and a reduction in active decision-making and health self-management (World Health Organisation, 2013). Health materials are often poorly written, with research demonstrating that health information is difficult for the layperson to understand, and therefore can impede the ability to make appropriate health management decisions (Pretheroe et al., 2015; McClure et al., 2016; Tran et al., 2018). This research also acknowledges that learning difficulties and cognitive impairments are common manifestations of NF1 (Acosta et al., 2012; Lehtonen et al., 2015; Vogel et al., 2017), with these also negatively affecting levels of health literacy.

HPs can play an important part in promoting a health-literate environment (Marquez and Ladd, 2019). However, a lack of rare disease knowledge amongst HPs is cited as a major contributing factor to delays in diagnosis (Molster et al., 2016). Both patients and their associates (e.g., relative, friend, carer) frequently report having to explain their condition to HPs, with these individuals becoming the 'experts' (Nutt and Limb, 2011; Budych et al., 2012). The importance of a person-centred approach that respects the unique needs, experiences, and preferences of the individual (Moore et al., 2017; Eklund et al., 2019) is recognised, endorsing individual capability and capacity to be in control of their own health and well-being (Ekman et al., 2011). This empowerment may shift the traditional power dimensions between patient and practitioner to a relational and collective process (Zimmerman, 1995). It is also important to consider the role of the associate within this research to increase BCA of young women with NF1. With learning difficulties being prevalent within the NF1 population, some individuals may have levels that may make it difficult to learn about BCA (Vogel et al., 2017). Associates may therefore be required to deliver this information to young women with NF1 that may not be eligible to take part in this research due to higher levels of learning difficulties, or age, for example.

1.3 Research aim

By young women with NF1 presenting earlier with potential symptoms, it contributes to an earlier diagnosis which potentially improves survival rates from breast cancer (Linsell et al., 2010; Ruddy et al., 2014). However, to the best of the researcher's knowledge, no BCA intervention specific to NF1 in the UK and ROI has been developed and is therefore available. Much of the information available online has come from this research as communicated primarily by the Childhood Tumour Trust and shared by other NF1 charities. With no intervention, young women with NF1 may continue to experience fear, confusion, and a lack of self-efficacy in knowledge of symptoms, risk, and screening eligibility. This research therefore explores objectification, fear, and motivation within the intervention development and feasibility to improve accessibility and acceptability of BCA within this cohort. Communication pertaining to risk and screening must be accessible and aligned to a suitable literacy level to aid in reducing misinterpretation and enable individuals to be competent and autonomous in making informed decisions (Hersch et al., 2015). This also includes accessibility for associates, whereby they may be better placed to deliver the intervention information to a young woman with NF1.

Therefore, this research aims to explore the development and feasibility of a novel BCA intervention for young women with NF1 and their associates. The objective of the intervention is to increase BCA in young women with NF1 and their associates and encourage prompt medical consultation for a breast concern. This is addressed by asking the research question:

To what extent is a novel animation feasible for increasing NF1 specific breast cancer awareness in young women with NF1 and their associates?

1.4 Overview of chapter objectives

Chapter Two – A detailed review of BCA within an NF1 context is provided. Aspects concerning BCA and NF1 in general, but also wider affects such as HP knowledge and health literacy are explored. An explanation is undertaken for employing the term ‘women’ and excluding men and trans individuals from the research.

Chapter Three (Systematic Review) – No NF1 BCA interventions are available to examine their efficacy by systematic review to contribute to intervention design. Considering the increased risk of breast cancer among young women with NF1, a systematic review examining the effect of breast cancer interventions specific to young women (< 50 years) is undertaken to explore intervention efficacy within this age cohort.

Chapter Four – Preliminary design steps of a novel BCA intervention for young women with NF1 employ PPI perspectives. Theoretical frameworks for health behaviour change of the Behaviour Change Wheel (Michie et al., 2011), and The Medical Research Council's framework for developing and evaluating complex interventions (Skivington et al., 2021) are employed.

Chapter Five – The design of a theoretically based NF1 BCA digital animation grounded in self-determination theory (Deci and Ryan, 1985), and an information leaflet are detailed to enhance motivation levels of NF1 BCA behaviours.

Chapter Six – Proposed methodologies within a mixed method approach with a qualitative emphasis are discussed within contextualist epistemological and critical realist ontological positions to explore the feasibility of an NF1 BCA intervention.

Chapter Seven (Study 1) – Pre-post intervention analyses are undertaken to measure changes in NF1 BCA levels from watching the animation. The Breast-CAM-NF1, an adapted version of the Breast Cancer Awareness Measurement (Linsell et al., 2010) is utilised. Changes in BCA levels for young women with NF1 and their associates are examined by Wilcoxon signed rank tests and McNemar's tests.

Chapter Eight (Study 2) - This study explores the influence of the researcher's position who has had breast cancer by reflexive thematic analysis of reflexive logs. This provides increased transparency, trustworthiness, and credibility (Lincoln and Guba, 1985), demonstrating meaning from the participants' and researcher's data interpretations.

Chapter Nine (Study 3) - Reflexive thematic analysis of interviews with both young women with NF1, and associates further explores animation feasibility. This allows for examination of BCA components to garner a better understanding of how these are understood. Comprehension of what aids BCA, but also what hinders it, design impact, and suitability are also considered.

Chapter Ten – A summary of preliminary evaluations is presented to present whether the utilisation of a novel NF1 BCA intervention, including the utilised research methodology indicates potential for further progression and development. Further recommendations for future research are communicated.

Chapter Two
A review of the research area

2.1 Introduction

This chapter provides a review of the literature on areas that are pertinent to the research focus of being breast cancer aware, and within the context of NF1. An explanation of NF1 is provided to allow for a better understanding of this condition, and the increased breast cancer risk. Important influences on levels of BCA, and the wider implications of knowledge levels of NF1 on both those with the condition, and of HPs, are also explored detailing health literacy, rare disease knowledge, and the effect of the perception of the woman's body on awareness. Considerations within person-centred care are also included towards the end of this chapter.

As inclusivity is important within healthcare, reasonings for the intervention solely communicating information pertaining to young *women* with NF1, and an explanation of why and when the term 'female' is utilised are also provided.

2.2 Neurofibromatosis type 1

Neurofibromatoses are a category of genetic disorders that cause the formation of tumours on nerve tissues, including the spinal cord, brain, and peripheral nerves (Evans et al., 2018; Coy et al., 2020, Nix et al., 2020; Tamura, 2021). Mutations within genes that are responsible for repressing progression of growth within nervous system cells are posited to explain the development of tumours within these conditions with NF1, NF2, SMARCB1, and LZTR1 being identified as inhibiting the production of proteins that control cell growth proliferation, resulting in the development of tumours (National Institutes of Health, 2020). There are three classes of neurofibromatosis: neurofibromatosis type 1, NF2-related schwannomatosis (formally known as neurofibromatosis type 2), and schwannomatosis (Kresak, 2016; Plotkin et al., 2022). NF2-related schwannomatosis is the second most common of the neurofibromatoses occurring in 1 in 25,000 individuals, with schwannomatosis being the least common and the most recently identified form with an incidence ranging from 1 in 40,000 to 1 in 1.7 million individuals (Tamura, 2021). NF2-related schwannomatosis is characterised by the establishment of benign tumours called vestibular schwannomas that develop along the nerve that transmits sound and balance information from the inner ear to the brain, often creating partial or complete hearing loss (Children's Tumor Foundation, 2016). Schwannomatosis tumours predominantly involve the spinal and peripheral nerves, with these manifestations referred to as schwannomas as these tumours develop from Schwann cells which form part of the nerve sheath that insulates nerves (Tamura, 2021). NF2-related schwannomatosis is caused by pathogenic variants in a gene detected on chromosome 22, while schwannomatosis involves LZTR1 and SMARCB1, which are also both located on chromosome 22 (Children's Tumor Foundation, 2016; Tamura, 2021).

NF1, also known as von Recklinghausen disease or peripheral neurofibromatosis, has a global prevalence of approximately 1 in 2,500 to 3,000 individuals (Cieza Rivera et al., 2024) making it the most prevalent of neurofibromatoses, accounting for 96% of all cases (Tamura, 2021) regardless of gender or ethnicity (Karwacki, 2020; Children's Tumor Foundation, 2021). To put this into context with other rare disorders, NF1 is reported as being more prevalent than Huntington's disease, cystic fibrosis, and duchenne muscular dystrophy combined (Children's Tumor Foundation, 2021). Focusing on the geographical areas of the United Kingdom (UK) and the Republic of Ireland (ROI), with these being the population targets of this research, approximately 25,000 individuals in the UK have been diagnosed with NF1 (Nerve Tumours UK, n.d.). ROI figures are not as clearly communicated, with only an overall NF total that includes all NF-subtypes reported of 2,500 individuals (NF Association Ireland, n.d.). The numbers appear as substantially different, but they are comparative with the UK's population being 67,736,802 (Macrotrends, 2023a), and ROI's standing at 5,056,935 (Macrotrends, 2023b) (data captured on Thursday 12th January 2023). This neurofibromatosis arises from a mutation in the NF1 tumour-suppressor gene, located on chromosome 17 (17q11.2) that encodes the protein neurofibromin responsible for cell division regulation within the nervous system (Hirbe and Gutmann, 2014; National Institutes of Health, 2020). The NF1 gene is deemed as large, compared to other genes within the body, and is therefore prone to a substantial number of mutations (Wilson et al., 2021). Approximately 50% of individuals with NF1 have no family history of the disease, instead presenting with spontaneous mutations (Hirbe and Gutmann, 2014).

NF1 is a multi-system genetic disorder (Maani et al., 2019) potentially affecting any of the human body's systems (Legius et al., 2021) with a high rate of variable expression that manifests differently in every person, and within families (Antônio et al., 2013) including disease severity and progression rate (Uusitalo et al., 2015). Clinical manifestations that are found with NF1 can be summarised as predominantly a range of deviations in the neurological, cardiovascular, and musculoskeletal systems (Yap et al., 2014). Café-au-lait macules, freckling within folds of skin, and neurofibromas are common manifestations of the skin, with 95% of individuals with NF1 found to have café-au-lait macules, described by their brown colour. Lisch nodules, and optic gliomas can affect the eyes, with brain tumours, epilepsy, and headaches indicative of this condition affecting the central nervous system. Scoliosis of the bones demonstrate musculoskeletal irregularities, with other features including speech problems, and learning difficulties associated with the condition (Antônio et al., 2013; Anderson and Gutmann, 2015).

As previously mentioned, NF1 causes the development of neurofibromas, predominantly of cutaneous neurofibromas, which are benign peripheral nerve sheath tumours (Seo and Park, 2015). These can vary in both size and number, from being scarce to hundreds or thousands that cover the entire body (Friedman, 2005), are described as being soft in texture, violet or skin coloured, and are often asymptomatic but can be sensitive to touch, painful, and itchy (Tonsgard, 2006). Plexiform neurofibromas occur in approximately 30% of individuals with NF1 and are more extensive, developing from multiple nerves that manifest as bulging masses that involve connective tissue and skin folds (Tchernev et al., 2016). Despite being predominantly benign, these have the potential to develop into malignant peripheral nerve sheath tumours, carrying a cumulative risk of 11.7% by the age of 70 years (Ingham et al., 2011). With the increased number of tumours associated with the condition, those with NF1 have an increased risk of developing both benign and malignant tumours (Yap et al., 2014; Howell et al., 2017). The average life expectancy is reduced by 10-15 years with NF1, with cancer being the most common cause of death (Uusitalo et al., 2016). The lifetime cancer risk with NF1 is estimated at 59.6%, in comparison to the general population’s lifetime risk of 30.8% (Uusitalo et al., 2016). Some of these cancers include ovarian, breast, brain, osteosarcoma, and melanoma (Landry et al., 2021; Reynolds, 2021).

2.3 Neurofibromatosis type 1 and breast cancer

The association between an increased breast cancer risk and NF1 had previously been disputed, with this association possibly obscured by death certificates failing to disclose vital information that some women who had died of breast cancer, also had NF1 (Evans et al., 2012). However, research conducted predominantly within the last fifteen years demonstrated robust evidence that NF1 is a risk factor for breast cancer development, particularly in younger women aged <50 years (Walker et al., 2006; Sharif et al., 2007; Evans et al., 2012; Madanikia et al., 2012; Da Silva et al., 2015; Seminog and Goldacre, 2015; Uusitalo et al., 2017; Maani et al., 2019; Evans et al., 2020).

Sharif et al. (2007) reported that by 50 years, women with NF1 have a five-fold risk of developing breast cancer, with a standard incidence rate (SIR) of 4.9. Madanikia et al. (2012) also reported similar findings, with an SIR of breast cancer among women with NF1 under the age of 50 years being reported at 4.4. There is now consensus that having the condition of NF1 increases the risk of developing breast cancer by up to five-fold in women under the age of 50 years (Maani et al., 2019; Hovinga and Temel, 2020; Viskochil, 2021) with cases reported to predominantly present in women aged 34 to 44 years (Suarez-Kelly et al., 2019). One theory of why breast malignancies occur earlier in women with NF1 is that gene mutations accumulate, causing an earlier occurrence of malignancy (Uusitalo et al., 2017). However, this risk does not significantly differ to the general population after 50 years of age, arguably because the NF1 population being susceptible to developing breast cancer prior to 50 years, decreases the susceptible number of women in the older population (Suarez-Kelly et al., 2019).

Breast cancer is a clinically and biologically heterogeneous disease, with several subtypes that have different aetiologies, responses to treatments, and prognoses (Pashayan et al., 2020). Subtypes of breast cancer are defined by both histopathological appearance, hormone receptor expression, and growth factors of oestrogen receptor (ER), progesterone receptor (PR), human epidermal growth factor receptor 2 (HER2), and triple negative (Britt et al., 2020). Genetic factors include pathogenic mutations, for example BRCA1 and BRCA2 mutations (Pouptsis et al., 2020). Comparative onco-genomics of The Cancer Genome Atlas Network (Koboldt et al., 2012) associate the NF1 gene as a breast cancer driver (Wallace et al., 2012), with NF1 aberrations presenting in 33% of breast cancer cases, with a significant development in ER negative and HER2 positive subtypes (Wallace et al., 2012; Uusitalo et al., 2017; Evans et al., 2020). Among women with NF1, the occurrence of breast cancer tumours predominantly present as aggressive grade 3 (Yap et al., 2018). Presentation often consists of an increased tumour size and a later staging, compared to non-NF1 breast cancers (Uusitalo et al., 2017), with Akcakanat et al.

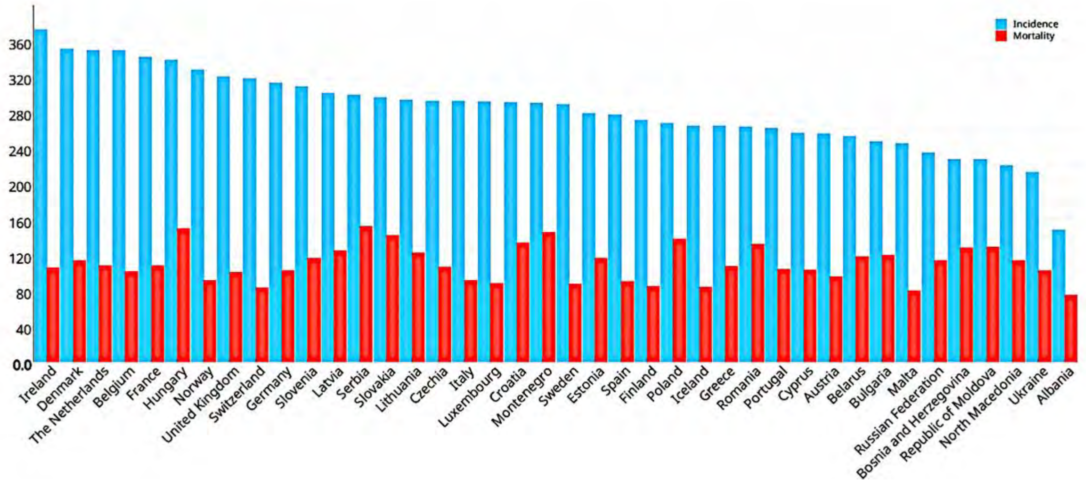
(2021) reporting an enrichment of NF1 gene mutations involved in metastatic breast cancer with a resistance to endocrine therapy.

2.4 Breast cancer screening and NF1

Cancer prevention can be categorised as either primary or secondary in method, with primary prevention targeted at avoiding or reducing cancer development by employing educational and environmental control strategies, and secondary prevention employing screening programmes to detect precancerous activity or early-stage cancers, potentially allowing for a more effective treatment (Ali and Katz, 2015; Bellanger et al., 2018). Primary prevention includes attention to body mass index, alcohol consumption, exogenous female hormone use, and physical activity (Britt et al., 2020). Within secondary prevention, the World Health Organisation (WHO; 2017) defines two distinct but connected strategies for the early detection of cancer. These are early diagnosis, whereby symptomatic cancer is recognised at an early stage, and screening, which is primarily utilised to identify asymptomatic disease in target populations (WHO, 2017). The main aim of secondary prevention is to decrease mortality rates caused by cancers, by detecting any potential changes that may be of concern (Kolak et al., 2017). Both primary and secondary prevention are particularly important to the ROI and UK, with these geographical areas within the top ten of European cancer incidence rates as outlined by the Global Cancer Observatory (2020a) in Figure 1.

Figure 1

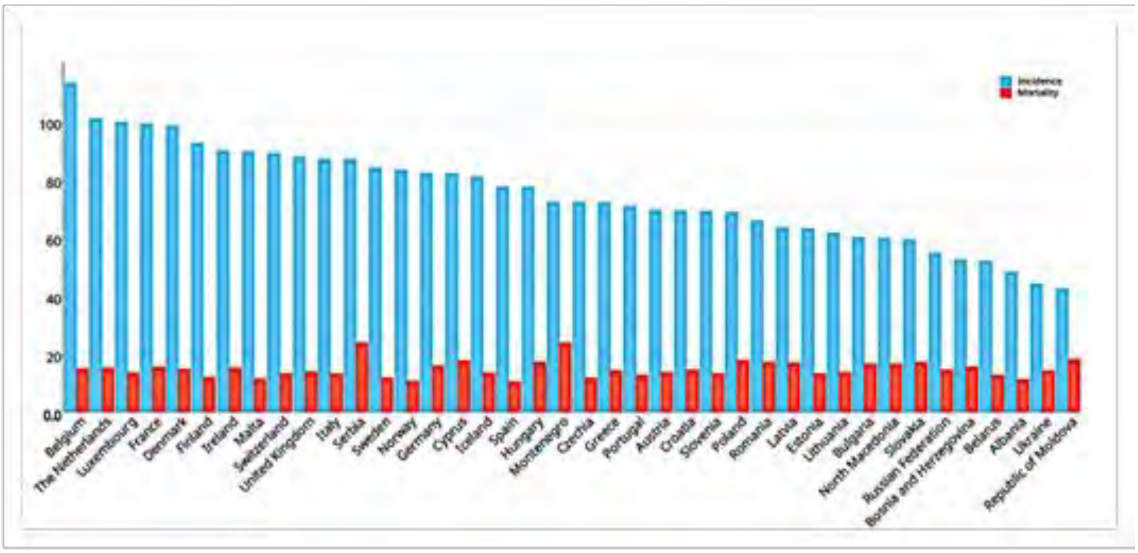
Global Cancer Observatory: Estimated Age-Standardized Incidence and Mortality Rates (Europe) in 2020, all Cancers, Both Sexes, per 100,000 of Population



For breast cancer (females), the UK and ROI rank highly in incidence rates among their European counterparts, with ROI ranking as 7th and the UK ranking as 10th (Global Cancer Observatory, 2020b) (Figure 2).

Figure 2

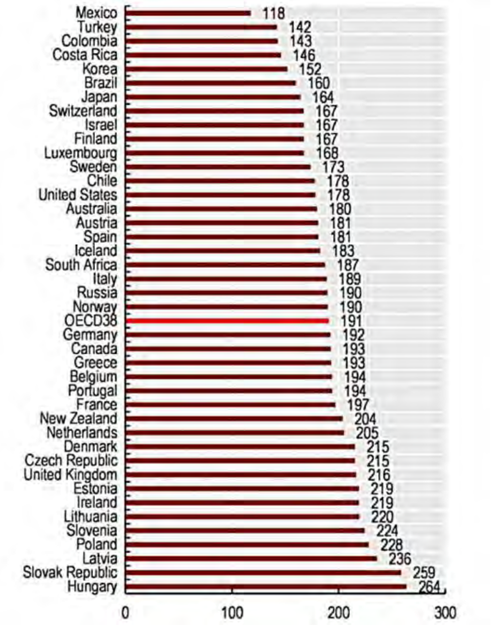
Global Cancer Observatory: Estimated Age-Standardized Incidence and Mortality Rates (Europe) in 2020, Breast Cancer, Females, per 100,000 of Population



While the high rate of incidence may arguably demonstrate the UK's and ROI's success in screening uptake allowing for diagnoses, the mortality rates are positioned higher than the Organisation for Economic Co-operation and Development's (OECD; 2021) average (Figure 3). This accentuates the importance of primary and secondary prevention that includes formal screening and being breast cancer aware for an earlier diagnosis and a better prognosis.

Figure 3

OECD Health Statistics (2021) OECD 38 Countries, Estimated Age-Standardized Rate per 100,000 Population All Cancer Mortality Rates



Effective prevention, and early detection approaches also have a positive impact on the wider environment, aiding in a cost reduction to both individuals and health systems with early-stage cancer diagnoses requiring less expensive treatment options (Ginsburg et al., 2020). Treatment for advanced breast cancer is more invasive and intensive (Sun et al., 2020), with this associated with greater resource utilisation and requirements (Lo-Fo-Wong, 2015), and the necessitation of more expensive treatment options (Ginsburg et al., 2020). From a healthcare cost per individual, breast cancer in women over 50 years within 1 year after diagnosis was predicted to equate to £5,167 at stage I, compared to £13,330 at stage IIIA when controlled for demographics and tumour characteristics (Sun et al., 2020). This is consistent with a global systematic review conducted by Sun et al. (2018) that indicated increased breast cancer care costs for advanced stages, with breast cancer treatment costs at stage II and stage III communicated to be 32% and 95% higher than stage I on average. However, these studies did not include stage IV breast cancers which incur different costs such as palliative care, including palliative chemotherapy. With this research focusing on younger women, it is important to highlight that older patients incur lower costs compared to younger patients with breast cancer within the health system. This difference in cost may be attributed to unmeasured differences in disease with younger women often presenting with more aggressive subtypes that require more aggressive treatment, differences in severity and prevalence of comorbidities that may contraindicate treatment for breast cancer (e.g., radiotherapy, chemotherapy, surgery), individual differences in patient preferences, and increased involvement among younger patients in the decision-making process (Sun et al., 2018).

The cost of cancer to the individual undergoing treatment is also important to highlight. Figures discussed in a Dáil Éireann (ROI's House of Parliament) debate in February 2022 obtained from research conducted by The Irish Cancer Society communicated that medication, counselling, wigs, childcare, parking fees, and heating cost on average per person €756/£645 per month, but can be over €1,000/£853 in some cases, particularly if the cancer stage is advanced requiring more treatment and hospital visits and stays, more medication, and increased incidences of treatment side effects (National Cancer Strategy, 2018). An individual undergoing cancer treatment may experience a loss of income on average of more than €1,500/£1280 a month, which can be more prolonged for those with an advanced breast cancer presentation (Dáil Éireann, 2022) (All sterling conversions correct as of Monday 12th February 2024). From a cost perspective, both to the healthcare system and to the individual, the importance of detecting breast cancer at an early stage from enacting the behaviours of being breast cancer aware, and from screening is evident. This is pertinent within this research, with it previously discussed that breast cancers among young women with NF1 are often found at a later stage, therefore incurring higher costs.

Screening for breast cancer using imaging can take either a systematic or opportunistic approach (Albeshan et al., 2020). Systematic, or organised screening, concerns formal screening programmes designed for a particular population, involving specific guidelines regarding screening intervals, and target age (Panieri, 2012). Both the ROI and the UK implement this approach through their national breast screening programmes. Opportunistic screening occurs when an individual has no symptoms of breast pathology but is referred for screening outside of systematic programmes or when a patient requests a test for their own reasons (Panieri, 2012). Screening mammography more commonly referred to as 'mammogram', is the most widely utilised and available tool for detecting breast cancer early (MacBride, 2012; Zaidi et al., 2021). In the UK, mammograms are offered every three years to women aged 50-70 years in the general population (National Health Service; NHS, 2021a). Within the ROI, this screening is offered every two years to women aged 50-69 years within the general population (Health Service Executive; HSE, 2022a). For women with NF1 within the UK and ROI, the National Institute for Health and Care Excellence's guidance (NICE; 2023) is followed, placing women with NF1 at moderate cancer risk, with the recommendation of earlier annual mammograms from 40 years of age. However, the National Comprehensive Cancer Network of North America (2021), the NSW Cancer Institute of Australia (2021), and the Protocole National de Diagnostic de Soins (mandatory French clinical practice guidelines for rare diseases) (Bergqvist et al., 2020), recommend screening from 30 years of age. Recent guidelines published by the European Reference Network on Genetic Tumour Risk Syndromes (ERN GENTURIS) also recommend earlier breast screening from the age of 30 years (Carton et al., 2023). The collaborative efforts of this publication include prominent clinicians such as the UK's Professor Gareth Evans who has previously recommended earlier screening and the inclusion of women with NF1 gene defects in national high-risk screening protocols particularly due to a substantial risk of contralateral breast cancer and an overall poor prognosis (Evans et al., 2020). However, it is important to note that these are guidelines and recommendations based on evidence-based and/or expert opinion-based information that are provided to assist HPs with surveillance with those with a confirmed NF1 diagnosis (Carton et al., 2023). They are therefore not prescriptive and may be adjusted to local available resources and include recommendations such as those provided on NHS websites. Unlike a national screening programme, there is currently no breast cancer screening programme for women with NF1 that systematically invites individuals from an earlier age. This highlights the importance of being breast cancer aware within an NF1 context, to not only recognise the increased breast cancer risk at a younger age, but to be cognisant of the recommendations for earlier screening to act upon this, and develop self-efficacy of having a perceived confidence in capability to perform this specific behaviour (Bandura, 1977; Prestwich et al., 2018). However, despite NF1 requiring lifelong surveillance, education, and psychosocial support, not everyone with NF1 is under a specialist that may have knowledge of the increased breast cancer risk, or one may experience poor access to care and subsequently limited disease knowledge (Radtke et al., 2023). Several barriers to care include lack of service co-ordination, transferring of, and access to medical records, lack of HP knowledge, and poor communication between HPs and patients (Rietman et al., 2018; Fleming et al., 2023). Within the UK, research exploring the pathways of care for NF1 echoes these barriers, with 54% of NF1 patients, families, and carers found to be dissatisfied with NF1 care; with regional disparities evident in specialist care access, and care pathways that lack standardised national guidelines (Ju et al., in prep.). With the absence of a specialised NF1 breast cancer screening programme, to the best of the researcher's knowledge, currently no research has been undertaken that provides data, firstly to explore the extent the recommendation for earlier screening is being followed, and secondly, how many of these individuals are attending screening and for what reasons (e.g., screening recommendations, or for a breast concern).

Despite mammograms considered as the best tool for diagnosing breast cancer at an early stage (Morris et al., 2015), this method can carry diagnostic issues for individuals with NF1. Difficulties in interpretating differences between benign neurofibromas and malignant breast masses may contribute to delayed medical care (Evans et al., 2011), and to the greater mortality rate of NF1 associated breast cancer (Uusitalo et al., 2016). Cutaneous neurofibromas may impede the view of additional benign or malignant lesions on mammograms, or correspondingly these may generate false-positive screening recalls (Maani et al., 2019) and in overdiagnosis and overtreatment (Monticciolo et al., 2018). Overdiagnosis is the detection of breast cancer that would not instigate harm or develop in the absence of screening (Oeffinger et al., 2015; Albeshan et al., 2020). Mammography also has a reduced sensitivity in women with increased breast density (Sprague et al., 2017), with this issue more common in younger women. This is important to consider within the target population of this current research of young women with NF1. However, current mammography is normally in the form of digital mammography that captures higher digital quality images that are received directly on a computer for sections to be scrutinised more closely (Mehnati and Tirtash, 2015). This makes it a more accurate screening method for women who have dense breast tissue (Pisano et al., 2008; Mehnati and Tirtash, 2015). However, despite radiation exposure from mammography being low (Bergqvist et al., 2020), radiation from mammography is a concern with NF1, as individuals with this condition have been shown to develop secondary malignancies in response to therapeutic ionising radiation (Sharif et al., 2006). NF1 has therefore been identified as a condition related to both radio-sensitivity and radio-susceptibility (Combemale et al., 2021). MRI screening (or ultrasound if MRI is not feasible) has been advised in these instances of concern (Da Silva et al., 2015). Carton et al. (2023) also communicate that while radiation exposure is low, it is potentially safer to not use mammography, yet where MRI screening is not available mammography can be used.

Ultrasonography, more commonly referred to as 'ultrasound', delivers no ionising radiation, and is less invasive than mammography (Kolak et al., 2017) which may be a more suitable screening method for young women with NF1. Despite ultrasound considered as having a lower specificity compared to mammography (Mehnati and Tirtash, 2015), Ginsburg et al. (2020) report that in women aged 30 to 39 years, ultrasound offers similar diagnostic accuracies to mammography. Ultrasonography is particularly beneficial to young women with dense breast tissue that require breast screening such as those at an elevated risk of developing breast cancer (Mehnati and Tirtash, 2015). This method can distinguish between cysts, probable benign legions, and suspicious masses, which mammography may have difficulty with (Ginsburg et al., 2020). Another method that does not use radiation is Breast MRI, which utilises magnetic resonance to develop images (Kolak et al., 2017). MRI allows for precise imaging (Mehnati and Tirtash, 2015) and is often used by young women with genetic mutations who require increased surveillance (Godavarty et al., 2015), such as BRCA1 and BRCA2 mutations (Weinstock et al., 2015). However, this is an expensive method, often not available in every medical centre, and does not always differentiate between benign and malignant lesions which may contribute to false positive results (Kolak et al., 2017).

At the time of conducting this research, earlier screening from the age of 30/35 years of age is not routinely available within the UK and Ireland, and it is therefore important that young women with NF1 are aware of breast cancer symptoms and the associated increased risk of developing breast cancer at a younger age. Knowledge of malignancy symptoms, and risk may ensure prompt treatment-seeking behaviour (Park et al., 2015) to access breast screening if and when required.

2.5 'Breast self-examination', 'breast awareness', or 'breast cancer awareness'?

Breast cancer is the most common type of cancer (Figure 4), and a leading cause of death worldwide within this population (Figure 5) (Global Cancer Observatory, 2020c; Global Cancer Observatory, 2020d). It is the most common type of cancer in the UK (Figure 6), and the second most common in Ireland (Figure 7) (Gobal Cancer Observatory, 2020e; Global Cancer Observatory, 2020f).

Figure 4

Global Cancer Observatory (2020c): Top Cancer per Country, Estimated Age-Standardised Incidence Rates (World) in 2020, All Ages (Excluding Non-Malignant Skin Cancer)

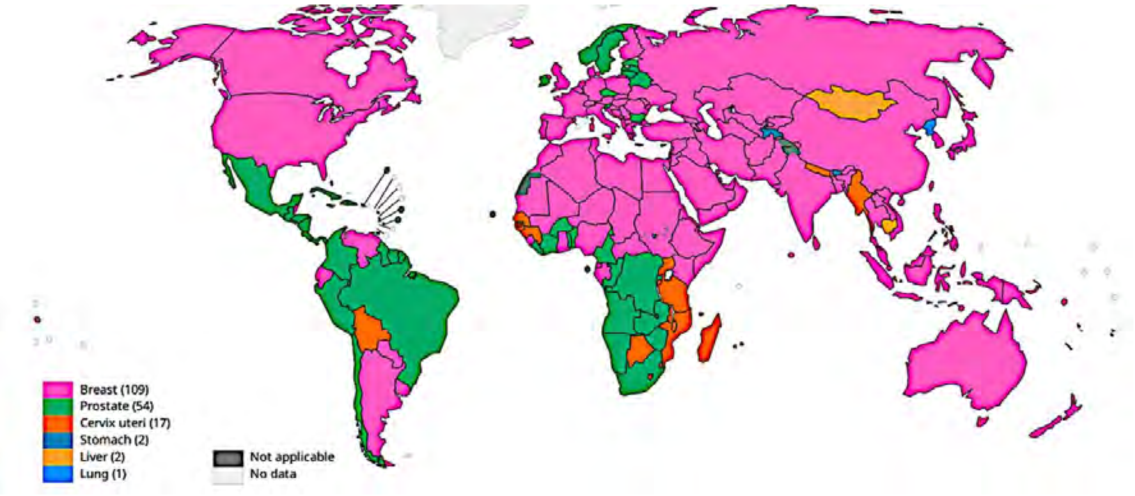


Figure 5

Global Cancer Observatory (2020d): Top Cancer per Country, Estimated Age-Standardised Mortality Rates (World) in 2020, Females, All Ages (Excluding Non-Malignant Skin Cancer)

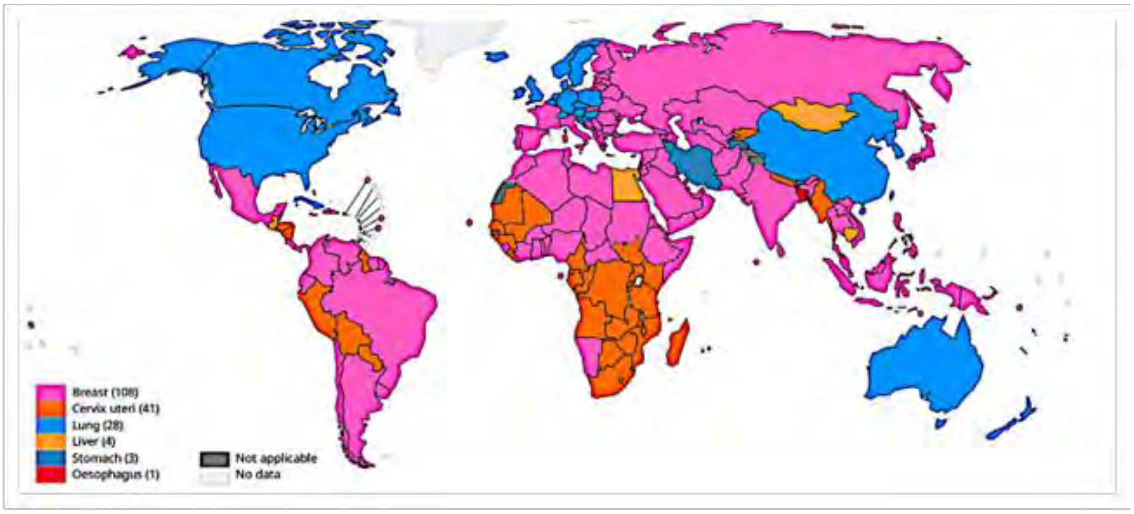


Figure 6

Global Cancer Observatory (2020e): Estimated Age-Standardised Incidence Rates per 100,000 in the United Kingdom (Excluding Non-Malignant Skin Cancer)

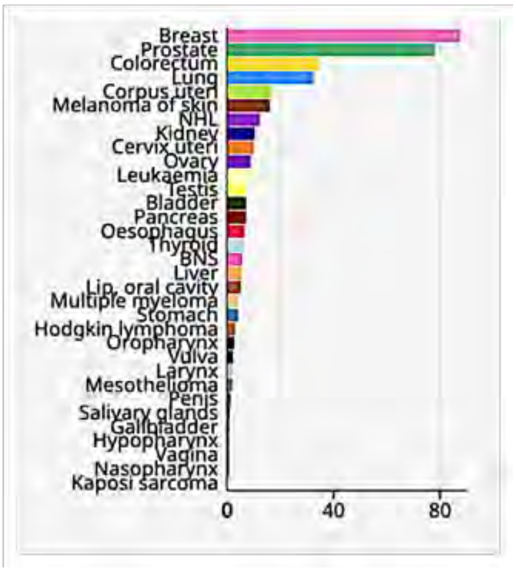
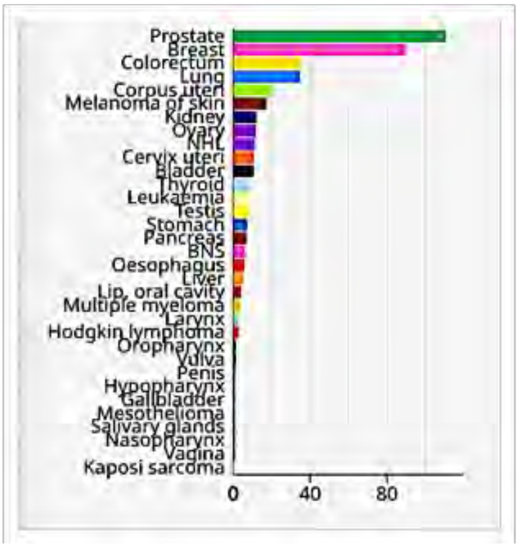


Figure 7

Global Cancer Observatory (2020f): Estimated Age-Standardised Incidence Rates per 100,000 in the Republic of Ireland (Excluding Non-Malignant Skin Cancer)



Many breast tumours are initially detected by women themselves (Cancer Research UK, 2020a). Women have become familiar with the common signs through awareness campaigns and clinical information sheets such as those by the National Health Service's (NHS, 2024) *Breast Cancer in Women* page that provides information on symptoms, diagnosis, causes, treatment, and breast cancer prevention, and the colourful and engaging campaigns from CoppaFeel! (2024) Of *Breast Cancer Symptoms and Signs* and Breast Cancer Now's (2024) *Learn the Signs of Breast Cancer* where both use infographics to demonstrate what signs and symptoms to be aware of. Common symptoms of breast cancer are a lump, a change in size or shape of one or both breasts, nipple discharge that may have blood in it, a lump or swelling in either armpit, dimpling on the skin of the breasts, a rash around the nipple area, and a change in the nipple's appearance, for example, becoming sunken into the breast (NHS, 2024).

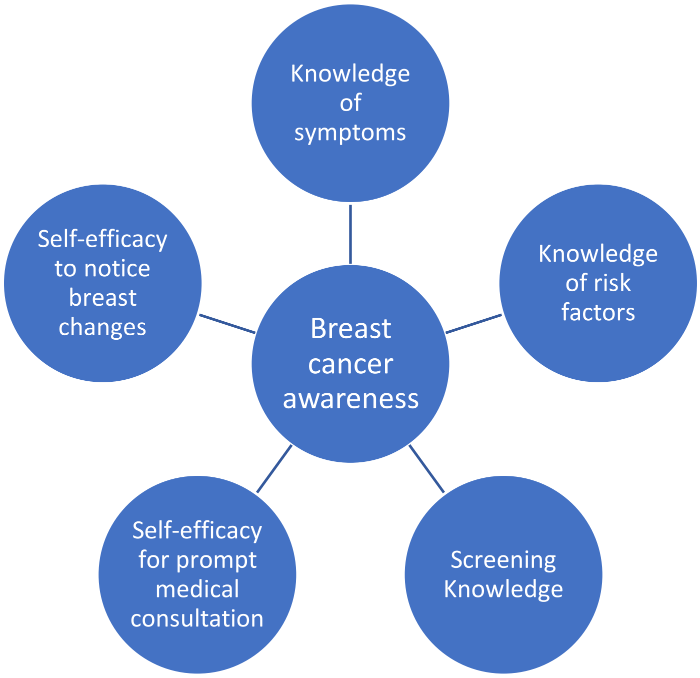
Traditionally, women were encouraged to perform monthly breast self-examinations to discover breast changes by following a formally taught and rigorously set method (MacBride et al., 2012) involving repetitive palpations at the same time each month (Thornton and Pillarisetti, 2008). However, a Cochrane Review reported lack of evidence to support breast self-examination or clinical breast examination by a HP in improving breast cancer mortality rates, with an increase in anxiety, consultation visits, and costly follow-up screening communicated (Kösters and Gøtzsche, 2003). Arguably, considerable time has passed, and breast *self-examination* may be understood differently in today's context as having a breast *awareness*. This is evident in measures for BCA that assess actions such as frequency of 'breast checking' (Linsell et al., 2010; Forbes et al., 2012), which could be comprehended as breast self-examination. An example of breast self-examination that is communicated as awareness is provided by the NHS (2021b), within *How Should I Check my Breasts?* However, to the researcher's best ability, no recent systematic reviews including breast self-examination were found, with reviews excluding breast self-examination within its search criteria when examining BCA interventions (O'Mahony et al., 2017; Anastasi and Lusher, 2019). This creates omissions in understanding BCA interventions, their designs, and implementation strategies. With breast self-examination being understood as 'breast checking', which is important within breast awareness, potentially important findings on what may be beneficial or may not be when designing a breast cancer intervention are being excluded.

'Breast awareness' or breast self-awareness involves individuals having the confidence to 'look and feel' their breasts to become aware of what is normal for their own body (Kennerley, 2015; Monticciolo et al., 2018). Unlike breast self-examination, breast awareness does not subscribe to the examination of the breasts in a rigorous systematic way (Monticciolo et al., 2018). MacBride (2012) communicates breast awareness as not only an awareness of breast changes, but also that of the signs of breast cancer which may require seeking medical advice. The term ‘breast cancer awareness’ and the behaviour of being ‘breast cancer aware’, rather than just ‘breast aware’, also involves having knowledge of breast cancer symptoms, but it also encompasses risk factors, and breast screening information (Linsell et al., 2010; Chao et al., 2020). Self-efficacy plays an important aspect within BCA for both having the ability and confidence to spot any breast changes, and for prompt medical consultation for a breast concern with the stronger the perceived self-efficacy, the higher the confidence with which women advocate for their health (Chang et al., 2014). By increasing BCA, it may encourage women to present earlier with potential symptoms, resulting in an earlier diagnosis and treatment for an improved survival rate from breast cancer (Linsell et al., 2010; Ruddy et al., 2014; O’Mahony et al., 2017). A study conducted by Zaidi et al. (2021) found that more than a quarter of patients with screen detected cancer had a clinically palpable lump that they were not conscious of, indicating that many women do not identify palpable disease manifestations themselves. This is not entirely surprising considering the results from a YouGov survey (2021) conducted on behalf of the charity Breast Cancer Now. It was found that almost half (47%) of women in the UK do not regularly check their breasts. One in ten women reported that they never check their breasts. A fifth of women (19%) have only checked their breasts once every six months or less, while 13% only check once a year or less. Women reported not checking their breasts for a variety of reasons, with almost half (46%) citing ‘they forget’, and 21% reporting they do not check breasts as they are ‘not confident’ in what to be aware of. Key reasons also reported included feeling awkward or embarrassed, particularly if a General Practitioner (GP) visit was required. A similar investigation was conducted by Breast Cancer Ireland (2022), whereby it was revealed that only 34% of Irish women over 18 check their breasts once a month. 30% of women who do not check their breasts are not sure of what they need to be aware of. Of these women, 9% believe that breast checking is something that can only be conducted by a trained professional.

Breast awareness and breast cancer awareness are often interchangeably utilised within campaigns and research (O’Mahony et al., 2017). To remove any uncertainty within this research, breast cancer awareness, or BCA, is utilised to highlight the importance of considering each of its components. From these literature findings, BCA can be conceptualised by five main facets (Figure 8).

Figure 8

Conceptualisation of Breast Cancer Awareness within this Thesis



However, there is a lack of consistency with naming and conceptualising BCA within the literature and BCA measures, often with a focus on specific components rather than all its components as demonstrated in Table 1. This further confounds a clear communication and measure of BCA as a standardised concept.

Table 1

Examples of BCA Measures, Components, and Limitations

Measure	BCA components measured	Limitations
Breast-CAM (Linsell et al., 2010)	Knowledge of symptoms Confidence, skills and behaviour in relation to detecting a breast change Anticipated delay in contacting the doctor (can be understood as self-efficacy for prompt medical consultation)	Focus on general population statistics for screening and risk. Does not account for variability e.g., women with NF1, BRCA.

	Barriers to seeking medical help Knowledge of age-related and lifetime risk Knowledge of the NHS Breast Screening Programme Knowledge of risk factors	
Breast Cancer and Heredity Knowledge Scale (Ondrusek et al., 1999)	Incidence and risk factors Disease presentation and treatment Primary and secondary prevention Genetics	Does not include breast self-examination knowledge, or self-efficacy. No consideration of confidence to present to HP.
Knowledge of Breast Density and Awareness of Related Breast Cancer Risk (Manning et al., 2013)	Breast density knowledge Risk factor awareness	Does not include breast cancer symptom knowledge, self-examination knowledge, confidence in recognising changes, promptness to seek help for a breast concern, or screening knowledge.
Validity and Reliability of Health Belief Model for Promoting Breast Self-Examination and Screening Mammogram for Early Cancer Detection (Mohamed et al., 2019)	Self-efficacy mammogram Barriers BSE and mammogram Susceptibility to breast cancer Severity of breast cancer Cues to action and benefits mammogram – e.g., Effective for early detection Benefits of BSE – e.g., early detection Motivation – e.g., I exercise at least 3 times a week Self-efficacy BSE	Does not address breast cancer warning symptoms, risk statistics, or reasons for avoiding seeking help for breast concern.

However, from examining the components measured within the Breast-CAM (Linsell et al., 2010), these appear to address most holistically the components of BCA and what this thesis communicates as BCA. This is also echoed in its preference for application within various BCA studies, both in its current guise, and in adapted translated formats (e.g., Green et al., 2023; Kharaba et al., 2021; Radi, 2013). While further details and application of this measure will be discussed within Chapter Six, Table 2 demonstrates the comparableness of what this thesis comprehends BCA as, and how the Breast-CAM specifies BCA components.

Table 2

BCA Conceptualisation Comparableness to Breast-CAM

Breast cancer awareness	Breast-CAM
Knowledge of symptoms	Knowledge of symptoms
Self-efficacy to notice breast changes	Confidence, skills and behaviour in relation to detecting a breast change
Knowledge of risk factors	Knowledge of age-related and lifetime risk
	Knowledge of risk factors
Screening knowledge	Knowledge of NHS Breast Screening Programme
Self-efficacy for prompt medical consultation	Anticipated delay in contacting the doctor
	Barriers to seeking medical help

However, the conceptualisation of BCA when placed within an NF1 context has additional challenges that are unique to this cohort, such as screening and risk differences compared to the general population. These pose a challenge for not only the patient with NF1, but also for the HP that may not be knowledgeable about this rare disease (Zagouri et al., 2012; Da Silva et al., 2015). The Breast-CAM, while a good fit for measuring general components of BCA, lacks these important data for NF1 BCA which needs to be remedied for it to be applied within a feasibility study that focuses on NF1 BCA levels. This highlights the importance of having a comprehensive understanding of NF1 BCA barriers within this research.

2.6 Breast cancer awareness barriers and the woman's body

Advances in treatment and survivorship have been made within the research field of breast cancer, with 85% of women diagnosed with breast cancer in England surviving this disease for five years or more (2013-2017) (Cancer Research UK, 2020b). However, research has found that young women, particularly those ≤ 40 years of age that are diagnosed with breast cancer, often experience more aggressive biological features with a higher rate of recurrence and subsequently poorer survival (Narod, 2012; Assi et al., 2013; Johnson et al., 2018; Poggio et al, 2018; Howell et al., 2022). With the firm establishment that young women with NF1 are at an increased risk of developing breast cancer, this is a pertinent point within this research, as it further highlights the importance of designing a BCA intervention for this cohort.

Potential reasons for delays in presenting to a HP with a breast concern is important to explore. While some women postpone presenting to a HP on finding a symptom due to a fear of a cancer diagnosis (O'Mahony, 2011) or of dying from the disease (Moser et al., 2021) (discussed later in this section), it may also be due to a lack of knowledge, and therefore self-efficacy in recognising symptoms, including non-lump breast symptoms such as changes to the nipple (O'Mahony et al., 2013). Self-efficacy is defined as one's perceived confidence in capability, or self-mastery to perform a specific behaviour (Bandura, 1977; Prestwich et al., 2018), and in this regard, it is behaviours associated with BCA within an NF1 context. Increasing knowledge, shared decision-making, and having accessible and acceptable resources about breast cancer and risk levels may have positive effects on an individual's level of self-efficacy. Prior research in non-NF1 populations with increased cancer risk has found that many underestimate this risk, with a lower perceived cancer risk associated with decreased cancer screening adherence (Katapodi et al., 2009). Therefore, accurate perceptions of cancer risk and symptoms may aid in ensuring timely treatment-seeking behaviour (Park et al., 2015). Expectations of personal mastery affect motivation to perform specific behaviours, with motivation central for both behaviour initiation and persistence (Bandura, 1977; Didarloo et al., 2017). Self-efficacy expectations determine how much effort people will apply, and how long they will persist, even when faced with challenges, with individuals that fear and avoid threatening situations believing that these exceed their coping skills, whereas those that judge themselves capable behave assuredly (Bandura, 1977).

It is therefore important that women with NF1 have the knowledge surrounding both their condition, and the associated breast cancer risk to develop a personal proficiency in being breast cancer aware and subsequently develop a motivation to continue positive behaviours associated with this. However, NF1 knowledge limitations have been found in varying geographical locations, recognising that this issue is not UK and ROI specific. Karwacki (2020) reported significantly limited knowledge about NF1 related breast cancer risk, with 68% of polish women with NF1 not receiving such information. Similarly, only a limited number of participants within an Australian cohort had a good understanding of NF1, and its related complications and risks, with many not pursuing appropriate medical advice (Oates et al., 2013). Brazilian participants with NF1 also lacked sufficient NF1 knowledge, with some unaware of the associated and increased predisposition to cancers (Bicudo et al., 2016). Comparable results were found within the UK (Benjamin et al., 1993) with specific information pertaining to NF1 complications being poor and often limited to own family experiences, or information from patient support organisations.

However, while it has been found that well established efforts such as increasing knowledge and having access to reliable and comprehensive information aid in improving prevention and cancer awareness (Smith et al., 2013; Hovick et al., 2014), a dearth of considerations about information avoidance remains, acting as a barrier to these aspects (Link and Baumann, 2022). The avoidance of cancer information is a purposeful decision, often enacted by a lack of desire or the experience of a fear to learn about information pertinent to cancer that is perceived as emotionally distressing, and threatening (Sweeny et al., 2010; van't Riet and Ruiter, 2013). Despite progress within the medical and oncological fields, the perception of cancer continues to be coupled with the assumption of death (Moser et al., 2014; 2021). A negative perception of cancer has been shown to have a damaging effect on screening attendance and subsequently the stage at which a cancer is diagnosed (O'Mahony, 2011). Women who do not attend routine screenings are found to be at a significantly higher risk of mortality from breast cancer (Duffy et al., 2021). Terror management theory (TMT; Greenberg et al., 1986), can be utilised in this instance to provide a clearer understanding of the behaviour of fatalism, and how it might be mitigated for the development of more adaptive responses (Courtney and Goldenberg, 2021) which is important to successfully have young women with NF1 adopt positive behaviours and attitudes towards aspects of BCA.

According to TMT, much of human behaviour and cognition is targeted at managing anxiety that results from the awareness of mortality, by adhering to cultural worldviews that permeate life, placing importance on symbolism, structure, and meaning (Morris et al., 2018). TMT also posits that when mortality cognition occurs, individuals are more likely to engage in behaviours that are relevant to their identity, presentational appeal, and to their level of self-esteem, sometimes at the expense of their health even in situations where there is knowledge of potentially negative consequences (including fatal ones) (Ginis and Leary, 2004; Oyserman et al., 2007; Morris et al. 2019). Self-esteem refers to an individual's subjective evaluation of their personal worth (Rosenberg, 1965).

This can include body esteem (Goldenberg et al., 2000), with Fallon et al. (2014) finding that body dissatisfaction and shame can relate to poor cancer screening engagement. Individuals with high self-esteem are found to be healthier than those with low self-esteem, with these findings based on both subjective and objective health measures (Orth and Robins, 2022). This is important to consider within the field of research of young women with NF1, as individuals with NF1 that have visible aspects of the disease negatively appraise their bodies more than patients with a dermatological or psychiatric disorder (Granström et al., 2012). Hamoy-Jimenez et al. (2022) also report that women with NF1 have worse perceived physical appearance, anxiety, and mental health than men with NF1, however, perceived physical appearance was not always found to correlate to disease visibility.

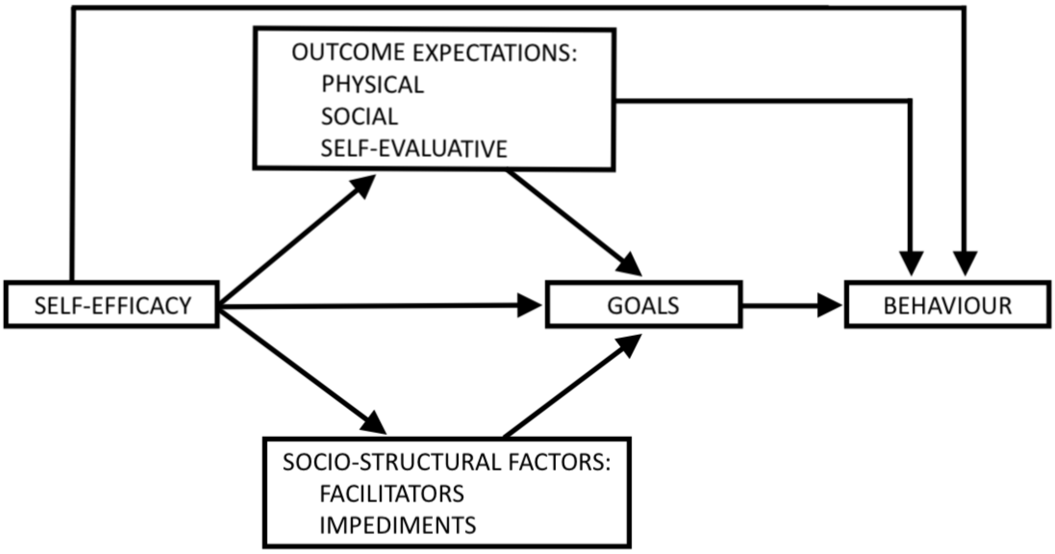
Objectification theory (Fredrickson and Roberts, 1997) recognises that women's bodies, compared to those of men's bodies, have a higher tendency to be viewed more on external appearance or as objects (including sexual objectification), or as a body rather than as a human being. These aspects that are often tied to the identity of the woman's physical form, particularly presentational appeal, and body esteem (Courtney and Goldberg, 2021), are important facets to consider within women's health and associated cancer awareness interventions due to their ability to both hinder and help positive health behaviours. From a TMT perspective, the physical body by virtue of its 'creatureliness' serves as a reminder of death's inevitability, as all corporeal creatures will eventually die (Goldenberg et al., 2000; Courtney and Goldenberg, 2021). Within BCA, performing breast self-examinations among women has been argued to make cognitions of death more accessible (Goldenberg et al., 2008) due to the direct placement of awareness by the woman on the physical form of their own breasts. However, within the category of cancers experienced by women, including gynaecological cancers such as cervical and ovarian, breast cancer also has a unique association as an external representation of femininity as a sexualised form; one that is open to objectification, particularly within Western society (Courtney and Goldenberg, 2021), compared to a man's body (Grabe et al., 2005).

Previous research has reported that this can create an internalisation of self-objectification that creates a monitoring solely of the body's outward appearance which may contribute to lower internal body awareness, anxiety, shame, and reduced feelings of self-worth or self-esteem (Fredrickson and Roberts, 1997; Moradi and Huang, 2008). However, it has been argued that self-objectification may potentially be beneficial in creating better BCA amongst women (Courtney and Goldenberg, 2021). Considering TMT from this viewpoint, self-objectification may reduce the perceived threat of mortality, as if a woman utilises this perception, it may also aid in distancing from the potentially threatening association of creatureliness and therefore death (Goldenberg and Roberts 2011; Morris et al., 2018). If individuals are motivated to reduce vulnerability to health concerns by self-objectifying their breasts, rather than perceiving them as socially constructed sexualised symbols associated with creatureliness, this can potentially provide health-promoting responses, including attending screening, checking their breasts with reduced fear, and increased BCA self-efficacy behaviours (Arndt and Goldenberg, 2017). This is particularly pertinent to women who are at an increased breast cancer risk, arguably including women with NF1, who often unknowingly engage in objectification detachment strategies to reduce this threat perception (Courtney and Goldenberg, 2021). This is evident in women with genetic mutations by being more likely to undergo risk-reducing surgeries prophylactically, and contralaterally following a unilateral diagnosis (Siegel et al., 2021; Marcinkute et al., 2022).

As demonstrated, both objectification and self-efficacy may contribute to fatalism/fatalism avoidance and therefore to behaviour avoidance/motivation within BCA. However, objectification, both of social and self-capacities, are not as characteristically explored as self-efficacy, which therefore arguably omits a crucial part to a greater understanding to designing women's health awareness interventions that comprise of anatomy such as breasts. They may be perceived as a taboo subject through misunderstanding (Kapoor and McKinnon, 2021), or one that attaches stigma to it, due to its association with cancer and therefore death (Balmer et al., 2014). Goffman (2014) explains stigma as socially unacceptable. Stigma in this context, relates to it not being socially acceptable to talk about breasts, or BCA behaviours. Self-efficacy is a dominant facet in a variety of behaviour change theories including protection motivation theory (Rogers, 1983), the health belief model (Rosenstock, 1974), the theory of planned behaviour (Ajzen, 1991), and social cognitive theory (Bandura, 1996; 2004). Objectification, although not blatantly stated, can also be incorporated within some, such as social cognitive theory. This theory posits that behaviour results from both social influence and cognitive processes that are based on the principle of 'triadic reciprocity' whereby the three facets of person, behaviours, and environment influence each other (Figure 9) (Al Rawahi et al., 2020).

Figure 9

Bandura's Social Cognitive Theory



Bandura (1998) argues that modelling, physiological experience, social persuasion, and mastery experiences are all facets that influence self-efficacy that aid in the formation of behaviour. Both facilitators and impediments are also considered to gain a greater understanding of the behaviour that is to be actioned upon. Within this theory, objectification can also be examined, particularly as a sociocultural factor that has been evidenced to act as an impediment due to the socially constructed sexual objectification of breasts, but also as a facilitator, as an act of self-objectification to develop less fear and fatalism towards a BCA intervention (Courtney and Goldenberg, 2021). There is evidence that campaigns as exemplified by Know your Lemons Foundation (2021) that objectify breasts (in this case as lemons), are showing success in increasing early detection and survivorship, with a steady annual decrease of 1.3 percent in breast cancer deaths since 2010 (US figures) (National Cancer Institute, 2022), similar to the time when the first instances of BCA objectification campaigns are noted approximately in 2008 (Courtney and Goldenberg, 2021). However, there is a need for this approach to be expanded upon within the design of a psychological theory-based BCA intervention to gain a better understanding for transference to other campaigns.

2.7 Health literacy levels and breast cancer awareness

Health literacy is a critical component in improving health behaviours, improving health outcomes, enhancing self-management skills, addressing health inequalities, and for aiding in the prevention and control of noncommunicable diseases (Gibney et al., 2020). Health literacy is a person's capacity within their own individual context, to obtain and interpret information to manage and improve health (Liu et al., 2020). It involves having literacy and numeracy skills, language, understanding, knowledge, and a confidence to access, understand, evaluate, utilise, and navigate health information and services (Public Health England, 2015). This wide-ranging concept of health literacy can be summarised as consisting of three levels (Nutbeam, 2000; Nutbeam et al., 2018):

1) **Basic/functional health literacy:** the reading and writing capacities that assist in health concern understanding.

2) **Communicative/interactive health literacy:** the ability to apply one's health and wellbeing knowledge to new circumstances for active participation in healthcare, and engagement with a wider variety of health information.

3) **Critical health literacy:** the ability to critically think and objectively analyse health information.

Low levels of health literacy are associated with poor health outcomes (Bergström et al., 2014), including difficulties in accessing healthcare providers and services (Marquez and Ladd, 2019), a limited knowledge of diseases, a decline in health promoting, and disease detection behaviours (Rudd, 2013; Gibney et al., 2020). Limited health literacy can reduce opportunities for individuals to develop the capabilities needed to be actively involved in decision-making, which can debilitate their ability to manage their own health (WHO, 2013). Within the literature, it often states that an *adequate* level of literacy is required for individuals to communicate effectively with HPs, to obtain, share, and understand information (Muscat et al., 2021). However, it is not explicitly stated what this 'adequate level' is. The onus is squarely placed on the patient to have the 'adequate level of literacy', despite 43% of adults aged 18 – 65 years in England not having adequate literacy skills to understand health information, and 61% not having adequate numeracy skills to comprehend health information (Rowlands et al., 2015). Irish research findings summarised by the HSE (2022b) communicate a similar message, with 38.8% of Irish people having limited health literacy. Putting this further into perspective, it is recognised that most adults in England are in the 11-14-year-old reading age group, which is at or below Level 1 of the literacy national standard, as set out by the government's *Skills for Life Survey* (2012). Writing health materials for those with low literacy skills is required to increase patients' access and understanding of their health needs (Marquez and Ladd, 2019). Health materials are often poorly written, with research demonstrating that health information is difficult for the layperson to understand, and therefore can impede the ability to make appropriate health management decisions (Pretheroe et al., 2015; McClure et al., 2016; Tran et al., 2018). While specialised medical language needs to be translated as best as possible into lay terms, HPs and scientists may instead be used to writing for their peers instead of the layperson, there may be no alternative to certain terminology, or there may be a fear that by generalising their findings, they become inaccurate (Salita, 2015). However, this can make accurate information non-accessible for many (NHS, 2020).

Widely used formats for accessible information delivery include computer software, easy-read information, Internet-based systems, and audio systems (Oldrieve and Waight, 2013). Finding free reliable health information in an accessible online format that increases health literacy and that is written for a low reading level can be difficult, with online information potentially being either too complex to understand, or unreliable (Marquez and Ladd, 2019) creating learning complexities (Biancovilli et al., 2021), and misinformation (Wang et al., 2019; Barua et al., 2020). Developing higher health literacy levels is important when exposed to online sources, with Diviani et al. (2015) finding an overall positive association between health literacy and an individual's ability to evaluate online health information. With online information, limited information accuracy is a significant risk, often the result of the ability for anyone to potentially publish health-related information online (Diviani et al., 2015). Health misinformation are health-related claims of stated fact that are incorrect due to a lack of scientific evidence (Chou et al., 2018). This could either be deliberate to cause harm or may have been created without the intention to cause harm, with these referred to as disinformation and misinformation respectively (Suarez-Lledo and Alvarez-Galez, 2021).

Misinformation on noncommunicable diseases is particularly prevalent within media sharing platforms whereby users can broadly describe disease symptoms, therapies, and medical treatments (Loeb et al., 2019). Evidence of numbers of page visits and 'likes' can convey arguments as more convincing for those seeking health information, or the application of scientific language with logically structured statements that match scientific community rationality can make a reader believe that the information is accurate (Faase et al., 2016). Plunkett and Pilkington (2024) reported that whilst women with NF1 cited using evidence-based sources such as cancer charities for BCA information, there was also a reliance on networking sites, and social media with these being influential health platforms for knowledge acquisition (Capurro et al., 2014). This reliance on information that may not always be evidence-based may negatively affect health literacy levels (McGloin and Eslami, 2015). Social media platforms have demonstrated usefulness for certain health promotions such as dietary behaviour change (McGloin and Eslami, 2015), and for empowering patients whereby they have a platform to aquire information about a medical condition, communicate with HPs, share experiences, and support others with the same condition (Househ et al., 2014). Likewise, effective use of social media by HPs and organisations can function as an influential real-time tool for the implementation and dissemination of important prevention, screening, and treatment behaviours (Xu et al., 2016). However, false or misleading health information may also spread more easily on these platforms (Vosoughi et al., 2018). Individuals that are exposed to misinformation may become more vulnerable to subsequent misinformation, misinterpretation, and overstatements that can lead to confusion, and mistrust in scientific reporting (Diviani et al., 2015). Health consequences such as a decrease in vaccination uptake (Wilson and Wiysonge, 2020), and anti-cancer screening messages (Okuhara et al., 2017) that affect screening attendance, for example, negatively affect health-literacy levels, and self-efficacy in not only knowing, but having the confidence to perform a health behaviour.

Within this research, it is important to consider that learning difficulties and cognitive impairments are common manifestations of NF1 (Acosta et al., 2012; Lehtonen et al., 2015; Vogel et al., 2017), with these also negatively affecting levels of health literacy. Cognitive impairments can affect up to 80% of children with NF1 (Hyman et al., 2005), with behavioural difficulties such as attention deficit hyperactivity disorder, and autism spectrum disorder (Garg et al., 2013; Morris et al., 2016). Research findings for adults with NF1 have been found to vary in relation to attention and motor learning (Castricum et al., 2022). However, it emerges that NF1 is associated with an average but mildly reduced overall IQ that is stable over the course of a lifespan (Potter and Mendoza, 2019). Variations in findings are not surprising, given the high degree of variability of NF1 making it difficult to predict which individuals will experience the greatest learning difficulties (Geoffray et al., 2021). Other comorbidities experienced with NF1 may also affect learning and cognitive function, such as epilepsy and hydrocephalus (Geoffray et al., 2021). Social determinants such as the home environment, economic hardship, or childhood adversities can also have an impact on learning, health, and behaviour (Zhang et al., 2020), with socioeconomic challenges affecting both the functional and structural brain development during early childhood (Fox et al., 2010) that can subsequently impact adulthood. As individuals with NF1 age, the reduction in academic performance continues, particularly in reading and writing skills (Geoffray et al., 2021). Hou et al. (2020) suggest that the inability for those with NF1 in childhood to keep up with their peers causes them to fall further behind, notably if social impairments or ADHD exist (Morris et al., 2016), subsequently negatively affecting health literacy levels.

Those with low levels of health literacy are also less likely to participate in decision making pertaining to their own health (Altin and Stock, 2016). Conversely, those with improved levels of health literacy are enabled to move progressively towards greater autonomy and empowerment (Walters et al., 2020) when managing conditions and making informed health decisions. However, adults with NF1 have a decreased uptake of health management and monitoring due to low levels of health literacy, whereby a lack of accessible and evidence-based disease knowledge pertaining to disease-monitoring guidelines for NF1, and often inaccurate personal perceptions and beliefs about the condition (Crawford et al., 2016) negatively affect attempts to build health literacy levels. This can be further explained by applying the health belief model (Rosenstock, 1974) which is chiefly based on core beliefs pertaining to perceived susceptibility, perceived severity, and perceived benefits. Crawford et al. (2016) reported that some individuals with NF1 were unable to identify the benefits of health monitoring due to an incorrect perception that nothing could be done for NF1. The dismissal or lack of awareness of perceived benefits of preventative action, such as BCA in this research’s instance, therefore also influenced these individuals’ perceived susceptibility and perceived severity of NF1. The findings further revealed that many adults with NF1 who perceived themselves to be healthy irrespective of disease severity, held the belief that the condition posed no threat to their health. This also aligns with Plunkett and Pilkington’s (2024) research that found that young women with NF1 were not aware of their susceptibility of the five-fold increased risk of developing breast cancer at a younger age, that they were entitled to earlier breast cancer screening, or indeed at all.

Not having the correct information related to disease-monitoring guidelines for NF1, or evidence-based information pertaining to breast cancer risk associated with the condition can affect a person’s sense of control with making health decisions. A sense of autonomy, or a perceived behavioural control within the individual, is important for effective behaviour change to occur. This is evident in several theories of behaviour change and maintenance, such as the theory of planned behaviour (Ajzen, 1991), and self-determination theory (SDT; Deci and Ryan, 1985). Within the theory of planned behaviour, perceived behavioural control plays a pivotal role, moderating the link between behavioural intentions and the desired behaviour, with intentions therefore more likely to lead to behaviour when a person is in possession of high levels of perceived behavioural control, rather than lower levels (Prestwich et al., 2018). Within SDT, the perception of having autonomy is important for influencing the level and type of motivation for behaviour. This works in tandem with levels of relatedness of needing to have a sense of connectedness to others, and competence as an experience of mastery (Ryan and Deci, 2017). Without autonomy or perceived behavioural control due to low levels of health literacy, it subsequently impacts on the other components within SDT. By not having accessible tools to increase health literacy (competence), it reduces the ability of an individual to perceive that they are part of the decision-making process (autonomy) within a patient-professional setting (relatedness).

2.8 Healthcare professionals’ knowledge of, and approaches to, rare disease

HPs can play an important part in promoting a health-literate environment (Marquez and Ladd, 2019). However, a barrier to communicative/interactive health literacy is placed against a HP when there is a lack of rare disease knowledge which subsequently hinders engagement with a wider variety of health information pertaining to the condition. Susceptibility to online misinformation is not only experienced by the layperson. Suarez-Lledo and Alvarez-Galvez (2021) reported that HPs often utilise social networks for information on noncommunicable diseases, with this cohort evaluating online health content as adequate for health training. Domaradzki and Walkowiak (2021) found that medical, physiotherapy, and nursing students reported that the Internet was the most valuable resource for information on rare diseases. In an earlier study (Domaradzki and Walkowiak, 2019), 51.7% of medical student respondents cited that they obtained their knowledge about rare disease from mandatory courses, and 22% from elective courses, however, 59.8% of these respondents also deemed the Internet as an essential source for information on rare diseases. This is congruent with reports from interviews conducted with women with NF1 (Plunkett and Pilkington, 2024), whereby HPs were described as using the Internet to gather information about NF1 during consultation times with some of these women. However, Pauer et al. (2017) evaluated rare disease information found on the Internet as low, with similar findings for selected platforms such as YouTube that is evaluated as an information source for health students, establishing that this is not an advisable source for HPs, or furthermore, any health information seekers.

Rare diseases are often complex, progressive, and chronic, frequently requiring the necessity of multiple specialist healthcare facilities on an ongoing basis (Anderson et al., 2013; Karpman and Höglund, 2017). Individually one type of rare disease may be atypical, however when rare diseases are collectively counted, the number of individuals that experience a rare disease globally amounts to 400 million, with this being greater than the entire population of the United States of America (Global Genes, 2021). Diagnosing a rare disease is difficult, sometimes necessitating biotechnological involvement (Walkowiak and Domaradzki, 2021). Despite the development of modern technologies such as Artificial Intelligence, and next-generation sequencing to provide opportunities to accelerate the diagnosis of rare diseases and develop treatments (Liu et al., 2019), there remains a need to increase rare disease knowledge amongst HPs (Bokayeva et al., 2021). A significant contribution to delays in diagnosis is often a human one, with evidence being overlooked that may delay a diagnosis or contribute to a misdiagnosis (Walkowiak and Domaradzki, 2021). A lack of knowledge of less common conditions amongst HPs, such as those found within rare diseases, are cited as a major contributing factor to delays in diagnosis (Molster et al., 2016). Javaid et al. (2016) estimate that a quarter of patients surveyed with rare diseases experienced delays in diagnosis of between 5 and 30 years. It is therefore assumed that HPs will also lack important knowledge about associated risks, such as the increased risk of breast cancer in young women with NF1.

While it is not feasible to expect that HPs will be privy to information on every rare disease, it has been noted that one of the main ways to reduce diagnostic delays within rare diseases is to educate HPs about rare diseases (Kopeć and Podolec, 2015). The lack of rare disease knowledge has been reported previously both among students of various medical faculties, and qualified HPs (Kopeć and Podolec, 2015; Ramalle-Gómara et al., 2015; Domaradzki and Walkowiak, 2019; Ramalle-Gómara et al., 2020; Sanges et al., 2020; Domaradzki and Walkowiak, 2021). The approach to the education of rare diseases in medical schools has been cited as a major contribution to HPs' lack of knowledge in this area, with medical training of students often explicitly focusing on scientific foundations that are bolstered by a biomedical approach to more common disorders, rather than a critical and holistic one that includes a strong foundation of rare disease education (Domardzki and Walkowiak, 2021).

Within the UK the General Medical Council (GMC), and within the ROI the Medical Council, are responsible for setting the standards of medical education in their respective countries. The GMC provides a 'Curriculum for Clinical Genetics Training Implementation August 2021', outlining the training route and content of this course. While it is thorough in what it entails as evidenced by a 49-page online document, it only mentions the term 'holistic' three times throughout, with two of these referring to the holistic development of the professional rather than the holistic care and involvement of the patient, with one mention to 'holistic patient care' within a list, rather than a full section on what this is and what are the requirements to adopt this. No evidence of such publications towards rare diseases was evidenced within the ROI's Medical Council website. Despite the progress that has been made in medicine, there continues to persist a biomedical approach that is heavily influenced by the often-standard Cartesian philosophy of reductionism and duality, with biomedical training often neglecting both the humanistic and psychosocial facets of patient care, instead approaching disease as independent from the patient, and something that can be explained by abnormal clinical, pathological, and molecular markers (Kusnanto, 2018; Williams, 2019). This contrasts with the biopsychosocial model (Engel, 1980) that integrates social, psychological, and biological knowledge concurrently. Anjum et al. (2015) argue that a correct understanding of biology must include the psychosocial, where biology is influenced by contextual factors. While it has been argued that the biopsychosocial model is difficult to implement with no clear 'guidelines' that many within the medical field may be more accustomed to (Borrell-Carrió et al., 2004), the model itself is arguably one that instead requires an understanding of a holistic approach for it to be integrated within the day-to-day interactions with patients (Wittink et al., 2022).

High workloads and fatigue amongst established HPs may also create barriers to rare disease knowledge acquisition (McGowan et al., 2013), as these professionals often work within a healthcare model that is well designed to tend to those with common ailments but are often unsuitable for complex multisystem diseases (Van Groenendael et al., 2015) such as NF1 and its associated risks and comorbidities. The lack of knowledge of rare disease amongst HPs that routinely deal with more common conditions potentially impedes the ability to consider a suspected rare disease diagnosis (Sanges et al., 2020). Many HPs that do not have a speciality in rare diseases, particularly GPs, have frequently rated their rare disease knowledge as substandard or poor (Vandeborne et al., 2019). This lack of knowledge has been attributed to not knowing where accurate information about rare diseases can be sought, a perception that they only required rare disease information when a patient with a rare disease was attending their practice, and a lack of interest in training courses dedicated to rare diseases (Vandeborne et al., 2019). Online information sites such as Orphanet (2023) provide evidence-based information on rare diseases, however it has been noted that this is not always utilised, or even known about amongst GPs. Within a sample of GPs in Ireland, Byrne et al. (2020) reported that only 35.5% of those surveyed were aware of Orphanet, and only 12.9% had ever used this resource. Instead, the most used resource for finding information on rare diseases was found to be GP Notebook (2023) (17%), which is a medical platform providing information on a range of conditions. It is positively noted that in 2023 during this research, the platform was updated to communicate the increased risk of developing breast cancer with NF1 where previously no such information was available. Worryingly, the second most utilised resources amongst these HPs that encounter patients with rare diseases was found to be Google (15%).

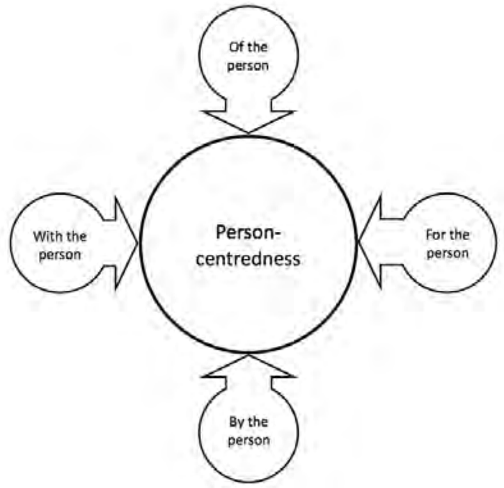
Both patients and their associates have reported frequently having to explain their condition to HPs included in their care (Nutt and Limb, 2011; Budych et al., 2012), with these individuals, particularly those with a rare disease, becoming ‘experts’ in their own condition as they attempt to decipher what is trustworthy and accurate amongst the limited information found online (Stephens et al., 2014). Within this research, associates of young women with NF1 can be identified as a relative, a friend, or a carer. Ramalle-Gómara et al. (2020) note that the patient becoming the ‘expert’ is experienced as a challenge for HPs who are not accustomed to their patients knowing more than them about an illness. This can also be assumed if the ‘expert’ is also an associate of the patient such as parents of children with rare diseases who demonstrate a more proactive approach to the involvement of care and decision-making (Gómez-Zúñiga et al., 2019). These parents can often feel frustrated with HPs’ lack of knowledge within rare diseases, often assessing this as the professional being unsupportive (Pelentsov et al., 2015). Associates of individuals with rare diseases may also be required to acquire knowledge on behalf of the patient if the patient requires support. Within this research’s focus, this may be because of the prevalence of learning difficulties within the NF1 population that has been discussed previously. Bryson et al. (2021) reported that many individuals with a recent diagnosis of a rare disease discussed their doctor’s lack of rare disease knowledge which often translated as HPs not believing their symptoms, not listening to the patient, the provision of inadequate treatment of symptoms, and a lack of compassion. Individuals often experience self-doubt, frustration, and anxiety when encountering insufficient HP knowledge (Vandeborne et al., 2019). This is akin to interview findings with young women with NF1 (Plunkett and Pilkington, 2024), whereby it was reported that HPs lacked NF1 knowledge and associated risks, with this being experienced as HPs being unsupportive towards them.

When rare conditions are not very well understood the patient or associate with rare disease knowledge can be incorporated as an ‘additional specialist’, with the potential of great value to be gained with partnering to understand the patients’ perspective (McCray et al., 2021). Despite the ‘Royal College of General Practitioners’ Curriculum: Being a General Practitioner’ (2019) acknowledging that patients experiencing long term health conditions are often experts in their illness management that GPs can learn from; from a power dimension perspective, the HP has a habitual motivation to ‘take the lead’. Deci and Ryan’s (1985) SDT can potentially be applied to better understand power relations within this instance. These individuals are traditionally assumed as having control and leadership, with autonomy and competence as medical expert, and relatedness arising from the patient-professional consultation time. However, within the rare disease community, where the patient often knows more about their own condition, the power dimension shifts. Patients come to the HP with autonomy and competence, necessitated by independent research into their condition to learn more, and relatedness often from the support received from support groups, and electronic resources such as social media (Long et al., 2022). With a lack of knowledge on the HP's part, and therefore lack of competence and autonomy as 'expert', a role reversal and a perceived 'loss of power' may occur.

The existence of these power dynamics reflects a lack of both a person-centred, and a holistic approach as applied within the biopsychosocial model. Person-centredness is a humanising theory in healthcare, and other practices, that aims to foster relationships of growth and empowerment within all parties involved (Jacobs et al., 2017). Mezzich et al. (2010) summarise person-centredness as promoting care within four aspects (Figure 10); *of the person* whereby all aspects of health are respectfully included, *for the person* which involves the active realisation of the individual's life project; *by the person* whereby HPs work to high ethical standards and are present as full human beings; and *with the person* which utilises a respectful and empowering mutual collaboration between both the HP and the patient.

Figure 10

The Aspects of Person-Centredness



The biopsychosocial approach, with its principal facets that address biological, psychological, and social components places the patient at the centre within the application of Mezzich et al.'s (2010) aspects of person-centredness. This challenges the biomedical approach by moving away from a 'one size fits all' method by seeing the individual with unique contextual factors (McCormack et al., 2017). Focusing on the patient's agenda within interactions, rather than that of the practitioner or system, facilitates person-centred decision making (Ekman et al., 2011). As the person-centred approach aims to respect the unique needs, experiences, and preferences of the individual (Moore et al., 2017; Eklund et al., 2019), there is an endorsement of the individual's capability and capacity to be in control of their own health and well-being (Ekman et al., 2011). This empowerment subsequently shifts the traditional power dimensions between patient and practitioner, placing the patient at the centre, in what is now both a relational and collective process (Zimmerman, 1995).

A 'therapeutic alliance' allows for both the patient and HP to align for growth and change (Kinsella, 2023). With a mutual agreement that both parties are 'experts' within their own rights, with patients as partners in rare disease diagnosis and research (McCray et al., 2021), both can experience a motivation for developing treatment plans, and an intrinsic motivation for the patient to partake in screening and awareness interventions, such as BCA, in this instance. Establishing a balance of power aids in ensuring good communication between all parties. This is a vital component of patient-centred care, constituting communication between HPs, patients, family members, and caregivers whereby patients are encouraged to provide health information to increase both understanding of their condition, and partnership (Epstein and Street, 2011).

2.9 Justification for only including women, and the application of 'woman', and 'female'

The fivefold increased risk of developing breast cancer at a younger age is specific to women with NF1. The BCA intervention within this research is therefore designed for this cohort due to the specificity of the statistical findings. On the surface, using the term 'woman' or 'female' may appear neglectful to inclusivity and gender-neutral language. However, within healthcare, the application of gender-neutral language does not always translate well to all fields, potentially creating instead an exclusionary action.

With 'woman', and 'female', and its plural counterparts being utilised, it is important to make explicitly clear the application of these terms within this research. The term 'woman' in the context of 'women's health' is applied to explain a field of medicine that concerns itself with matters of the female biological sex, just as the root of gynaecology stems from the Greek word for woman (Dahlen, 2021). 'Female' within sex is to be recognised as different to 'female' within gender. Sex refers to the genetic differences that start at conception and are concerned with chromosomes of either XX (female) or XY (male). Fundamentally, these are the differences in the molecular makeup of male and female cells (Arnold, 2017; Mauvais-Jarvis et al., 2020). Therefore, when 'female' is used within this research, it is to be only considered as biological, to recognise the molecular differences that can contribute to statistical risk factors as concerned here with the increased risk of breast cancer in young women with NF1.

'Female' as gender is instead a reference to socially constructed norms that is often met with much criticism and resistance due to its historical weight of this determining positions of power, roles, and relationships (Mauvais-Jarvis et al., 2020). I, as researcher, recognise that gender is not a binary term that is constructed of only 'male' and 'female', and respects that a person may describe gender incongruence, using terms such as (but not exhaustively) trans, gender minority, third gender, pangender, novigender, non-binary, transmasculine, gender variant, gender fluid, intergender, agender and gender non-conforming (Abrams and Ferguson, 2022).

Both gender and sex are important to consider within medicine, health, and disease, with both modifiers for mortality and morbidity. Genetic, hormonal, and epigenetic influences of biological sex affect disease and physiology, while the social constructs of gender can affect behaviour of not only patients, but also of HPs, and the wider reach of community (Mauvais-Jarvis et al., 2020). However, to increase inclusivity within not only this research, but within the literature of both women's health and healthcare interventions, the omission of the term 'female' that may be interpreted as socially constructed and therefore as an exclusionary act, on any participant information, recruitment material, or publications is undertaken. Instead 'woman' or 'women' is utilised to reflect what is meant within the field of women's health and its studies. Within the research itself the term 'female' is only utilised when is absolutely required within the capacity of demonstrating biological sex that relates to the important statistic that is relevant to this research, or as utilised as a common inclusion criterion within the conducted systematic review (Chapter Three) to study the effect of BCA interventions among young women.

With the frame of reference of considering effects at a molecular level and therefore at the breast tissue level, it is conceded that it is not possible to be entirely inclusive. The design of BCA interventions is one such area of healthcare where this is exemplified. It is not viable to have one entirely inclusive 'one size fits all' BCA programme for everyone. Breast cancer is complex and is made up of differing subtypes based on stage, grade, and hormone receptor, and can vary depending on genetics, sex, and age, for example. While every human has breast tissue and is at some risk of developing breast cancer, this does not equate to the same risk calculation for everyone.

Men are excluded within this research as breast cancer is rare in this cohort with about 1% of breast cancer cases within the UK occurring in males (Cancer Research UK, 2020c). Specific to NF1, findings from research do not assign the five-fold increased risk to men with NF1. Only individual cases of male breast cancer and NF1 have been found to be reported, with no firm associations established within this cohort (Lakshmaiah et al., 2014; Tandon et al., 2015; Evans et al., 2020). Following the same line of argument, transgender men and women are also excluded. The term transgender is an individual who identifies as a gender opposite to the one assigned at birth (Sieberg et al., 2021). Within transgender and breast cancer risk studies, data is limited and often conflicting due to other factors such as variation of factors such as the ingestion of hormones for therapy, and mastectomy for breast removal, creating heterogeneity in population cohorts (Braun et al., 2017). De Blok at al. (2019) communicate that transwomen who receive hormone treatment are at an increased risk of developing breast cancer compared to cismen, however the risk is found to be 70% lower across the lifetime compared to ciswomen. Cisgender describes individuals who identify with the sex and gender assigned at birth (Abrams and Ferguson, 2022). Among transwomen in a general population, most tumours have predominantly been found to be ER+ and PR+ positive, with only 8.3% being HER2 (de Blok et al., 2019). This differs to the often more prevalent and aggressive subtypes such as HER2 found in young women with NF1. Within the same study, it was found that there is a lower risk among transmen compared to ciswomen in developing breast cancer.

To the best of the researcher's knowledge, no research is yet available that communicates population numbers of transmen and transwomen with NF1 within the UK and ROI, or that demonstrates molecular analyses of breast cancer subtype and statistical risk of developing breast cancer with this genetic condition within this cohort. However, based on available research concerning differences between general population statistics of transmen and transwomen, and cismen and ciswomen, it can be cautiously concluded that statistical risk differences may also exist between transmen and transwomen with NF1 and cismen and ciswomen with NF1. It is therefore argued that it is not possible to include transgender individuals with NF1 within this research that communicates a specific five-fold increased risk of developing breast cancer at a younger age.

Finally, it is recognised that not everyone identifies with the term ‘woman’ or ‘women’, and some individuals may associate female anatomical terms such as ‘breasts’ to historical ‘female’ (socially constructed) oppression. However, while removing socially constructed gender terms like ‘female’ can and should be done unless arguably required, within some health research it is not always possible to be absolutely gender neutral. This research is an example of this. While we may utilise ‘individuals with a cervix’, which is part of the female’s biological anatomy, this attempt to be more inclusive and use a more gender-neutral phrase may in fact exclude individuals due to the confusion for some of what is a cervix, or the exclusionary act of using jargon-heavy terminology, potentially creating a negative effect on cervical screening (Quann, 2020). The issue becomes deeper within BCA. It is not possible to communicate ‘individuals with breasts’ in this regard, knowing that whilst everyone has breasts, the statistical risk differs from cohort to cohort. Dahlen (2021) argues it is a concern that changes to gender inclusive linguistics may have the unintended consequence of making biological sex less visible and more challenging to explain in healthcare. Therefore, the potential of neglecting more individuals in striving for inclusivity exists. While some have argued for using ‘chestfeeding’ instead of ‘breastfeeding’ (Dahlen, 2021) to be more inclusive, it becomes quite evident the serious issue that would be faced if this was done within BCA. Anatomically, ‘chest’ can be considered very differently to ‘breast’, arguably communicating different cancers, alongside the ensuing confusion. Using breasts and woman(en) is therefore essential in this research. Importantly, the communication within health interventions should be clear with messages that can be understood. Poor communication contributes to social isolation and low self-esteem, with these being associated with poorer health outcomes (Jackson et al., 2014).

Focusing within this research alone and based on the evidence presented, it is important to communicate ‘young women with NF1’ rather than ‘individuals with NF1’. Removing the term ‘woman(en)’ would make the specific statistical risk for this cohort null and void. It would also be erroneous to disseminate. The word ‘woman(en)’ is also utilised within this research to carry continuity across the valuable work within research and awareness surrounding breast cancer, with charities such as the American Cancer Society, the Irish Cancer Society, the National Health Service (UK), Breast Cancer Now, and the Health Service Executive Ireland, all using the term ‘woman’.

2.10 Conclusion

It is important that a BCA intervention is designed that is easily comprehended by as many individuals as possible. This is particularly pertinent within BCA for individuals with NF1 that may have a learning difficulty, as those with a learning disability are less likely to attend cancer screening compared to the general population, owing to several factors including fear (Byrnes et al., 2020). Decreased levels of health literacy may also negatively affect self-efficacy of young women with NF1 to be breast cancer aware, with Plunkett and Pilkington (2024) reporting uncertainty in BCA within an NF1 context of what to be aware of. It is also pertinent that the design is inclusive, considering that some associates may be better placed to deliver the intervention information to some young women with NF1 that may have significant levels of learning difficulties.

Panieri (2012) states that for effective early detection, women need to be both educated on how to recognise breast cancer signs and encouraged to consult a HP promptly if any changes are discovered. It is by better understanding through exploration of issues particular to women’s health, and more broadly women with NF1 that have been explored within this chapter, that more successful efforts to have women confidently present to a HP may be observed. This confidence to present to a HP also furthers the potential for a person-centred approach to occur, whereby they can be placed, and place themselves within the centre of care.

2.11 Summary of chapter key points

- Women with NF1 have an up to five-fold increased risk of developing breast cancer before the age of 50 years.

- The terms ‘woman’ and ‘female’ are used within this research, in the context of ‘women’s health’, a field of medicine that concerns itself with matters of the female biological sex, rather than of the socially constructed gender.
- Despite the increased earlier risk of breast cancer, earlier screening for women with NF1 occurs only from 40 years within the UK and Ireland. It is therefore important that young women with NF1 have a good awareness of breast cancer signs and the associated increased risk of developing breast cancer at a younger age.
- Barriers that women with NF1 may experience to being breast cancer aware also include the effects of the objectification of the woman’s body, and health literacy levels.
- HPs have been found to have low levels of rare disease knowledge often hindering care, BCA, and a person-centred approach. This contributes to power imbalances.

2.12 The next stage of the research

Having explored important findings pertaining to BCA, screening, barriers to becoming breast cancer aware, and associated risks of developing breast cancer at a younger age within a broad and NF1 specific context, it is important for the design and implementation of an NF1 BCA intervention to consider literature findings surrounding the effects of such interventions. However, with a dearth of NF1 BCA literature, it is not feasible to conduct a systematic review that is as specific as one would wish. The following chapter explores by systematic review, another important aspect specific to this research, of that being the effect of BCA interventions specifically on young women.

Chapter Three

The effect of breast cancer awareness interventions on young women aged 18-50 years: A systematic review

3.1 Rationale

Ideally, a systematic review would be conducted to investigate breast cancer awareness (BCA) interventions among young women with NF1 to gain a better understanding of methods that have been found to be effective within this cohort, and to support a clearer direction towards the design and implementation of a novel NF1 BCA intervention. However, when entering search terms and Boolean phrases without any limitations being imposed such as language or publication date ranges of "breast cancer aware*" OR "breast aware*" OR "breast self-exam*" OR "breast self exam*" AND intervention OR program OR programme OR educat* OR promot* AND woman OR women OR "young woman" OR "young women" OR student AND "neurofibromatosis 1" OR NF1 OR "neurofibromatosis type 1", 0 results were returned in the databases of Cochrane Library (CENTRAL), APA PsycArticles, APA PsycInfo, MEDLINE, The Cumulative Index to Nursing and Allied Health Literature (CINAHL), and Web of Science. Within the Applied Social Sciences Index and Abstracts (ASSIA), 5 results were returned, however, none of these were BCA interventions in the first instance, let alone related to NF1.

While that systematic review was not possible to undertake within the search terms and Boolean operators specified, considering another influential dynamic of age that necessitates consideration within this thesis, the main concentration to examine became that of a specific cohort of *young women*. While the feasibility study will focus on young women with NF1 aged 18 – 40 years, early-onset cancers are those diagnosed in adults between the ages of 18 and 49 years (Katella, 2024), with the cohort of young women that get diagnosed with breast cancer often categorised as those that are younger than 50 years (Valdez et al., 2024). Therefore, this systematic review will focus on young women and therefore includes those within the age range of 18 – 50 years, allowing for BCA considerations that may also be applicable to young women with NF1. However, much of the BCA literature does not always explicitly state or specifically recruit younger women aged 18-50 years, often requiring a thorough search to investigate the literature to discover age ranges that have a younger cohort of under 50 years, either by design or by coincidence.

While there is substantial literature available concerning BCA, much of it explores individuals' attitudes towards specific components of BCA such as screening (e.g. Eibich and Goldzahl, 2020), and breast self-examination (e.g. Nde et al., 2015), or it aims to examine BCA levels of particular cohorts such as those within particular communities (e.g. Mena et al., 2014 (rural Ghana); Dey et al., 2015 (Delhi, India); Chattu et al., 2018 (Buraimi, Oman)), there is considerably less within the literature that directly measures several outcomes simultaneously of BCA. Furthermore, there is a prevalence of this literature being aimed at older women that are over 50 years of age (e.g., Linsell et al., 2008; Forbes et al., 2011), or at *all* and *any* women (Taha et al., 2014; Talib et al., 2016; Laughman et al., 2017). A scarcity of research has been conducted with a purposeful aim to examine BCA between the ages of 18 to 50 years inclusive. This omission within the literature overlooks important differences that may not only consequently affect BCA levels, but also education preferences within this younger cohort.

Screening is not available until the age of 50 years for the general population, and currently from the age of 40 years for women with NF1 within the UK and ROI. It is therefore important for those within a younger cohort to have an awareness of breast cancer risk, screening eligibility, and the general signs and symptoms of breast cancer. While young women, particularly those under the age of 50 years with NF1 have an up to five-fold increased risk of developing breast cancer (Maani et al., 2019), all younger women, no matter their genetic makeup, are more likely than older women to present with aggressive subtypes of breast cancer if they develop the disease, and at a more advanced stage translating into poorer survival compared to older women (Cathcart-Rake et al., 2021). Breast cancers among young women often have high-risk features that include oestrogen receptor negative or HER2 subtype with a high grade 3 histology and lymphatic penetration (Parker et al., 2009). It is therefore worthy to investigate which interventions have a significantly positive effect on BCA among young women who are aged under 50 years.

Within Almutairi et al.'s (2019) systematic review conducted to examine knowledge and awareness of breast cancer and risk factors among young women (age range across studies of 14-52 years), the importance of BCA within this cohort is highlighted to aid in lowering breast cancer mortalities. The importance of detecting breast cancer early by increasing BCA therefore cannot be overstated. However, BCA appears to be multi-faceted and variable within its components of what is understood as BCA, including terms that have been carried over owing to historical influences such as breast self-examination (BSE) which traditionally followed repetitive palpations of a formally taught set method at the same time each month to detect any breast changes (Thornton and Pillarisetti, 2008). However, within today's contemporary societies, particularly those with more advanced healthcare systems, there is a reduction in BSE utilised as a stand-alone intervention. Rather, it has become incorporated as a BCA component alongside screening and risk factor education, and understood more broadly as awareness, rather than a rigorously set breast examination. Despite this, to the best of the researcher's knowledge, no recent systematic reviews investigating BCA interventions have included BSE as a search term (e.g., Anastasi and Lusher, 2017; O'Mahony et al., 2017).

3.2 Objectives

The objectives of this systematic review are outlined within the PICOS Table 3, demonstrating that the aim is to assess the effect of BCA interventions on young women's (aged 18-50 years) breast cancer awareness knowledge levels compared to standard available care, or no intervention.

Table 3

PICOS Table

Item	Definition
Population	Women aged 18 years to 50 years.
Intervention	Interventions that impact on BCA knowledge levels.
Comparison	Standard available care or no intervention.
Outcome	Self-reports and/or use of any measurements that measure BCA components.
Study design	Experimental design (e.g., RCT, CCT) or quasi-experimental design of pre-post-test design studies.
Proposed search terms	"breast cancer aware*" OR "breast aware*" OR "breast self-exam*" OR "breast self exam*" AND intervention OR program OR programme OR educat* OR promot*AND woman OR women OR "young woman" OR "young women" OR student
Proposed Limits	English language, only those with primary outcome of BCA knowledge (not only breast self-examination, for example).

Proposed Search Sites	Cochrane Library (CENTRAL), APA PsycArticles, APA PsycInfo, MEDLINE, ASSIA, CINAHL, Web of Science.

3.3 Methods

Research design

This systematic review is conducted in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) checklist. Methods of the analysis and inclusion criteria were neither specified in advance, nor documented in a protocol.

3.4 Eligibility criteria for considering studies for this review

Studies

Experimental design (randomised controlled trials (RCTs) or controlled clinical trials (CCTs)) or quasi-experimental design of pre-test and post-test design studies that examine the effect of BCA interventions on young women's (aged 18-50 years) BCA knowledge levels were considered. Studies found on MEDLINE, ASSIA, CINAHL, Web of Science, Cochrane Library, APA PsychArticles, and APA PsychInfo published in their entirety in English, within the period of 2012 – 2022, and with an outcome of BCA knowledge of young women were eligible for inclusion.

Journals from 2012 onwards have been included to reflect a move away from an often-considered outdated method of BSE as a rigorously followed technique that has been attributed to psychological distress particularly among hypervigilant individuals (van Dooren et al., 2003). Instead, BSE within contemporary foci of highlighting awareness of what is normal for the individual, signs of breast cancer, and an education on screening eligibility and risk is adopted.

Participants

Females aged between 18 and 50 years (inclusive) were specifically targeted. Participants that were not within this age range, or any studies that did not explicitly state the age range for all participants were excluded. There were no restrictions placed on the setting of where individuals were recruited, such as within a clinic or educational setting.

Intervention

Studies comparing the effect of BCA interventions on young women's (aged 18-50 years) BCA knowledge levels with standard available care, or no intervention comparison were included.

Outcome measure

Studies that included either primary or secondary outcome measures of BCA knowledge levels were regarded as the principal outcome measure. Self-reports by participants, and/or use of any measurements that measure components of BCA (e.g., breast cancer risk, screening methods, signs of breast cancer, BSE) rather than as a standalone intervention were included.

3.5 Search methods for the identification of studies

Seven databases of MEDLINE through PubMed, Cochrane Library (CENTRAL), APA PsycArticles, APA PsycInfo, ASSIA, CINAHL, and Web of Science were searched by the Principal Investigator (PI) from 2nd to 9th November 2022 inclusive, with it important to have this conducted before commencement of intervention design in December 2022.

It is acknowledged that database selection should be directed by the review topic (Lorenzetti et al., 2014). Web of Science was included as it is recognised as the world's leading scientific citation search and analytical information platform (Li et al., 2018). MEDLINE is recommended by Cochrane for its broad wide-ranging database, consisting of over 25 million references to journal articles pertaining to health matters (Lefebvre et al., 2022). With BCA interventions also researched by nursing and allied health professionals, CINAHL, accessed through EBSCOhost, was also included with full text publications available that target these research audiences. Both APA PsycArticles and APAPsychInfo were also searched through EBSCOhost and were included as they provide information on psychological studies, and psychological interventions such as that within BCA behaviour. While APA PsycArticles provides full-text and peer reviewed articles from top-cited psychology journals, APA PsycInfo only provides abstracts and index resources (APA, 2022). This is similar to ASSIA (accessed through ProQuest), but it was deemed necessary to include this database due to its inclusion of pertinent areas within this research including health, psychology, and education (ProQuest, 2022). Cochrane's Central Register of Controlled Trials (CENTRAL) also does not contain full article texts, but it was included to identify studies as it is a source of randomised and quasi-controlled trials (Cochrane, 2022). Access to the papers' full texts were subsequently found within the other included databases such as CINAHL, and PubMed and through the online library provided by Manchester Metropolitan University.

Only research in English was reviewed due to not having translation services. Search strategy details can be found in Table 4. There were slight variations in limiter terms depending on the database to align as closely as possible to the eligibility criteria. Despite limitations varying in words due to database search engine differences, search terms and Boolean phrases remained constant:

"breast cancer aware*" OR "breast aware*" OR "breast self-exam*" OR "breast self exam*" AND intervention OR program OR programme OR educat* OR promot* AND woman OR women OR "young woman" OR "young women" OR student

Table 4

Set Limits Within Databases

Database	Limits
Medline (through PubMed)	Case reports, Clinical study, Observational study, Randomised controlled trial, in the last 10 years, English, Female, Medline.
APA Psychinfo	Publication year 2012-2022, Academic journals and dissertations, English, Adulthood (18 years and older), Quantitative.
APA PsychArticles	Publication year 2012-2022, All journals, English, Adulthood (18 years and older), Quantitative.
Web of Science	2012 -2022, Open Access and Early Access, Document types: Article and early access, English.
Cochrane Library	2012-2022, trials.
ASSIA	2012-2022, English, Scholarly journals, dissertations, and theses. Article, English.
CINAHL	2012-2022, Female, All adult, Academic journals, English.

With MeSH terms available for MEDLINE, these were also utilised to widen the inclusion of potential literature suitable for the systematic review. The final search for MEDLINE with MeSH terms is outlined in Table 5. However, an extensive search of variation in terminology and phrases through literature and previous systematic reviews was conducted prior to final determination of search terms and Boolean phrases employed, with the * function utilised to broaden the possible stem variations of words within all database searches.

Table 5

MEDLINE MeSH Search

MEDLINE	Search results
(("breast cancer aware*"[All Fields] OR "breast aware*"[All Fields] OR "breast self exam*"[All Fields] OR "breast self exam*"[All Fields]) AND ("intervention s"[All Fields] OR "interventions"[All Fields] OR "interventive"[All Fields] OR "methods"[MeSH Terms] OR "methods"[All Fields] OR "intervention"[All Fields] OR "interventional"[All Fields] OR ("program"[All Fields] OR "program s"[All Fields] OR "programe"[All Fields] OR "programed"[All Fields] OR "programes"[All Fields] OR "programing"[All Fields] OR "programmability"[All Fields] OR "programmable"[All Fields] OR "programmably"[All Fields] OR "programme"[All Fields] OR "programme s"[All Fields] OR "programmed"[All Fields] OR "programmer"[All Fields] OR "programmer s"[All Fields] OR "programmers"[All Fields] OR "programmes"[All Fields] OR "programming"[All Fields] OR "programmings"[All Fields] OR "programs"[All Fields]) OR ("program"[All Fields] OR "program s"[All Fields] OR "programe"[All Fields] OR "programed"[All Fields] OR "programes"[All Fields] OR "programing"[All Fields] OR "programmability"[All Fields] OR "programmable"[All Fields] OR "programmably"[All Fields] OR "programme"[All Fields] OR "programme s"[All Fields] OR "programmed"[All Fields] OR "programmer"[All Fields] OR "programmer s"[All Fields] OR "programmers"[All Fields] OR "programmes"[All Fields] OR "programming"[All Fields] OR "programmings"[All Fields] OR "programs"[All Fields]) OR "educat*"[All Fields] OR "promot*"[All Fields]) AND ("womans"[All Fields] OR "women"[MeSH Terms] OR "women"[All Fields] OR "woman"[All Fields] OR "women s"[All Fields] OR "womens"[All Fields] OR ("womans"[All Fields] OR "women"[MeSH Terms] OR "women"[All Fields] OR "woman"[All Fields] OR "women s"[All Fields] OR "womens"[All Fields]) OR "young woman"[All Fields] OR "young women"[All Fields] OR ("student s"[All Fields] OR "students"[MeSH Terms] OR "students"[All Fields] OR "student"[All Fields] OR "students s"[All Fields]))) AND ((y_10[Filter]) AND (casereports[Filter] OR clinicalstudy[Filter] OR clinicaltrial[Filter] OR observationalstudy[Filter] OR randomizedcontrolledtrial[Filter]) AND (female[Filter]) AND (medline[Filter]) AND (english[Filter]))	33

3.6 Study selection

Eligibility assessment was performed independently by the PI. An inclusion-exclusion screening table (Appendix A) was utilised to determine suitable studies for review. From the results returned from the database searches (Table 6), titles and abstracts were screened. Those that included some evidence that participants were potentially young women aged 18-50 years, and that BCA was an outcome measure within an awareness intervention were included. Following this, those that were considered as possibly meeting the inclusion criteria, or where there was an uncertainty with whether it met the criteria or not, were read in their entirety to ascertain suitability. No investigators or sponsors of papers were contacted; therefore, research with missing information such as study methods or results were excluded. Papers were also omitted from the review when there was uncertainty pertaining to participant ages, or where age ranges were not clearly specified (e.g., Olgun and Dizer, 2021; Ranganath et al., 2020). Duplications were noted and removed.

Table 6

Returned Results of Each Database

Database	Results
Web of Science	333
CINAHL	165
ASSIA	138
APA Psychinfo	101
MEDLINE	33
Cochrane Library (CENTRAL)	23
APA PsychArticles	0
Total results number	785

3.7 Data extraction

Data extraction tables were based on a template offered by the university (Appendix B). The following data were extracted (Table 7): sample size, age range, study design, time point studied, intervention description and location, control intervention description, measure of BCA, and time point studied. Table 8 outlines analyses and findings. Information accuracy was not verified with the primary researchers. Included research studies were evaluated to confirm that they were not a multiple report of an identical study by ensuring contrasting author names, observing geographical location, sample sizes, and comparing interventions and outcomes.

3.8 Quality appraisal

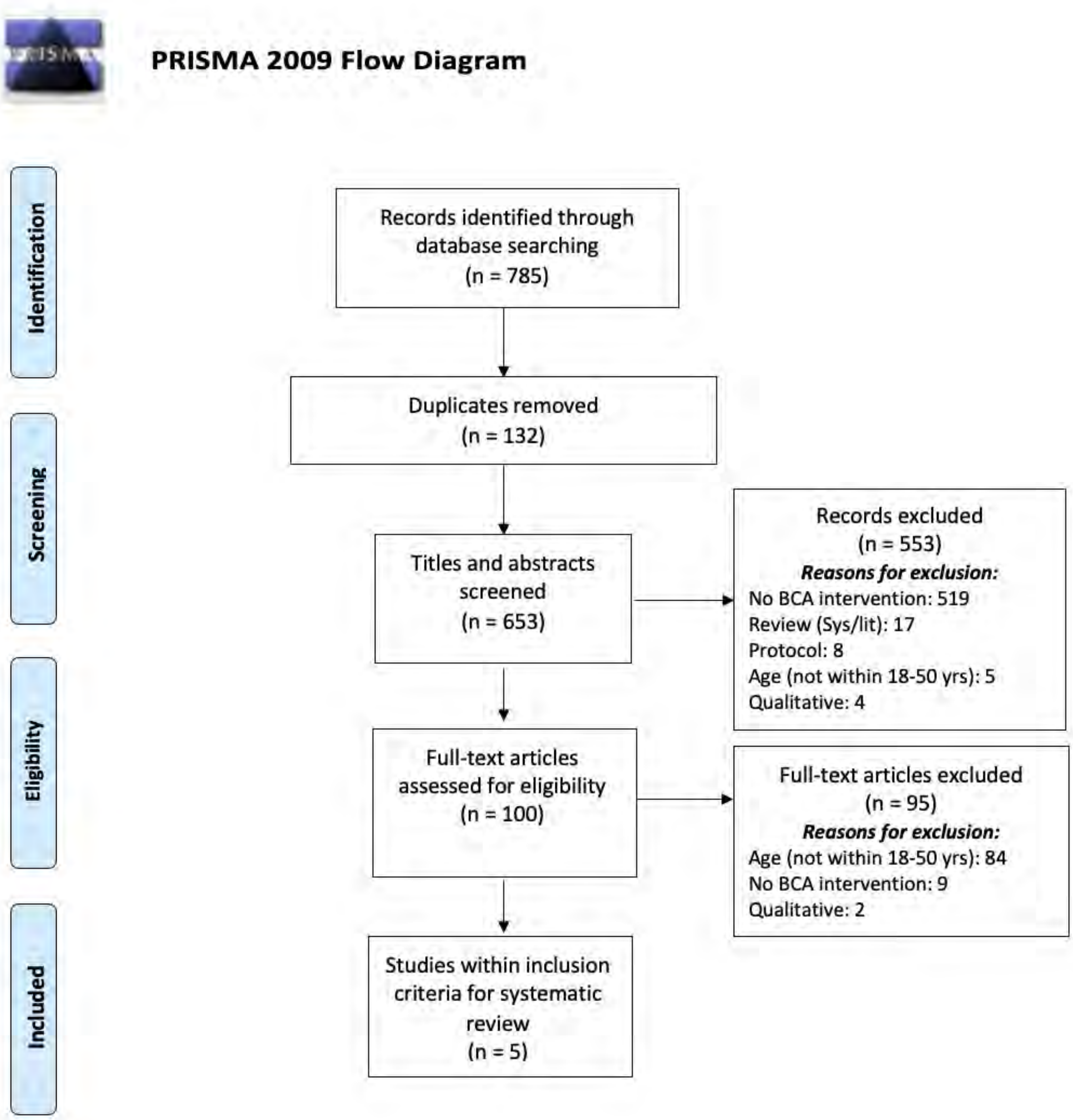
Quality was assessed by employing ‘The Effective Public Health Practice Project Quality Assessment Tool for Quantitative Studies’ (2004) (Appendix C) due to its strong content and test-retest reliability, and a capability for assessing diverse quantitative design approaches (Thomas et al., 2004). Quality is assessed by examining and rating (‘strong’, ‘moderate’, or ‘weak’) of selection bias, study design, confounders, blinding, data collection methods, and withdrawals and drop-outs. From global ratings of each paper, an overall global rating is ascertained. Intervention integrity, and analysis of allocation, unit of analysis, and statistical methods, are also undertaken for intervention appraisal.

3.9 Results

As outlined within the PRISMA flow diagram (Figure 11), a search of the databases provided 785 results, with 132 of these being duplicates that were excluded. 553 were then eliminated after title and abstract reviewing as they did not meet the inclusion criteria of BCA intervention outcome (519), or age (5), with further journals discarded due to being protocols (8), reviews (17), or only utilising a qualitative methodology (4). The full text of the remaining journals was examined, with a further 95 excluded due to not having a BCA intervention outcome, or where there was uncertainty of BCA conceptualisation (9), age not within the range of 18-50 years (84), and the application of a qualitative methodology and analysis (2). 5 journal articles were assessed as having met the criteria.

Figure 11

PRISMA 2009 Flow Diagram



From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). *Preferred Reporting Items for Systematic Reviews and Meta-Analyses*: The PRISMA Statement. PLoS Med 6(6): e1000097. doi:10.1371/journal.pmed1000097

For more information, visit www.prisma-statement.org.

3.10 Description of studies

Table 7 summarises the included study characteristics.

Table 7

Study Characteristics of Each Paper

Reference	Sample size	Age and location	Study design	Intervention description	Control intervention description	Measure of BCA used	Time point studied
Labrague et al. (2021)	Total: 128 Intervention group: 64 Control group: 64	18-49 years Philippines	Experimental RCT	Effects of mobile text messaging	No SMS. Provided with country's health agencies' brochures or pamphlets on BCA.	Breast Cancer and Heredity Knowledge Scale. Breast Self-Examination Knowledge Scale. Breast Self-Examination Self-Efficacy Scale (subscale derived from Champion's HBM Scale (1993). Frequency of Breast Self-Examination Scale.	Pre intervention and 1 month post intervention.
Sarker et al. (2022)	Total: 400	18-26 years Bangladesh	Quasi-experimental pre-post study	Health education intervention	No control group.	BC knowledge assessed by items on symptoms, risk factors, treatment, prevention, screening, and BSE.	15 days between pre-test and education session and post-test survey.
Occa and Suggs (2016)	Total: 194 Narr. video: 43 Did. video: 42 Did. info: 43 Narr. Info: 41 Control: 25	18-30 years Switzerland and Italy	Experimental RCT	Four treatment groups: 1.Narrative approach. 2.Didactic approach. 3.Didactic infographic. 4.Narrative infographic	No exposure to cancer communication.	Measures of BCA: BC diagnostic exams, BSE attitudes, screening.	In one session.
Alameer et al. (2019)	Total:150 Intervention: 75 Control: 75	Intervention group: 39.03 ± 4.96 Control group: 38.97 ± 4.43 Saudi Arabia	Quasi-experimental pre-test-post-test design	HBM based standardised health education	Pamphlets with general BCA information.	Modified version of Breast Cancer Knowledge Scale (Champion, 1993). Assessed BSE practices	Pre-intervention, and post-intervention at 6 weeks and 3 months.
Yi and Park (2012)	Total: 103* *Only 22 completed entire intervention.	20-40 yrs Korea	Quasi-experimental pre-test-post-test design	Breast health class	No control group.	Knowledge of Breast Cancer and BSE questionnaire. BSE skills and compliance. Self-efficacy.	I month and 3 months post-education.

Methods

Two RCT experimental studies (Occa and Suggs, 2016; Labrague et al., 2021) and three quasi-experimental of pre-test post-test design (Yi and Park, 2012; Alameer et al., 2019; Sarker et al., 2022) with varying durations in total of intervention analyses taken directly after the session (Occa and Suggs, 2016), 15 days (Sarker et al., 2022), 1 month (Labrague et al., 2021), and 3 months (Yi and Park, 2012; Alameer et al., 2019) post intervention were included.

Participants

The included studies involved 894 participants in total that completed the interventions (total includes only the 22 participants that completed entire intervention within Yi and Park's (2012) study), of young women aged 18-50 years, with no limitation on setting or recruitment method. Sample sizes ranged from 22 to 400 participants.

Intervention

Interventions occurred from 2012 to 2022 and varied in components and techniques used in the examination of the effect of these on BCA.

Labrague et al. (2021) examined the effect of mobile text messaging on BCA components, with 3-5 text messages sent to participants in the intervention group each day for 1 month. The specific BCA components examined were BSE practices, BSE self-efficacy, and BCA knowledge. The control group did not receive any text messages, instead they were provided with the country's health agencies' BCA brochures and pamphlets. Occa and Suggs' (2016) RCT examined the effect of varying types of messages on BCA with four treatment groups consisting of videos utilising a narrative approach with the communication of a breast cancer patient's story about discovering a breast lump after performing BSE, and a didactic approach with physician presented information. Both the narrative and didactic approaches communicated similar texts of the same quality and included the same actress. The third treatment group utilised a didactic infographic, with the fourth treatment group being presented with a narrative infographic. Both infographics contained the same key information as in the video and used the same colour themes. However, the narrative infographic also included a picture of the patient and two children that were also used in the narrative video. This infographic also contained a brief description of the actor's breast cancer experience. In addition to the four treatment groups, the intervention included a control group of no exposure to any cancer communication.

Within the quasi-experimental pre-test and post-test designs, all utilised a form of a health education intervention. Sarker et al. (2022) divided participants into groups of 10-15, and educated women on BCA, including a stepwise BSE process. Materials and methods used included a lecture communicating breast cancer knowledge of symptoms, risk factors, treatment, prevention, and screening. The researchers also used discussions, brainstorming, and BSE leaflets. Alameer et al. (2019) examined a BCA intervention based on the health belief model (Rosenstock, 1974) within an education programme that included a breast cancer lecture, detection and screening tools, a presentation containing pictures and videos, and a practical BSE session. Participants also were given time to ask questions, and to discuss within a focused group discussion, important barriers regarding BSE practice and visiting healthcare centres and clinics to undergo screening. A second group of participants acted as a control group, whereby they only received general breast cancer information pamphlets. Yi and Park (2012) examined the effect of a breast health class. Based on the self-efficacy theory of Bandura (1986), it utilised verbal persuasion and vicarious experience. An audio-visual presentation included general breast cancer and BSE facts. Breast silicone models, wooden bead necklaces with varying bead sizes to represent different lump sizes, and an information brochure and animations were utilised. Self-examination was encouraged during the intervention session. The educators were breast cancer survivors that shared their breast cancer experiences to raise awareness and overcome stigma. All participants underwent the intervention, with no control group.

Interventions ranged in geographical location: Philippines (Labrague et al., 2021), Bangladesh (Sarker et al., 2022), Switzerland and Italy (bordering communities) (Occa and Suggs, 2016), Saudi Arabia (Alameer et al., 2019), and Korea (Yi and Park, 2012).

Outcomes

The primary outcome assessed was BCA which comprised of all or some of the components of BCA including knowledge about breast cancer, risk, screening, and BSE. However, it was communicated and analysed in a variety of manners, timepoints, and questionnaire type.

Labrague et al. (2021) employed the Breast Cancer and Heredity Knowledge Scale (Ondrusek et al., 1999), Breast Self-Examination Knowledge Scale adapted from the American Cancer Society (Alkhasawneh et al., 2009), Breast Self-Examination Self-Efficacy Scale (a subscale from Champion's HBM Scale (1993)), and a Frequency of Breast Self-Examination Scale. Sarker et al. (2022) examined knowledge of breast cancer and BSE practices utilising a questionnaire that was designed for the research focusing on symptoms, risk factors, treatment, prevention, screening and BSE. Occa and Suggs (2016) assessed BCA including topics of information regarding breast cancer, breast cancer examination, symptoms, and risk factors. BSE attitude was measured using a semantic differential scale whereby individuals indicated the most suitable adjective that described their feelings towards BSE, and intentions to screen for breast cancer. All items were informed by previous studies (McCaul et al., 2003; Francis et al., 2004; Braithwaite et al., 2005) and were translated into Italian. Alameer et al. (2019) used a modified questionnaire that assessed knowledge of breast cancer screening tools and practice, and breast cancer knowledge based on the Breast Cancer Knowledge test (McCance, 1990), and BSE practices based on Champion's (1993) scale. Mammography practices were assessed utilising questionnaires based on those employed by de Oliveira et al. (2018), and Wang et al. (2012). Yi and Park (2012) examined breast cancer knowledge and BSE using the Knowledge of Breast Cancer and BSE questionnaire developed by Choi (1996), with items focusing on incidence, symptoms, high risk factors, mammography period, BSE period, BSE procedure, and BSE self-efficacy. However, it should be noted that when searching for Choi's (1996) questionnaire, it emerged that this is an unpublished dissertation and could not be examined.

Time points studied varied throughout the papers, from on the day with all parts including pre-test, intervention, and post-test conducted (Occa and Suggs, 2016), 1 month after the intervention (Labrague et al., 2021), 15 days between pre-test and education session, and post-test survey (Sarker et al., 2022), across three time points of pre-test, 6 weeks, and 3 months (Alameer et al., 2019), and 1 month and 3 months post-intervention (Yi and Park, 2012). No study included costs.

3.11 Effects of intervention

All interventions showed positive BCA effects, as outlined in Table 8, despite differing intervention methods being utilised, with varying BCA component targets.

Table 8

Intervention Effects

Reference	Analysis conducted	Findings
Labrague et al. (2021)	T-test and ANCOVA.	BCA $p = .001$*, BSE knowledge $p = .010$*, BSE self-efficacy $p = .232$, BSE frequency $p = .69$.
Sarker et al. (2022)	McNemar and paired sample t-tests.	Breast cancer symptoms $p < .001$*, risk factors $p < .001$*, treatment < .001*, prevention $p < .001$*, breast cancer screening $p < .001$*, process of BSE $p < .001$*, change in BSE practices $p < .001$*.
Occa and Suggs (2016)	T-test and ANCOVA.	Awareness $\eta p2 = .075$ $p = .006$*, knowledge of diagnostic exams $\eta p2 = .040$ $p = .111$, attitudes toward breast self-exam $\eta p2 = .071$ $p = .009$*, intentions to detect breast cancer early $\eta p2 = .064$ $p = .016$*. Greatest positive changes: narrative video group.
Alameer et al. (2019)	Independent t-test, chi-squared test, Mann-Whitney U test, McNemar's test, Friedman test, logistic regression.	Knowledge scores in intervention group post intervention OR = 29.5 $p < .001$*. BSE scores between groups 6 weeks and 3 months after intervention OR = 26.25 $p < .001$*. 3 months after, 93.2% of intervention group and 58.9% of control group practiced BSE ($p < 0.001$*). Overall, BSE score increased in intervention group $p < .001$*.
Yi and Park (2012)	T-tests Friedman test and Wilcoxon-signed ranks test.	Knowledge scores: $p < .001$*. BSE skills scores $p < .001$*. BSE performance $p < .001$*. Self-efficacy: $p < .001$*. No difference found between 1 month and 3 months post-education in any of these components.

*$p < .05$.

Within the two RCTs, Labrague et al. (2021) demonstrated a significant increase in specific components by mobile text messaging of 3-5 SMS per day to improve breast cancer, and BSE knowledge, BSE frequency, and BSE self-efficacy within the intervention group compared to the control group. BCA knowledge ($p = .001$) and BSE knowledge ($p = 0.010$) significantly increased. However, BSE self-efficacy, and BSE frequency were not found to be significant between the groups. Within Occa and Suggs' (2016) examination of differing modes of BCA communication of narrative and didactic methods within infographics and videos, each mode demonstrated positive changes in BCA components. Videos demonstrated the greatest differences, but results varied. Didactic was more effective for awareness and knowledge, and narrative for influencing attitudes towards breast self-exam and intention to perform it. One-way ANCOVAs compared intervention effects with significant results for awareness ($p = .006$), attitudes towards breast self-exam ($p = .009$) and intentions to detect breast cancer early ($p = .016$). However, no significant differences were found between the intervention groups for diagnostic exams knowledge.

The three quasi-experimental studies that utilised health education formats of classroom-type education also showed similar findings. Sarker et al. (2022) reported significant increases of BCA knowledge within its educational intervention group among female students. These increases were found within knowledge of breast cancer symptoms (*p* < 0.001), risk factors (*p* < 0.001), treatment (*p* < 0.001), prevention (*p* < 0.001), breast cancer screening (*p* < 0.001), process of BSE (*p* < 0.001), and change in BSE practices (*p* < 0.001). Alameer et al. (2019) also reported effects within their educational intervention based on the HBM. From this intervention, a significant increase in knowledge scores (*p* < .001) in the intervention group post intervention, and a significant difference in BSE scores between groups 6 weeks and 3 months post intervention (*p* < .001) were reported. Overall, the BSE score was significantly increased in the intervention group (*p* < .001).

Yi and Park's (2012) examination of a breast class delivered by trained breast cancer survivors reported a significant difference in knowledge scores (*p* < .001), BSE skills scores (*p* < .001), and BSE performance (*p* < .001). However, no significant differences were found within these components of BCA between 1 month and 3 months post-education.

Selection bias

Within the interventions assessed, it is not reported what percentage of individuals agreed to participate. It is therefore not included within this section rating.

Alameer et al.'s (2019) recruitment of female teachers came from eight schools that were randomly selected within a city, with the first four schools non-randomly allocated to the intervention group, and the remaining four to the control group. The evidence within this research does not indicate any selection bias issues with individuals very likely to be representative of the target population. Therefore, this research is rated as *strong* within this component.

Participants within Labrague et al.'s (2021) research were randomly selected from two communities, with those included very likely to be representative of the target population. Participants that met the eligibility criteria were again randomised to either the intervention or control group. A rating of *strong* is therefore assigned.

Sarker et al. (2022) also demonstrated a random sampling technique within a specified target population of female university students that is likely to be representative, however, only one university was recruited from. Overall, this indicates a *moderate* rating. Occa and Suggs (2016) communicated that participants were recruited by two differing methods for feasibility reasons, with students at a university in Switzerland recruited through face-to-face methods by the paper's lead author by directly approaching individuals and inviting them to participate. Participants in Italy undertook the intervention online and were recruited using a snowball sampling technique, with personal contacts of the lead author being directly invited through a direct Facebook message, with those approached asked to invite others or to provide names of interested individuals to the lead author. Despite the more direct nature of the recruitment strategies within this research that places participants as somewhat likely of the target population, those that agreed to participate in both groups were randomly assigned to one of the five groups. Overall, this research is rated as *moderate.*

Yi and Park (2012) advertised within a variety of institutions including community health clinics, colleges, private companies, and social groups, with six BCA health interventions performed in community health clinics, three in private companies, one at a college, and one in a social group. There was no random selection indicated as there was no control group utilised. It is also recognised that the attendance within the intervention of those within private companies was communicated as mandatory. This potentially affects the likelihood of participants being representative of the target population. Overall, this section for this research is rated as *weak.*

Study design

Two of the studies assessed were classified as experimental RCTs by the papers' authors. The method of randomisation was clearly described within Labrague et al.'s (2021) research with an appropriate method of randomisation performed using a computer-generated block randomisation (allocation ratio of 1: 1) and a permuted block design (block size of 2–4). The study design is therefore rated as *strong.* However, whilst Occa and Suggs (2016) report that participants were randomly assigned to one of the five groups (4 intervention type, 1 control group), the method of randomisation is not communicated, therefore demonstrating characteristics of a controlled clinical trial, rather than a randomised controlled trial. Nevertheless, this still gives the study design a *strong* rating as per the quality assessment tool.

The remaining three research studies are quasi-experimental in their approaches, with two as a cohort one group pre-post intervention design (Yi and Park, 2012; Sarker et al., 2022), and one as a cohort analytic type with a two group pre-post design study (Alameer et al., 2019). Within this assessment tool, these are therefore rated as *moderate.*

Confounders

From the evidence provided within each intervention, groups within the target populations were homogenous. Each intervention clearly displayed sociodemographic information such as SES, age, education, and marital status/family. From this perspective each intervention is rated as *strong*.

Blinding

As these interventions were to examine the effect on BCA, and therefore outcomes would have been clearly demonstrated and communicated to participants. It is therefore not possible to be certain whether the outcome assessor(s) was (were) aware of the intervention status of participants within those that had more than one group, or whether the study participants were entirely aware of the research question. Overall, within these BCA interventions and in line with the applied assessment tool guidelines, this component is rated as *weak.*

Data collection methods

All studies utilised self-reported data within survey and questionnaire methods demonstrating either a ‘face’ validity or ‘content’ validity, or both. Data collection methods were outlined, detailing components that were examined. Therefore, a *strong* rating is awarded.

Labrague et al. (2021) report that scales were translated to the local language (Filipino) using forward and backward translation. To ensure face validity, two experts in the Filipino and English language fields with a nursing education were consulted. From these translations and modifications, the Cronbach’s α of the breast cancer knowledge scale was

0.88, the breast self-examination scale was also 0.88, breast self-examination self-efficacy scale was 0.90, and the frequency of breast self-examination scale was 0.88.

Sarker et al. (2022) assessed breast cancer knowledge by designing and focusing measures on symptoms, risk factors, treatment, prevention, screening, BSE process, and BSE practice. The content breakdown of the measure demonstrates content validity within the collected self-reported data. Alameer et al.'s (2019) communication of the adaptation of previously utilised measures within this study area, also provides validity, with researcher designed measurements such as Yi and Park's (2012) BSE proficiency test openly communicated. Despite being unable to source the original measurement used by Yi and Park (2012) of Choi (1998), items and component focus are communicated.

Occa and Suggs' (2016) examination of the effects of communication on BCA components was undertaken by analysing four outcome measures of BCA, knowledge of breast cancer diagnostic exams, intention to screen for breast cancer through a breast self-exam, and attitudes toward breast self-exam. The items were informed by previous studies that were conducted in English on breast cancer communication and were subsequently translated into Italian. The authors have therefore demonstrated both face validity and content validity.

Withdrawals and Drop-Outs

Alameer et al. (2019) demonstrated evidence of 80-100% participation (loss of N=1 within the intervention group and N=2 within the control group at 3 months post-intervention). At the 6-week data collection point there was a 100% response rate in both groups. The 3-month data collection point had response rates of 98.7% and 97.3% in the intervention and control groups respectively. Loss of participation numbers was reported as due to either the inability to contact the participant, or refusal by an individual to participate any further. Overall, a *strong* rating is conferred.

Sarker et al.'s (2022) analyses indicate that there was a high participation level, with no loss in participant numbers throughout, again demonstrating a *strong* rating.

Occa and Suggs (2016) indicated that four ineligible individuals were removed, however the reasons were not communicated. Nevertheless, this indicates a high level of completion at 80-100%, giving the research a *strong* rating.

Labrague et al. (2021) did not indicate any withdrawal and drop-out numbers within the analysis which given the 1-month timeframe of a mobile intervention deems this a *weak* rating.

Yi and Park's (2012) research indicated a low percentage of participants completing the study of less than 60%. Despite a total of 103 agreeing to participate within the intervention, only 22 individuals responded both at 1 month and 3 months post-education (response rate 21.36%), with the reason given of not returning questionnaires at the time points required. This, therefore, gives this section a *weak* rating.

Intervention Integrity

Within Labrague et al.'s (2021) intervention, there was an equal distribution between the intervention group (50%) and control group (50%). Each participant within the intervention group received the same mobile text messaging, with it being stated that individuals within the control group were not provided with these text messages, instead receiving BCA brochures and pamphlets. However, it is not possible to ascertain how intervention consistency was measured, if at all, and the likelihood that subjects received an unintended intervention that may influence the results. For example, it is unclear what particular differences there are, if any, between the information contained within the brochures given to the control group, and the BCA messages that were sent to those within the experimental group.

All of Sarker et al.'s (2022) participants (100%) received the intervention due to this being a cohort one group pre- and post-test design. Measuring consistency of the intervention is unclear, however, it is noted that all BCA sessions were set in the respondents' dormitories, with similar group sizes (10-15), and sessions run in similar formats to each other. Again, it is also unclear of the likelihood that subjects received an unintended intervention caused by contamination or co-intervention within the teaching times, or outside these.

The participants within Occa and Suggs' (2016) intervention were divided into five groups, four being experimental, and one being a control as follows; control group (N= 25, 12.89%), narrative video (N= 43, 22.17%), didactic video (N= 42, 21.65%), narrative infographic (N= 41, 21.13%), and didactic infographic (N= 43, 22.17%). Groups were described as homogeneous. While the participant numbers within experimental groups are evenly distributed, the control group has considerably less individuals, which may affect outcomes. It is not possible to report if consistency of intervention was measured, or if subjects received an unintended intervention that may influence results.
There was equal distribution of participants within Alameer et al.'s intervention (50% intervention group and 50% control group). Again, there is no inclusion of details on consistency of intervention, or potential contamination or co-intervention at any of the time points studied (baseline, 6 weeks, or 3 months).

While Yi and Park (2012) reported the lowest level of participation (21.36%), all 103 individuals initially partook in the BCA education intervention due to the nature of the cohort design. It is uncertain how, if at all, intervention consistency was measured, or the likelihood of participants receiving an unintended intervention.

Analyses

It is considered that appropriate analyses have occurred in each intervention, within the unit of allocation and unit of analysis. For each intervention, the unit of analysis was each individual woman having been exposed to either an intervention to increase BCA, or to a control group. Utilising the units of allocation terminology provided by the Quality Assessment Tool for Quantitative Studies as denoted within brackets, the unit of allocation varied across interventions. These are from the community (community) (Labrague et al., 2020), university (organisation/institution) (Sarker et al., 2022), university and Facebook (organisation/institution and community) (Occa and Suggs, 2016), schools (organisation/institution) (Alameer et al., 2019), and via a variety of units within Yi and Park's (2012) intervention, including community health clinics, private companies, college, and social group (community, organisation/institution, and practice/office).

Summarisation

A global rating for each paper as per the quality assessment tool is awarded as follows:

1. 🟩 STRONG (No WEAK ratings)
2. 🟨 MODERATE (One WEAK rating)
3. 🟥 WEAK (Two or more WEAK ratings)

As demonstrated in Table 9, no papers demonstrate a *strong* study quality, with Sarker et al. (2022), Occa and Suggs (2016), and Alameer et al. (2019) indicating a *moderate* study quality. Labrague et al. (2021) and Yi and Park (2012), are described as having a *weak* study quality. The overall global rating is deemed as *weak*.

Table 9

Research Ratings of Papers Reviewed

	Selection bias	Study design	Confounders	Blinding	Data collection method	Withdrawals and dropouts	Paper global rating
Labrague et al. (2021)	🟩	🟩	🟩	🟥	🟩	🟥	🟥
Sarker et al. (2022)	🟨	🟨	🟩	🟥	🟩	🟩	🟨
Occa and Suggs (2016)	🟨	🟩	🟩	🟥	🟩	🟩	🟨
Alameer et al. (2019)	🟩	🟨	🟩	🟥	🟩	🟩	🟨
Yi and Park (2012)	🟥	🟨	🟩	🟥	🟩	🟥	🟥
Overall Global Rating	🟨	🟨	🟩	🟥	🟩	🟥	🟥

3.12 Discussion

This systematic review evaluated the effect of BCA interventions on young women's (aged 18-50 years) BCA knowledge levels. 2 studies were experimental in design, with 3 utilising a quasi-experimental approach with pre-and post-test analysis. All studies occurred within the last ten years of when the systematic review was commenced in 2022. Only five studies met the review criteria. This small number highlights a dearth of BCA interventions specific to young women, with often a stereotype association that breast cancer is for older ages, overlooking diverse social, personal and medical challenges that differ to women who develop breast cancer at a later age (Costa et al., 2024).

Despite all interventions demonstrating significant positive changes within BCA components, which is comparable to a previous systematic review investigating BCA and screening uptake via public health campaigns and educational interventions within the UK (Anastasi and Lusher, 2019); overall, the evidence is weak in investigating the effectiveness of BCA interventions on this cohort and is considered as inconclusive. Anastasi and Lusher (2019) also narrated a wide variety of methods and settings, highlighting the difficulty experienced in evaluating BCA interventions in a conclusive manner. Within this systematic review, significant positive effects on BCA levels were found within mobile text messaging (Labrague et al., 2021), health education interventions (Yi and Park, 2012; Alameer et al., 2019; Sarker et al., 2022), and by applying a variety of communication methods within narrative and didactic modes (Occa and Suggs, 2016). Only one valid RCT was found (Labrague et al., 2021) by clear communication of a randomisation method, with significant results across several components including BCA, and BSE knowledge. However, BSE self-efficacy, and BSE frequency were not found to significantly increase at the time point of analysis at 1-month post intervention. This is noteworthy, particularly when considering the design of a BCA intervention for young women with NF1. As previously stated, self-management and self-efficacy are important to foster within a person-centred approach (Geng et al., 2018). With self-efficacy being an individual's perceived confidence in their capability to perform a behaviour (Bandura, 1977), in this case BCA, this may negatively affect a person's level of effort or persistence in maintaining behaviours (Bandura, 1977), despite being educated on BCA components.

Variations in study quality also poses a concern for review discussion. Certain aspects such as Yi and Park's (2012) low percentage of participant completion create a difficulty in making a robust conclusion from its findings despite significant positive findings pertaining to knowledge, BSE skills and performance, and self-efficacy. Its finding of no significant differences between 1 month and 3 months post-education is problematic to appraise because of the low response rate. Only two papers (Occa and Suggs, 2016; Alameer et al., 2019) reported intervention effect sizes (partial eta squared, and odds ratio respectively), thus making a discussion of the magnitude of intervention findings impractical.

Randomisation was adequate within one of the two experimental studies. Both studies of Labrague et al. (2021) and Occa and Suggs (2016) claimed to be RCTs, however only Labrague et al.'s (2021) intervention communicated its randomisation method. Within Occa and Suggs (2016) research, the method of randomisation is not communicated which depicts it as a controlled clinical trial, rather than a randomised controlled trial. However, this method is still preferable to the remaining three studies within the review as per the Effective Public Health Practice Project's Quality Assessment Tool for Quantitative Studies (2004) that have utilised a quasi-experimental design, with two as a cohort one group pre-post intervention design with no control group (Yi and Park, 2012; Sarker et al., 2022), and one as a cohort analytic type, with a two group pre-post design study (Alameer et al., 2019). Findings from experimental designs allow for increased confidence in outcomes that can contribute to potential implications to PPI such as clinicians, individuals that design health behaviour interventions, and to the target audience of young women. RCTs represent a 'gold standard' in study design, predominantly for their ability to control for confounding factors (Sheikh et al., 2002).

Sample sizes and time periods broadly varied, with participant numbers greatly diverging from N=22 to N=400, and from one session to 3 months post intervention making it problematic to derive any significant conclusions across all studies. Perhaps most critical to note from the outcomes of this review, is that the interventions themselves varied from mobile phone messaging (Labrague et al., 2021), communication methods (Occa and Suggs, 2016), and health education type interventions (Yi and Park, 2012; Alameer et al., 2019; Sarker et al., 2022). Despite three out of the five papers utilising health education methods, these also varied considerably in measurements utilised to capture BCA levels, setting, country, and type of materials employed to affect levels of awareness. Future research may benefit from utilising a standard measure of BCA such as the Breast-CAM (Linsell et al., 2010), focusing on key factors of risk, screening, and self-examination. Varying measures creates difficulties in ascertaining a clear conclusion when examining intervention effects. Despite there being a variety of countries represented, it is not extensive enough for a global representation of findings.

While blinding is considered important particularly when conducting research into the efficacy of new interventions (Sheikh et al., 2002), no research within this review undertook blinding. However, due to the nature of the research making it quite evident that BCA was being targeted, it is difficult to achieve this for outcome assessors and participants. It is recognised that this may contribute to experimental bias.

Utilising theory can increase intervention effectiveness (Glanz and Bishop, 2010). Whilst three of the included studies cited theories; social cognitive theory (Labrague et al., 2021), self-efficacy theory (Yi and Park, 2021) and HBM (Alameer et al., 2019), and one recognised cognitive and heuristic aspects (Occa and Suggs, 2016), another did not apply theory (Sarker et al., 2022) despite exploring knowledge, attitudes, and practices. In many cases, interventions are designed and based on implicit common-sense behaviour models, without evidence of theory and formal target behaviour analysis (Davies et al., 2010). Despite the significant positive effects on BCA levels, none of the included studies demonstrated a well-mapped intervention with considered components of a behaviour change theory which may also explain differences. Recent developments highlight the importance of categorising intervention components and mapping these directly to change mechanisms (e.g., see Michie et al., 2014). A more systematic and targeted approach with proper application of health behaviour change mechanisms is warranted.

3.13 Strengths and limitations of the review

This systematic review solely included English-language publications and engaged with 7 databases: Cochrane Library (CENTRAL), APA PsycArticles, APA PsycInfo, MEDLINE, ASSIA, CINAHL, and Web of Science. Therefore, other publications may have been omitted. Despite there being 132 duplicates found within 785 results, this does not diminish the probability that other research was overlooked by the lack of consideration for example, of undertaking actions such as a grey literature search, or searching through literature that cited the included research.

The search terms and Boolean operators employed, and the inclusion and exclusion criteria imposed may have also reduced potential outcome numbers. However, previous systematic reviews concerning BCA such as those conducted by Anastasi and Lusher (2019) and O’Mahony et al. (2017) were referred to, to examine terms. From the research that has been undertaken for topic familiarisation, this also contributed to word choices and phrases. Nonetheless, it is recognised that with this review carried out by one-person, further consultation with others may have contributed a wider consideration of terms to include to widen the search strategy, and therefore results returned.

This review focused on the effect of BCA interventions, and therefore included only quantitative data. It is recognised that topics surrounding breast cancer including important awareness strategies such as help-seeking, and screening can be emotive (Burugu and Salvatore, 2025). Qualitative research can uncover further understandings, such as the 'why', of experiences within BCA interventions for young women (Seers, 2015). It is recommended that a qualitative review of BCA interventions is also undertaken to provide a more nuanced understanding in this field. However, it is also recognised that with a dearth of literature pertaining to BCA interventions including young women (only 5 studies met the inclusion criteria within this review), it is also considered that a lack of qualitative studies within this topic area may also be present.

It is acknowledged that the review was undertaken by one individual solely conducting this research and not within an established research team for example, with Cochrane advising that systematic reviews should be performed by several individuals, with double screening (Lasserson et al., 2022). It is recognised that researcher bias may have influenced outcomes. Additionally, with no inclusion criteria provided in advance, or protocol registered, it raises the concern of quality, with registration aiding in reducing research waste, and bias, and improving overall transparency (Cochrane, 2023). The systematic review was conducted in the early stages of the PhD and being considerably new to the process of conducting a review, I lacked the knowledge regarding this obligation and important step. Tawfik et al. (2020) also reports this as a main reason for not registering protocols.

3.14 Conclusions

From recognising the difficulty in generating concrete conclusions due to the variations in measures of BCA within this systematic review, a reasonable suggestion for future research would be to adopt a greater standardised approach within utilised measures (e.g., Breast-CAM; Linsell et al., 2010). Likewise, espousing more 'gold standard' experimental study designs such as RCTs or CCTs if complete blind randomisation is not possible may also foster enhanced comparisons and robust findings for improved communication of implications to both clinicians and patients. Further exploration of this pertinent topic would also benefit from a review of qualitative literature to garner a better understanding of the experiences of young women with BCA interventions.

From the small number of included studies, what may be ascertained, is that there were positive outcomes across all intervention designs concluding that young women under the age of 50 years may be receptive to a variety of engaging designs. However, this small number also highlights that there is a lack of specific BCA interventions for young women, and certainly with no available literature found pertaining to NF1, also to young women with NF1. This excludes needs and challenges that may differ from women of an older age (Costa et al, 2024). The findings of non-significant results in self-efficacy within the RCT, highlight a need for this to be considered and incorporated with greater attention within BCA interventions to develop positive habit formation over an extended period. This is something that is often overlooked in interventions that require longer maintenance such as starting BCA at a much younger age, compared to those targeted at older women. This detail is transferable to the objective within this current research that aims to explore the development and feasibility of a novel BCA intervention for young women with NF1, with self-efficacy required to aid in the self-management of their condition (Geng et al., 2018), and for habit formation (Bandura, 1977) of being breast cancer aware.

3.15 Summary of the key points in this chapter

- A systematic review was conducted to examine the effect of BCA interventions on young women to gain a better understanding that would contribute to the development of a BCA intervention for young women with NF1.
- 5 papers were deemed suitable for analysis. 2 studies were experimental in design, with 3 utilising a quasi-experimental approach with pre-and post-test analysis. All studies occurred within the last ten years of the commencement of the systematic review in 2022.
- Despite all interventions demonstrating significant positive changes within components of BCA, the evidence was weak in investigating the effectiveness of BCA interventions on BCA knowledge levels among young women aged 18 to 50 years. The outcomes are considered as inconclusive.

- The non-significant result of self-efficacy within the RCT highlights a need for this to be considered within BCA interventions for positive habit formation over an extended period.
- Recognising the difficulty in generating concrete conclusions due to variations in BCA measures, future research may benefit in adopting a standardised approach within the measures utilised.

3.16 The next stage of the research

The systematic review has aided in the initial design considerations for a novel NF1 BCA, primarily targeted at raising awareness among young women with NF1. While this review revealed inconclusive outcomes, the non-significant result in self-efficacy within the RCT is an important consideration within the development of the intervention for positive habit formations and BCA behaviour. The next chapter discusses the preliminary steps of the design of a tailored made BCA intervention for young women with NF1 by detailing the application of theoretical frameworks and patient and public involvement for health behaviour change. These include the Behaviour Change Wheel (Michie et al., 2011), a systematic process for designing interventions, and The Medical Research Council's framework for developing and evaluating complex interventions (Skivington et al., 2021).

Chapter Four

The application of theoretical frameworks and PPI involvement for health behaviour change

4.1 Introduction

Health behaviour is an act that an individual engages in with the objective to attain, maintain, or regain good health, but additionally to prevent illness (Rodham, 2019). The social-ecological model posits that health behaviours result from multifaceted interactions at varying levels of individual, interpersonal, and social (McLeroy et al., 1988). BCA, or the act of being breast cancer aware is also a health behaviour that involves having the knowledge and confidence to 'look and feel' breasts to familiarise with what is normal (Kennerley, 2015). It also encompasses the education of risk factors and breast screening information (O'Mahony et al., 2017). Within the research's NF1 context, this involves the promotion of positive health behaviours of BCA, of having the self-efficacy, or self-mastery, to perform a specific behaviour (Bandura, 1977) to recognise what is normal for them as a woman with NF1, to be knowledgeable of the associated increased risk of developing breast cancer at a younger age, and eligibility for breast screening.

Behaviour change is regarded as a difficult process with humans having a limited capacity for self-regulation, with structural barriers also inhibiting potential changes such as lack of time and resources (Phillips and Mullan, 2022). Behaviour change interventions are co-ordinated activities that are intended to change specific behaviour patterns and are commonly used to aid in the promotion of healthy lifestyles, and the uptake and optimal utilisation of clinical services (Michie et al., 2011). However, in many cases, interventions are designed and based on implicit common-sense behaviour models, without evidence of robust application of theory and formal target behaviour analysis (Michie et al., 2009; Davies et al., 2010). It is proposed that utilising theory when designing interventions can increase their efficacy (Glanz and Bishop, 2010). Recent developments have also highlighted the importance of categorising intervention components and mapping these directly to change mechanisms, however while some interventions that utilise theory identify what needs to change, they often do not specify how (Conner and Norman, 2017).

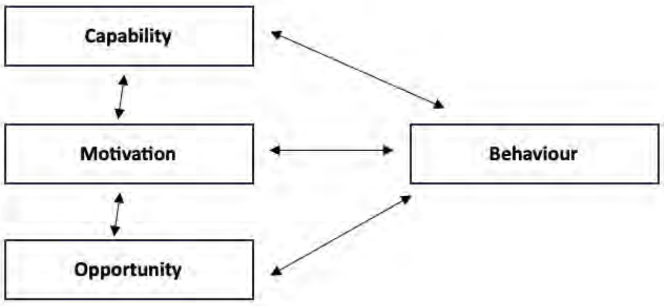
Numerous psychological theories highlight key factors that contribute to behaviour formation. For example, the health belief model (Rosenstock, 1974) hypothesises that engagement in disease prevention and health promotion is associated with beliefs about an individual's perceived risk of a health problem, the perceived barriers, benefits of behaving in a certain way, and self-efficacy. The theory of planned behaviour (Ajzen, 1991) highlights the influence of behaviour on a person's own attributes such as perceived behavioural control and intention, external influences, and subjective norms through the influence of others' judgements. However, whilst these theories are operated in interventions, a well-defined problem in behavioural terms that analytically considers the behaviour's source, or an evaluation of what needs to change, is often omitted. This chapter will detail the application of theoretical frameworks to not only identify *what* needs to change, but also *how* this change is posited to occur.

4.2 Implementing a theoretical framework with a systematic approach

Michie et al. (2011) comprehensively conceptualised and summarised the determinants of theories within behaviour formation, establishing that behaviour change occurs by the modification of capability, opportunity, and motivation. These components form a 'behaviour system' that interacts with each other to generate behaviour (Michie et al., 2011; Michie et al., 2014) and are communicated as the COM-B model (Figure 12) within the behaviour change wheel (BCW) that provides an understanding of the problem in behavioural terms with intervention and implementation options (Michie et al., 2014). Capability involves the knowledge and skills required to engage in behaviour change, opportunity considers physical and social environmental barriers, and motivation includes automatic motivational processes and psychological aspects such as locus of control, self-efficacy, decision-making, and emotional readiness to change (Michie et al., 2011; Michie et al., 2013).

Figure 12

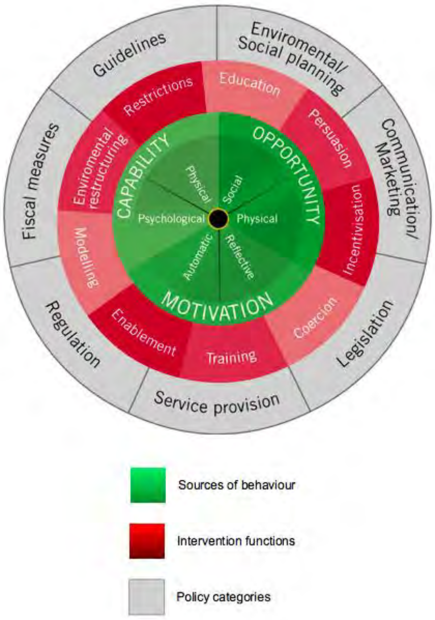
COM-B Model Components of Capability, Opportunity, and Motivation



From an analysis of 19 behavioural frameworks, 9 intervention functions and 7 policy categories were yielded within the BCW (Figure 13). Further addressing behaviour change barriers, the BCW specifies behaviour change techniques recognised as 'active ingredients' that create change, are observable, replicable, and irreducible (Michie et al., 2014). Michie et al. (2011) argue that this rigorous approach prevents intervention designers and policy makers neglecting influential opportunities.

Figure 13

Components of the Behaviour Change Wheel

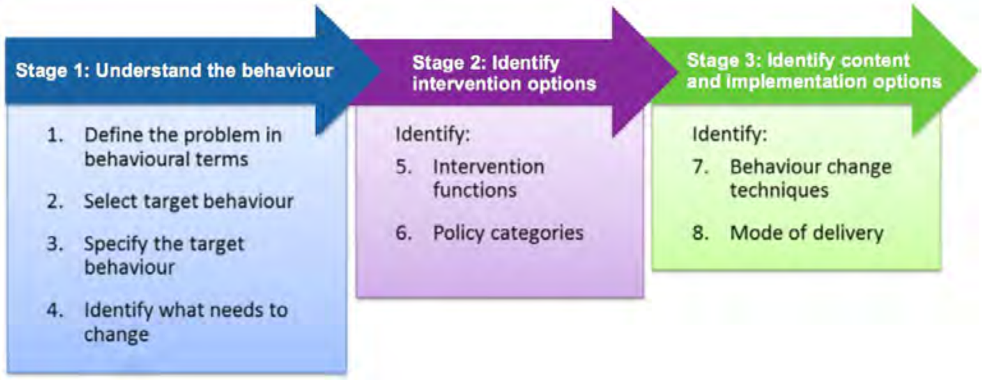


Note. Diagram taken from Michie et al. (2014) *'The behaviour change wheel: a guide to designing interventions.'* London: Silverback.

The BCW design process consists of 8 steps that are divided among 3 stages to address key aspects (Figure 14).

Figure 14

Intervention Design Stages and Steps



Note. Diagram taken from Michie et al. (2014) *'The behaviour change wheel: a guide to designing interventions.'* London: Silverback.

As behaviour change interventions occur within social contexts, it is important to consider a variety of aspects to ensure that the intervention is appropriate by applying an APEASE criteria exploring affordability, practicability, effectiveness/cost-effectiveness, acceptability, side-effects/safety, and equity (Michie et al., 2014).

Affordability

The intervention is deemed acceptable if it is deliverable and accessible within a suitable budget to all that it is both relevant and beneficial.

Practicability

If the intervention can be delivered as designed through the intended means to the target population.

Effectiveness and cost-effectiveness

Effectiveness within the intervention design is concerned with the effect size in relation to the desired aims from a 'real world' perspective. This is separate to efficacy which is the effect size of the intervention. Michie et al. (2014) consider cost-effectiveness as what will be most effective on cost such as timescale between intervention delivery and intervention effect.

Acceptability

This involves the degree to which the intervention is deemed to be appropriate by relevant PPI of a person, group, or organisation involved in, or affected by a decision (Lemke and Harris-Wai, 2015).

Side-effects/safety

Any unintended consequences or undesirable side-effects are required to be considered to decide whether to undertake the intervention.

Equity

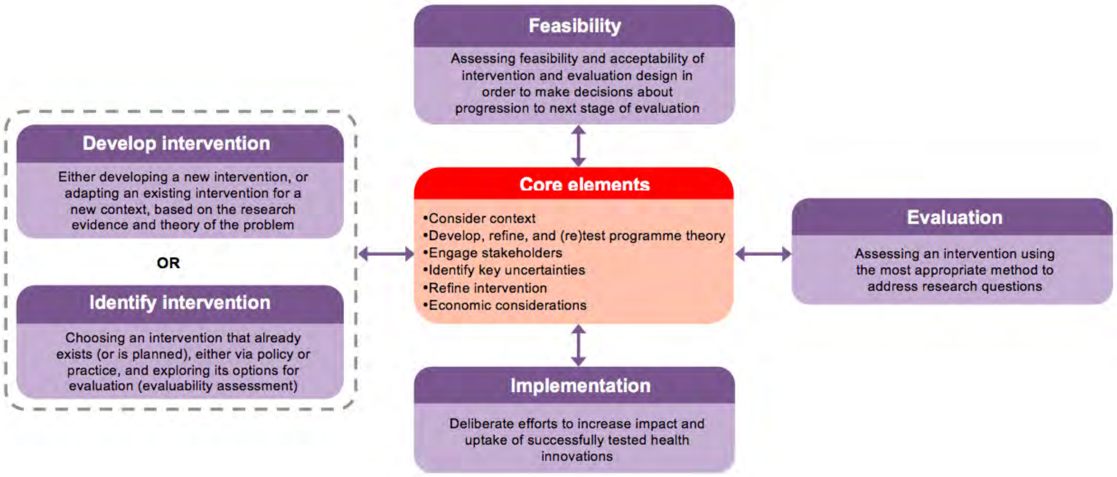
It is important to consider the extent to which the intervention may either increase or decrease disparities in areas such as wellbeing, standard of living, or health between varying divisions within society.

4.3 The incorporation of the MRC framework for complex interventions

A BCA intervention for young women with NF1 and their associates may be considered as a complex intervention in that it comprises various parts that interact with one another, with complexity based on the number of interacting components which in this context are BCA components (Craig et al., 2008). Considering this, the Medical Research Council's (MRC; Skivington et al., 2021) framework for developing and evaluating complex interventions as outlined in Figure 15, can be incorporated within the BCW stages (Figure 16).

Figure 15

Framework for Developing and Evaluating Complex Interventions



Feasibility

Assessing feasibility and acceptability of intervention and evaluation design in order to make decisions about progression to next stage of evaluation

Develop intervention

Either developing a new intervention, or adapting an existing intervention for a new context, based on the research evidence and theory of the problem

OR

Identify intervention

Choosing an intervention that already exists (or is planned), either via policy or practice, and exploring its options for evaluation (evaluability assessment)

Core elements

- Consider context
- Develop, refine, and (re)test programme theory
- Engage stakeholders
- Identify key uncertainties
- Refine intervention
- Economic considerations

Evaluation

Assessing an intervention using the most appropriate method to address research questions

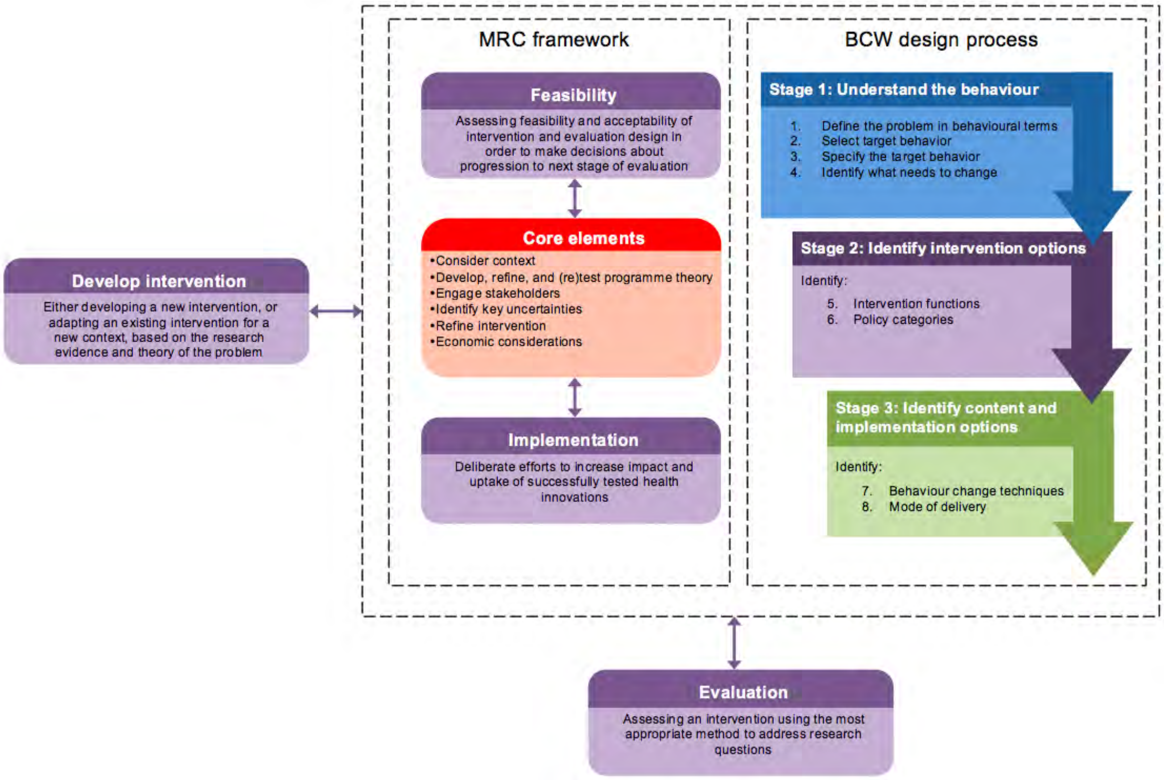
Implementation

Deliberate efforts to increase impact and uptake of successfully tested health innovations

Note: Image taken from Skivington et al.'s (2021) 'A New Framework for Developing and Evaluating Complex Interventions: Update of Medical Research Council Guidance'. BMJ, 374(2061) pp. 1-11.

Figure 16

Incorporating the MRC Framework Within the BCW



Feasibility

Assessing feasibility and acceptability of intervention and evaluation design in order to make decisions about progression to next stage of evaluation

Core elements

- Consider context
- Develop, refine, and (re)test programme theory
- Engage stakeholders
- Identify key uncertainties
- Refine intervention
- Economic considerations

Implementation

Deliberate efforts to increase impact and uptake of successfully tested health innovations

Develop intervention

Either developing a new intervention, or adapting an existing intervention for a new context, based on the research evidence and theory of the problem

Stage 1: Understand the behaviour

1. Define the problem in behavioural terms
2. Select target behavior
3. Specify the target behavior
4. Identify what needs to change

Stage 2: Identify intervention options

Identify:

5. Intervention functions
6. Policy categories

Stage 3: Identify content and implementation options

Identify:

7. Behaviour change techniques
8. Mode of delivery

Evaluation

Assessing an intervention using the most appropriate method to address research questions

Following Michie at al.’s (2014) BCW and across the eight steps, firstly core elements within the MRC are considered. The context is considered specifically across Stage 1: *Understand the behaviour,* of defining the problem in behavioural terms, selecting and specifying the target behaviour, and then from these deliberations, identifying what needs to change. A core element that the MRC framework focuses upon is that of developing, refining, and (re)testing programme theory. Programme theory expresses the principal factors of an intervention and how they interact, intervention mechanisms, and context features that are expected to influence those mechanisms (Skivington et al., 2021). These can be likened to both Stage 2: *Identify intervention options* and to Stage 3: *Identify content and implementation options* within the BCW, whereby a greater understanding can be gained from investigating within the steps between these stages. Specifically, intervention mechanisms, context features, and influences on intervention mechanisms as considered within the MRC framework can be equated to intervention functions and policy categories, mode of delivery, and behaviour change techniques within the BCW.

The MRC framework (Skivington et al., 2021) and the BCW (Michie et al., 2014) emphasise the importance of PPI within intervention design to gain a better understanding of contextual factors that may otherwise be omitted. Within this research, a person-centred approach remains central within the design of the intervention, with broad integrative communication heard by PPI, of not only health professionals, but also young women with NF1, and their associates. It is acknowledged that patients’ engagement is essential within health research (Mitchell et al., 2022), not only for increased accuracy of information, but also to ensure that their voices are heard and respected. Ekman et al. (2011) note that when patients’ values are respected, they may be more receptive to advice and information from the practitioner.

The remaining core elements of identifying key uncertainties, refining intervention, and economic considerations are also perhaps considered in greater detail within the BCW. Any uncertainties are appraised and reviewed within Stage 1 of the intervention design, which consequently allows for refining the intervention if required. Across the stages and within the eight steps of the BCW, a thorough understanding of the behaviour is endeavoured, allowing for a more robust identification of intervention options within

Stage 2, and identification of content and implementation options within Stage 3. It is within these stages that an investigation of potential moderator effects can occur, which further enhances the intervention effectiveness (Conner and Norman, 2017).

The MRC also highlights the importance of assessing intervention economic considerations. However, this can also be deemed as a limitation within the updated framework, as it is considerably one-dimensional. Michie et al.'s (2014) APEASE criteria offers a multi-faceted approach, with cost-effectiveness being tied with equal value to effectiveness. Assessing feasibility and acceptability of the intervention is also considered within the MRC framework, however, it is within the APEASE criteria that feasibility is assessed within intervention design acceptability, but also within the criteria's accompanying components of practicability, side-effects/safety, and equity. Implementation within the MRC framework implicates the deliberate effort to increase impact and uptake of a health intervention that is successfully tested (Skivington et al., 2021). This is considered within Stage 3 of the BCW: *Identify content and implementation options*, whereby it is further broken down into components that are important to consider:

- Content (what was delivered)
- Provider (who delivered it)
- Setting (where it was delivered)
- Recipient (to whom it was delivered)
- Intensity (Over how many contacts it was delivered)
- Duration (over what period it was delivered)
- Fidelity (the extent to which it was delivered as intended)

Evaluation is the final MRC framework component. This is the assessment of the intervention by utilising what is deemed the most appropriate method to address research questions. The authors of the BCW communicate that the systematic approach is primarily designed to aid with the first processes of theory development and evidence synthesis, and implementation. One limitation of the BCW is noted, in that it does not allow for a full investigation into what are appropriate methods for evaluating the outcomes. However, Michie et al. (2014) utilised the MRC guidance (Craig et al., 2008) within their textbook guide of designing interventions when looking to evaluate behaviour change interventions and to synthesise evidence. It is therefore determined that the updated MRC framework components are also thoroughly considered within this research's main theoretical framework of the BCW.

It is established that there are similarities and limitations of both the BCW, and the MRC. It is prudent to ensure that all components of these frameworks are considered to create a multidimensional consideration for intervention design. The BCW offers a more comprehensive consideration of the MRC components within the intervention design (Michie et al., 2014). However, it is the MRC framework's consideration of evaluation that demonstrates a greater appreciation of how the intervention output is measured compared to the BCW. This research recognises this, and therefore incorporates this MRC framework component by presenting thorough methodology, analyses, and discussion chapters within the thesis.

4.4 Intervention design stages: The centrality of PPI involvement in intervention design

It is imperative that the BCW framework is interpreted in the environment in which behaviour occurs for the design and implementation of a health behavioural intervention (Davis et al., 2015) by initiating Stage 1 *Understand the behaviour*. Conner and Norman (2017) maintain that there is robust justification for seeking to investigate effects of potential moderators, as this further enhances intervention effectiveness. PPI is therefore important to develop a better understanding of contextual factors that may otherwise be omitted, assist in building trust, and aid in the development of an accessible and acceptable intervention (Petkovic et al., 2020). Patient and public involvement (PPI) has experienced difficulties in gaining a consensus on a precise meaning or justification of PPI with diverging assumptions such as who it should involve, and how it should be undertaken (McCoy et al., 2019). Within the research, the term of PPI is applied to refer to inclusive involvement of patients, carers (associates), and public being more limited in application at this stage of a feasibility study to professionals such as academics, NF charity representation, and HPs. PPI aims to improve the efficiency and values of research by increasing patient relevance, recruitment and retention rates, the range of study representation, dissemination of findings beyond academic audiences (Domecq et al., 2014; Crocker et al., 2018), and increasing accountability and transparency (Oliver et al., 2015). The UK Standards for Public Involvement (2019) of inclusive opportunities, working together, support and learning, governance, communications, and impact were applied by the utilisation of Padlets.

Padlet is a collaborative web platform that allows users to work together and upload, organise, and share information in a virtual collaborative space. Despite Padlet not routinely used as a tool for PPI (to the best of the researcher's knowledge), this method was chosen due to it being a platform that allows for quick and easy responses within education and collaborative learning (Mehta et al., 2021). It was therefore posited that Padlet may have transferable value in being utilised as an accessible and collaborative tool for collecting research insights, contributing to *inclusive opportunities*, and *working together* components of the UK Standards for Public Involvement (2019). This creative approach of utilising Padlet was undertaken when it was observed how difficult it was to gather a group of individuals together via Microsoft Teams to work as a traditional focus group. Originally, the researcher planned to hold traditional focus groups via Microsoft Teams for young women with NF1, associates, and HPs. However, difficulties in undertaking this became apparent, with it difficult to garner interest in suitable numbers from these cohorts and finding times to suit one another. The reason for this increased difficulty during this period is not entirely clear, however, it is plausible that with COVID-19 restrictions greatly reduced or removed within the UK in July 2021 (UK Parliament, 2021), and in February 2022 (Gov.ie, 2022) in the Republic of Ireland, this created shifts back to 'normalcy' and 'resocialisation'. This period aligned with the first year of the PhD when PPI was sought, making it difficult to gather individuals together. HPs' research embargos and an increased workload due to the ongoing effects of the COVID-19 pandemic (Bratan et al., 2021) may also have contributed. Braun and Clarke (2013) offer other possible suggestions such as the traditional focus group format not being suitable for busy individuals. It is also possible that being within groups may be a negative experience for some, with the possibility of encountering individuals such as a dominant talker, or a 'self-appointed expert' (Braun and Clarke, 2013). With Padlet, the experience appeared positive due to its speed of collecting opinions, and its ease of sending and sharing, with contributions accumulating over a short period (2 weeks), as witnessed particularly from associates. This demonstrates that practical and social barriers that would normally stop individuals becoming involved in public involvement within research were reduced, and aids in *support and learning*.

The format therefore offered *inclusive opportunities*, with the research informed by both experience, insight, and professional knowledge. PPI within this research was two young women with NF1 (aged 18-40 years), and approximately 13 individuals associated with these women such as friends, families, partners, and carers, and HPs. While exact numbers of HPs and young women with NF1 were ascertained by communications with either the individuals or an organisation directly, it was difficult to ascertain exact numbers within the associates' group due to respondents not having to contribute to all questions asked and it being shared within the closed Facebook Childhood Tumour Trust page. Within the HPs' cohort, a GP and nurse were included to ascertain how best to improve NF1 knowledge and its associated increased risk of breast cancer at a younger age. An expert in rare disease genetics who is also a medical doctor was also involved. Insights were also garnered from two HPs employed within a cancer centre. Questions were adapted depending on who it was to be addressed to, with feedback received from a Nurse Researcher for HP question adaptation. The questions were also given to the Childhood Tumour Trust founder to ascertain suitability and readability. Following the UK Standards for Public Involvement (2019) within *communications*, it was ensured that questions were succinct and used plain language with only 5 questions posed via Padlet for young women with NF1, and associates of young women with NF1, and 6 for the HPs when gathering information pertinent to the design and implementation of the intervention. These questions are outlined in sections 4.5 and 4.6 respectively. Communication was also enhanced by the design, allowing individuals to click a link and contribute anonymously at their own time and speed if they deemed the research relevant.

By utilising information collected within the BCW and the MRC framework, this also aided both *governance* and *impact*, placing the valued and respected voices and experiences of PPI at the centre of the research. While the information gathered within the Padlets allowed for valuable insights that shaped the direction and design of the research process, it is acknowledged that using Padlets in this manner was novel, and further exploration by other researchers is recommended. With a novel approach, it is also important to highlight both limitations and strengths experienced. While speed and ease of use is a positive feature of Padlet, Mehta et al. (2021) also highlight that it becomes difficult to ascertain exact numbers of respondents if this knowledge is required. Within this research it was difficult to ascertain the exact number of associates, as it is apparent that some may not have answered all questions, or entered multiple comments for certain questions. With anonymous answering this also adds to this uncertainty. Padlet appeared to aid in garnering important insights which were helpful in considering research and intervention design, with it found to be beneficial with enhancing personal reflections of respondents, and increasing engagement (Phenwan, 2023; Zainuddin et al., 2020). However, it is also recognised that some individuals may provide more depth and length of responses than others, lacking an ability to probe and go further on certain aspects that are revealed as within a focus group setting, for example. However, it is also recognised that for some, they may have more confidence and perceive it as a 'safe space' (Phenwan, 2023), rather than a traditional focus group which may be a negative experience for them (Braun and Clarke, 2013).

The information provided within the Padlets was utilised to aid in the intervention content design following the BCW process, ensuring that firstly the problem is defined in behavioural terms (Step 1) (Table 10).

Table 10

Defining the Problem in Behavioural Terms

What behaviour?	Increasing breast cancer awareness of young women with NF1
Where does the behaviour occur?	Being breast cancer aware (e.g., breast checking): In personal environments, in clinical settings (particularly GPs). Increasing BCA (education and information): Available materials online to download and use anywhere.
Who is involved in performing the behaviour?	Young women with NF1, HPs, associates. Potential ripple effect recognised to include general population, charities, etc.

4.5 Considerations taken within Padlets

The Padlet for young women with NF1 was sent directly to those who expressed interest in being part of PPI in the intervention design. This was advertised by the Childhood Tumour Trust's social media platforms including X, Facebook, and Instagram. However, as only two women actively engaged with the Padlet, it was important to expand PPI to garner information. A Padlet for associates of young women with NF1 (e.g., family, friends, and carers) was shared on the Childhood Tumour Trust's Facebook private page. As difficulties are recognised in recruiting individuals within rare disease research (Whicher et al., 2018) it was important to ensure that it was clearly advertised to only be used by these individuals (Appendix D) so as not to exhaust eligible participants of young women with NF1 within the intervention and mixed method research. As this Facebook Padlet was not used for data collection, ethical approval was not required. However, the Psychology Ethics Lead was contacted to ensure that there were no foreseeable issues with what was proposed. It was accepted that the Padlet would be used as part of the research's Public Patient Involvement to aid the intervention design. With the agreement of the Childhood Tumour Trust, and in line with their policies and regulations, it was shared on their Facebook page with additional precautions suggested by the Psychology Ethics Lead (Appendix E). These were switching off attribution mode so names would not be displayed, activating 'filter profanity' and 'require approval' to ensure comments were appropriate. Each Padlet asked similar questions with variations to better address each cohort.

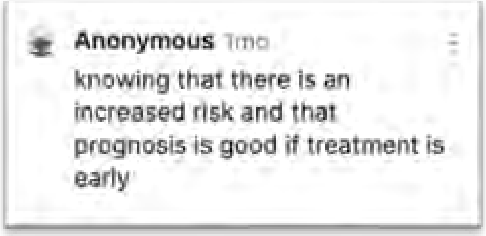
1. What does being breast aware mean to you as a person with NF1/What should breast awareness mean within the context of NF1?
2. Who is responsible for, or should be involved in breast cancer awareness for young women with NF1?
3. What may stop young women with NF1 being breast cancer aware?
4. What may encourage young women with NF1 to be breast cancer aware?
5. Any further comments?

Padlet responses

Common consensus across the two Padlets echoed the findings from Plunkett and Pilkington (2024) that explored beliefs, screening attitudes, and breast cancer awareness in young women with NF1.

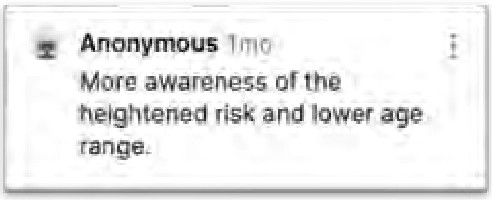
1. What does being breast aware mean to you as a person with NF1/What should breast awareness mean within the context of NF1?

The lack of available information on the increased risk of breast cancer at a younger age was highlighted.



Anonymous 1mo

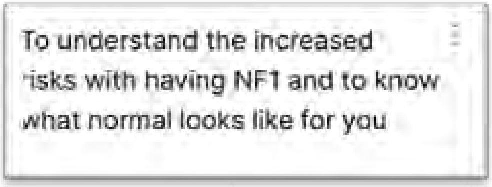
knowing that there is an increased risk and that prognosis is good if treatment is early



Anonymous 1mo

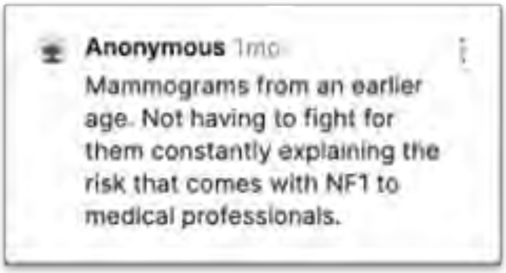
More awareness of the heightened risk and lower age range.

Certain models of behaviour, specifically the health belief model (Rosenstock, 1974), assert the importance of acknowledging risk, with individuals who perceive that they are susceptible to a health threat and perceive the severity to be high being more likely to have increased motivation to act against this threat (Norman and Brain, 2005). BCA was also understood as having self-efficacy to understand what to be aware of when checking breasts.



To understand the increased risks with having NF1 and to know what normal looks like for you

Appeals for earlier and regular checks, including mammograms from 30 years were noted as a common thread. This was found to be of particular interest on observation, as without the undertaking of a systematic analysis to understand the behaviour within the BCW (Michie et al., 2011), this appeared to be what was required and therefore the behaviour defined due to its frequency. However, this would be a heuristic action, whereby individuals often use shortcuts to evaluate information that may consequently incur biases leading to suboptimal decision-making (Tversky and Kahneman, 1981). Introducing earlier screening has been argued to be of benefit (Evans, 2020), with the age of breast cancer diagnoses of women with NF1 predominantly occurring from 34-44 years (Maani et al., 2019). However, with the continuous acknowledgement that there is a lack of awareness of the increased risk of breast cancer among young women with NF1, with this also being found among HPs that are required for screening referrals, this would inadequately address the issue.



Anonymous 1mo

Mammograms from an earlier age. Not having to fight for them constantly explaining the risk that comes with NF1 to medical professionals.

2. **Who is responsible for, or should be involved in breast cancer awareness for young women with NF1?**

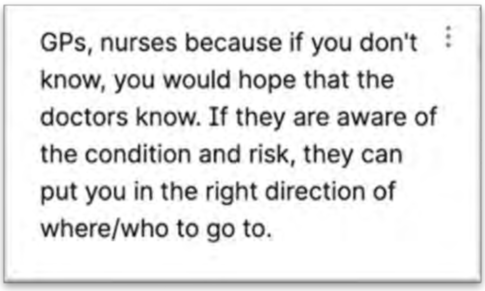
It was conveyed that HPs, with GPs most referred to, should be responsible for, or should be involved in BCA for young women with NF1.

Anonymous 2mo

All health professionals! Too many don't know nearly enough about NF. The increased risk of breast cancer should be known and shared by GPs etc so that both patients and health professionals know what to look for.

Anonymous 1mo

breast cancer awareness charities, nhs, GPS, national breast screening clincs. letter sent out automatically to all women with NF1 at age 30 to inform them they need screening. Main medic looking after patient. NF Specialists in fact all medics associated with patients care

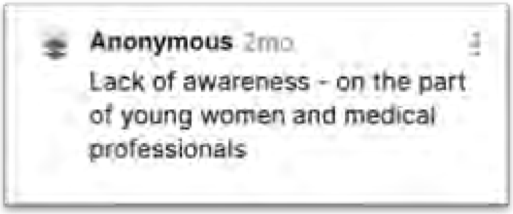


GPs, nurses because if you don't know, you would hope that the doctors know. If they are aware of the condition and risk, they can put you in the right direction of where/who to go to.

However, what is noteworthy is that no comments explicitly recognised women with NF1 as responsible for or should be involved in BCA. Instead, a profound concentration on HPs as being responsible for this exists, without acknowledgement of the importance of action that needs to be taken by individuals to seek medical help by firstly knowing the increased risk, secondly of having self-efficacy of knowing what to be aware of when examining breasts, and thirdly from this self-efficacy of having self-confidence to seek medical help. While earlier screening is beneficial in diagnosing cancer earlier, it is correspondingly important that individuals with NF1 have these fundamental cited means, acknowledging that breast cancer in young women tend to be aggressive and are therefore often diagnosed at a later stage (Howell et al., 2022). Ensuring that self-efficacy of BCA exists is prudent, with anything of concern being addressed promptly by the women themselves.

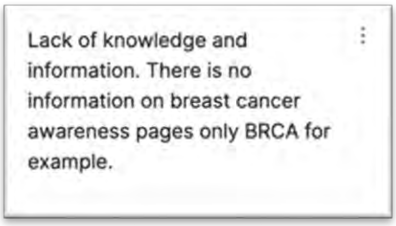
3. What may stop young women with NF1 being breast cancer aware?

Lack of knowledge and information pertaining to the association between NF1, and the increased risk of breast cancer were cited as significant barriers to women with NF1 being breast cancer aware. HPs’ lack of awareness was acknowledged. Fear was also highlighted as a key barrier.



Anonymous 2mo

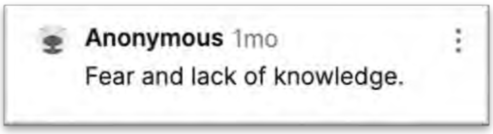
Lack of awareness - on the part of young women and medical professionals



Lack of knowledge and information. There is no information on breast cancer awareness pages only BRCA for example.

Anonymous 1mo

Lack of awareness that they need to be extra vigilant. Also that they may feel they will be ignored



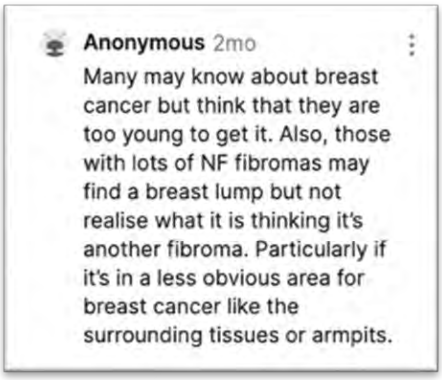
Anonymous 1mo

Fear and lack of knowledge.

Anonymous 1mo

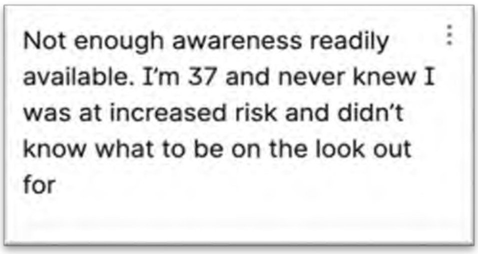
Lack of awareness or fear

Women are uncertain of what to be aware of within an NF1 context, particularly with neurofibromas that might instead be a malignant breast tumour. Developing breast examination self-efficacy within the intervention is essential as it has been found to be one of the most powerful predictors of health behaviour, with women more likely to engage in this behaviour if they can examine breasts with fewer barriers (Norman and Brain, 2005).

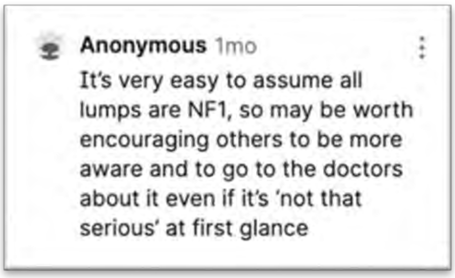


Anonymous 2mo

Many may know about breast cancer but think that they are too young to get it. Also, those with lots of NF fibromas may find a breast lump but not realise what it is thinking it's another fibroma. Particularly if it's in a less obvious area for breast cancer like the surrounding tissues or armpits.

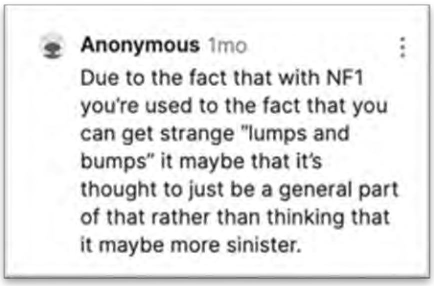


Not enough awareness readily available. I'm 37 and never knew I was at increased risk and didn't know what to be on the look out for



Anonymous 1mo

It's very easy to assume all lumps are NF1, so may be worth encouraging others to be more aware and to go to the doctors about it even if it's 'not that serious' at first glance

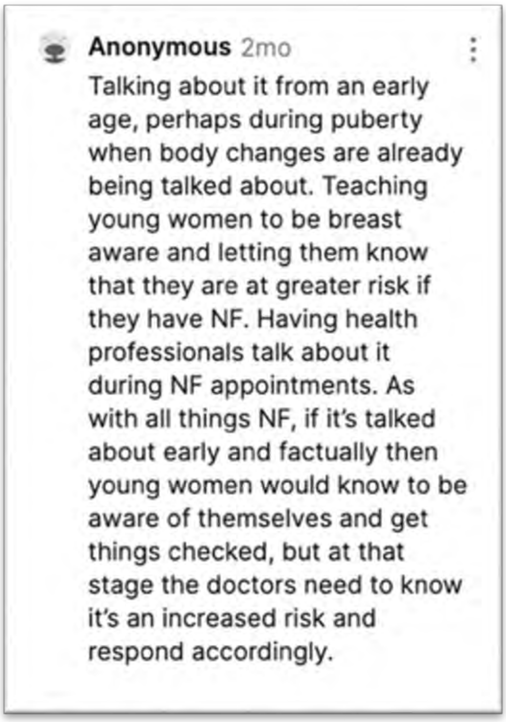


Anonymous 1mo

Due to the fact that with NF1 you're used to the fact that you can get strange "lumps and bumps" it maybe that it's thought to just be a general part of that rather than thinking that it maybe more sinister.

4. What may encourage young women with NF1 to be breast cancer aware?

Awareness, talking about the increased risk from an earlier age, normalising it, and having more readily available and reliable information were common responses considered as important in encouraging young women with NF1 to be breast cancer aware. Again, HPs were also perceived as playing a crucial role in this aspect.

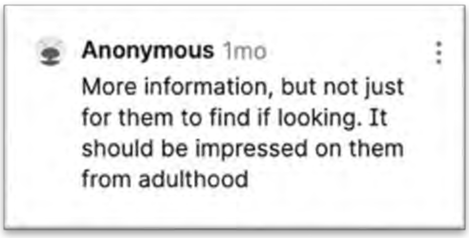


Anonymous 2mo

Talking about it from an early age, perhaps during puberty when body changes are already being talked about. Teaching young women to be breast aware and letting them know that they are at greater risk if they have NF. Having health professionals talk about it during NF appointments. As with all things NF, if it's talked about early and factually then young women would know to be aware of themselves and get things checked, but at that stage the doctors need to know it's an increased risk and respond accordingly.

Anonymous 2mo

More information on this, i was diagnosed at 50 with breast cancer, and had no idea that I was at risk from 30, I found that out after doing some research online again


Anonymous 1mo

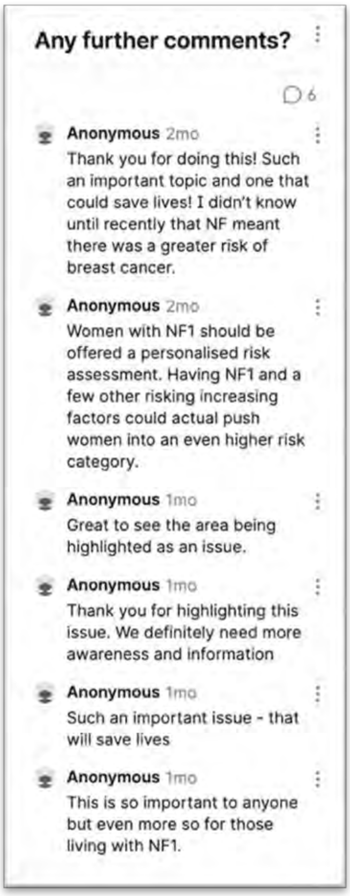
More information, but not just for them to find if looking. It should be impressed on them from adulthood


Anonymous 1mo

Increased awareness. Being taught how to check correctly.

5. Any further comments?

This question was posed to allow individuals to add any other information that may be pertinent for the intervention development. Instead, five out of the six comments highlighted support and appreciation for this research. A comment discussing the potential importance of a personalised risk assessment was also added. With the intended benefit of increasing self-efficacy in being breast cancer aware, to know what to be aware of within an NF1 context and to seek medical help promptly, it is acknowledged that this may aid all women with NF1 regardless of their statistical risk, as an earlier diagnosis is one with a better prognosis for all. It is also acknowledged that the communication of important points is aimed at educating any other person that may interact with the intervention in the future such as HPs.


Any further comments?

Anonymous 2mo

Thank you for doing this! Such an important topic and one that could save lives! I didn't know until recently that NF meant there was a greater risk of breast cancer.

Anonymous 2mo

Women with NF1 should be offered a personalised risk assessment. Having NF1 and a few other risking increasing factors could actual push women into an even higher risk category.

Anonymous 1mo

Great to see the area being highlighted as an issue.

Anonymous 1mo

Thank you for highlighting this issue. We definitely need more awareness and information

Anonymous 1mo

Such an important issue - that will save lives

Anonymous 1mo

This is so important to anyone but even more so for those living with NF1.

4.6 Important Padlet observations

It is noted that when asked '*Who is responsible for or should be involved in breast cancer awareness for young women with NF1?',* the responsibility was conveyed as predominantly that of HPs, with no responders expressing that women with NF1 themselves should be the key drivers for BCA responsibility. This was found across both Padlets of young women with NF1 and associates, with no responsibility found to be taken by associates either in being involved in BCA education or the imparting of information to the women with NF1 that they are closely associated with. This is concerning. As previously stated, self-efficacy is accepted as a crucial component for motivation for behaviour to occur (Michie et al., 2013), and one of the most powerful predictors of health behaviour (Norman and Brain, 2005). The research's objective of increasing BCA knowledge pertaining to NF1 among associates, also intends fostering self-efficacy in young women with NF1 to take responsibility to not only be breast cancer aware, but to promptly seek medical help for a breast concern if required. However, from the Padlet responses there was instead evidence of a distancing of the women from the self, and the required ownership of this behaviour to be breast cancer aware. It was also observed that fear was expressed as a barrier for these women to being aware. These two important points of lacking self-efficacy and therefore distancing themselves from their own body in a failure to safely self-objectify, and the potential effects of fear on BCA have been discussed in detail within Chapter Two. Both objectification of the woman's body, and fear, created by the creatureliness of this objectification are highly relevant to the design of this NF1 BCA intervention.

There is, therefore, the consideration of objectification and how it can be utilised within the intervention design, not as a socially constructed sexual objectification of the breasts, but as a move to objectification as a facilitator to awareness as an act of self-objectification that aids in the production of less fear and fatalism towards a BCA intervention. This can arguably be achieved by creating distance from 'creatureliness' (Courtney and Goldenberg, 2021), with terror management theory (TMT; Greenberg et al. 1986) positing that when mortality cognition occurs, this awareness of creatureliness occurs. Adopting self-objectification arguably places the woman as controlling the objectification, and considering TMT from this viewpoint, self-objectification may reduce the perceived threat of mortality by distancing from the potentially threatening association of creatureliness and therefore death (Goldenberg and Roberts, 2011; Morris et al., 2018). Certain campaigns have conveyed breasts as objects instead of in human form with reported success in increasing early detection and survivorship (NCI, 2022). An example of this is demonstrated in Figure 17 whereby lemons are used instead of breasts for educating on breast cancer warning signs (Know Your Lemons Foundation, 2021).

Figure 17

Signs and Symptoms of Breast Cancer, from https://knowyourlemons.org/

4.7 Padlet for Health Professionals

HPs are also important contributors within PPI involvement. However, there were difficulties in gathering information from this cohort. With the continued affects associated with the COVID-19 pandemic within clinical settings including high levels of absenteeism, a shortage of staff, higher work demands, and in some cases embargos on outside projects, it became apparent the importance of resilience and adaptability (Bratan et al., 2021) in ensuring that information was sought for the delivery of a high standard and accurate intervention. Considering the positive interaction that was observed within the Childhood Tumour Trust's Facebook Padlet to gather information and suggestions, it was decided that a similar approach would be taken for HPs, with a Padlet designed to capture information with six key questions asked to aid the intervention design from a medical perspective (Figure 18).

Figure 18

Healthcare Professionals' Padlet Contributions

Stakeholder Involvement: Health Professionals

1. How often should women with NF1 check their breasts for any changes?

2. Should there be any differences in the method of breast checking by women with NF1, compared to what is advertised as standard breast checking?

3. In your experience, are there differences that can be seen and/or felt between a neurofibroma and a potential malignant breast mass? Please describe these details.

4. What resources do you use to increase your knowledge of NF1 and the associated risks?

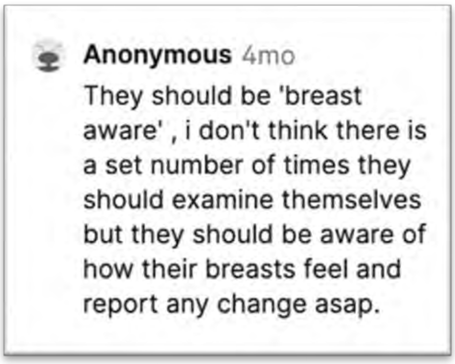
5. What resources do you share with women with NF1 within your consultations?

6. What are your views on how breast checking by women with NF1 can be improved?

1. How often should women with NF1 check their breasts for any changes?

Communicating information on how often a woman with NF1 should check their breasts for any changes is important to allow the opportunity for an intention to be built on frequency to aid in habit formation. Wood et al. (2022) define a habit as a direct context-response connection that is learned through repetitive reward responding. Habits are important in aiding the promotion of behavioural maintenance (Kwasnicka et al., 2016), as once formed they act automatically with minor demand on self-regulatory and cognitive resources (Phillips and Mullan, 2022). It may also aid in action planning which involves establishing a plan for performing the desired goal behaviour in a specified situation (Hagger and Luszczynska, 2014).

Across both the UK and Ireland, HP answers were consistent, in that women with NF1 should check their breasts monthly. However, it is noted that one HP from a UK Cancer Centre, communicated that, 'they should be breast aware' and that they didn't think there was a set number of times they should examine themselves.


Anonymous 4mo
They should be 'breast aware' , i don't think there is a set number of times they should examine themselves but they should be aware of how their breasts feel and report any change asap.

The breast cancer nurse specialist (ROI) incorrectly stated that women with NF1 attend breast screening form the age of 35 years. This demonstrates that there is a confusion and a lack of knowledge when it comes to what is the correct information that HPs should communicate to their patients and accompanying associates within clinical appointments.

2. **Should there be any differences in the method of breast checking by women with NF1, compared to what is advertised as standard breast checking?**

The resounding answer to this question was ‘no’. This is important within this research on two levels. Firstly, for the intervention content it is established that information pertaining to the potential signs of breast cancer that is already publicly available can be utilised. Secondly, this is important to acknowledge for data collection, as BCA levels of warning signs may already be high due to this information being already available.

3. **In your experience, are there differences that can be seen and/or felt between a neurofibroma and a potential malignant breast mass? Please describe these details.**

This is important in relation to developing self-efficacy, however, it emerged from HPs that there is a lack of knowledge when it comes to answering this question. This supports the findings that HPs lack knowledge of rare conditions (e.g., Kopeć and Podolec, 2015; Ramalle-Gómara et al., 2015; Javaid et al., 2016; Domaradzki and Walkowiak, 2019; Ramalle-Gómara et al., 2020; Sanges et al., 2020; Domaradzki and Walkowiak, 2021). This was ascertained from Padlet responses of ‘*no experiences of differences*’, ‘*question for surgeon/radiologist’* (as answered by a breast cancer specialist nurse), and an explanation from a GP that they have not had any experience of examining a person with NF1; however, they also added that if any woman presented with a lump that they would refer them on for further tests. The answer from the geneticist that worked within a complex NF1 clinic at this time was clearer; ‘*Yes skin neurofibromas are soft and not a concern. I* *have never seen a nodular neurofibroma in the breast but if they occur could cause a differential diagnosis issue and may feel similar'*. This echoes the potential difficulty in differentiating between a benign and malignant breast tumour as outlined within the literature review.

This question was presented to aid in developing self-efficacy for women with NF1, and their associates (if required to communicate this important information), in knowing what to be aware of, and what is normal for their own (young women with NF1) breasts. It is also recognised that this building of self-efficacy through knowledge acquisition aids in reducing complexity. Kaushal and Rhodes (2015) explain complexity as an individual's perceived difficulty, and therefore self-efficacy in performing a particular behaviour. McCloskey and Johnson (2019) understand perceived behavioural complexity as the perceived difficulty in participating in a behaviour, but they also include the amount of planning, time, and attention required to engage in a behaviour. It is argued that by ensuring these potential barriers are addressed by communicating frequency, the method, and what to be aware of, that it reduces both the actual complexity and the perceived complexity to being breast cancer aware.

4. What resources do you use to increase your knowledge of NF1 and the associated risks?

With HPs within PPI, it is recognised that not only are they better qualified to answer medical questions pertaining to NF1, but to also ascertain what resources are commonly used for knowledge acquisition and continued professional development to best disseminate the intervention resources within this cohort. A variety of resources were cited including medical literature (PubMed in particular), NICE guidelines, and online resources 'GP Notebook' and 'Up to date' that offer information on conditions and diagnosis. This further highlights the findings within Chapter Two that HPs use online resources for rare disease information.

5. What resources do you share with women with NF1 within your consultations?

From the Padlet, only one HP communicated that they offer information to patients with NF1, with this individual positioned within an NF1 complex clinic team as a geneticist. This person communicated that they offer charity website and leaflet information. Others either left this blank or said that they have not had an encounter with a patient with NF1.

This further highlights HPs' often low levels of rare disease knowledge (Domaradzki and Walkowiak, 2021), as they are unaware of the condition and the risks in the first instance to offer information resources themselves.

6. What are your views on how breast checking by women with NF1 can be improved?

From the responses, there was a shared consensus that awareness needs to be improved, with this increase in awareness also needing to include both patients and multidisciplinary team members (UK cancer centre), and among GPs (response provided by a GP), with resources needing to be online as GPs predominantly use these type of continuous professional development tools. This answer was left blank by the breast cancer nurse specialist. Interestingly, these answers convey an understanding that BCA should be a shared experience involving not just the women with NF1, but also the wider HP team.

4.8 Selecting the target behaviour

The Padlets allowed for Step 2 of the BCW (*Select target behaviours*) to be completed. Behaviours were rated as: Unacceptable, Unpromising but Worth Considering, Promising, Very Promising (Michie et al., 2014) by considering:

1. Impact behaviour change will have on desired outcome
2. How likely the behaviour can be changed
3. Likelihood that behaviour will have positive/negative impact on other related behaviours
4. How easily behaviour can be measured

Potential target behaviours were ascertained and rated from PPI responses and meetings, observations of Padlet responses, and literature evidence. These are outlined below within Table 11.

Table 11

Selecting Target Behaviour

Aim:
To develop an intervention to increase BCA in young women with NF1 and associates.
Potential behaviours identified:
Education of increased risk of breast cancer at a younger age in women with NF1.

Education of breast screening eligibility at a younger age due to increased risk.
Reducing fear of breast anomalies and breast cancer.
Increasing ownership of being breast cancer aware and seek help promptly for any breast concerns.

Behaviours deemed *Unacceptable* and excluded as outside this research scope:
Introducing mammograms and regular checks from an earlier age (25/30 years).
National campaigns to educate on condition and increased breast cancer risk.
Introducing personalised risk assessment.

Potential target behaviour relevant to Increasing BCA in young women with NF1	Impact of behaviour change	Likelihood of changing behaviour	Spill-over score	Measurement score
Education of increased risk of breast cancer at a younger age in women with NF1.	Very promising	Very promising	Very promising (Designed intervention may also educate HPs, public etc.)	Very promising
Education of eligibility of breast screening at a younger age due to increased risk.	Very promising	Very promising	Very promising (as above)	Very promising
Reducing fear of breast anomalies and breast cancer.	Very promising	Promising	Promising	Promising
Instructions on what to be aware of when checking breasts within an NF1 context.	Very promising	Very promising	Promising	Very promising
Increasing ownership of being breast cancer aware, and self-confidence to seek help promptly for any breast concerns.	Very promising	Promising	Very promising (May encourage other young women with NF1 to be empowered to seek help).	Very promising

Target behaviours selected: All of the above

From the careful considerations made from both the Padlets and from the observations concerning self-efficacy, fear, and objectification, this allowed for a more meticulous approach when deciphering the information required within Step 3 (*Specify the target behaviour*) as outlined in Table 12.

4.9 Specifying the target behaviour

Table 12

Specifying the Target Behaviour

Target behaviour:	Increasing NF1 BCA of young women with NF1 and associates through: 1. Education of increased risk at a younger age in women with NF1. 2. Education on screening eligibility. 3. Instructions on what to be aware of when checking breasts within an NF1 context. 4. Reduction of breast cancer fear. 5. Increasing ownership of being breast cancer aware, and self-confidence to seek help promptly for any breast concerns.
***Who* needs to perform the behaviour?**	This is warranted as a recommended principal change. Women with NF1 may benefit from taking ownership of being breast cancer aware, and for associates to understand that they are important in raising awareness to those around them with NF1. While HPs are important in the ‘Who’, it is imperative that BCA begins with the women as breast examination is primarily performed by themselves. However, it is important for HPs to have knowledge of the condition and the increased breast cancer risk. While not included within this evaluation, the material designed may be utilised by them and/or public, charities, etc.
***What* do they need to do differently to achieve the desired change?**	To engage in education within an NF1 BCA context, including screening and risk. It is important to consider the mindset of fear towards breast cancer that may impede this.
***When* do they need to do it?**	Check breasts once a month at a time that is suitable to the woman with NF1 but have a continuous awareness.
***Where* do they need to do it?**	BCA predominantly takes place privately, but also within a consultation with HPs.
***How* often do they need to do it?**	Once a month.
***With whom* do they need to do it?**	For breast checking: alone or with HP.

4.10 Identifying what needs to change

These preceding points allowed for an identification of *what needs to change* (Step 4) for the target behaviour to occur as outlined within Table 13. These considerations will be incorporated within the content and design of the intervention.

Table 13

Identify what Needs to Change Using the COM-B Model

COM-B components	What needs to happen for the target behaviour to occur?	Is there a need to change?
Physical capability	Have the physical skills to check breasts.	Change needed as women are unsure of what to be aware of when checking within an NF1 context.
Psychological capability	Know what to be aware of when checking breasts for increased risk, and screening eligibility.	Change needed as lack of BCA across various contexts listed within Padlets.
	Know that breast cancer is not an automatic 'death-sentence', and when caught early has improved outcomes.	Change needed as fear of cancer with the associated 'creatureliness' and objectification of the woman's body within society that carries an association with death may act as a barrier to seeking help and being able to treat cancer early for a better prognosis.
Physical opportunity	Have resources available and accessible to educate on components of BCA.	Change required as findings from Padlet and within the literature report that individuals including those with NF1, and HPs are using online sources that may not be accurate. No tailor-made resources are currently available.
Social opportunity	Once data collection has been completed it is important to have resources available on social media platforms and websites (e.g., Childhood Tumour Trust website), to educate individuals and get people talking with correct information.	Change needed to make available online evidence-based resources specific to NF1 BCA.

Reflective motivation	Hold beliefs that having the self-efficacy to be breast cancer aware with checking breasts, knowing increased risk, information on screening etc.may aid in spotting any potential malignant tumours earlier for a better prognosis.	Change recommended as findings from Padlets and Plunkett and Pilkington (2024) report that women with NF1 are not confident knowing what they are to be aware of. This was also found within the Padlets completed by associates, with a lack of knowledge found pertaining to NF1 breast screening age eligibility, for example.
Automatic motivation	Have an established routine and habit for checking breasts.	Change needed to establish routine and habit formation.
Behavioural diagnosis of the relevant COM-B components	Address all components to meet target behaviour.	

Within Stage 2 (*Identify intervention options*), suitable intervention and policy options are selected to aid in further establishing the determined target behaviour.

4.11 Identifying suitable intervention options, policy categories, and behaviour change techniques

From the Padlet suggestions and from the researcher’s further explorations, the following intervention functions (Step 5) were identified as suitable in addressing COM-B components, as outlined in Table 14. Suitability was further considered by applying the APEASE criteria. Certain intervention functions were deemed unsuitable for inclusion within this intervention. These were incentivisation, coercion, and restriction. There was no monetary incentivisation in the form of cash or a voucher, for example, to take part in any component of this research. Subsequently, coercion was not utilised whereby there is an expectation of cost or punishment (Michie et al., 2014). The taking part within this research, and the watching of the intervention as a tool to raise BCA in any individual once the resources are made public, are voluntary. Restriction is not a suitable intervention function for this project. While it may be suitable for other interventions such as prohibiting the sale of alcohol to individuals under 18 years of age, it is important that BCA information pertaining to NF1 is widely shared without restriction to raise awareness about NF1 and therefore its associated risk of developing breast cancer at a younger age.

Table 14

Intervention Options

COM-B	Intervention functions	Does each intervention function meet the APEASE criteria?
Physical capability	Education, training	Yes
Psychological capability	Education	Yes
Physical opportunity	Enablement	Yes
Social opportunity	Enablement	Yes
Reflective motivation	Education, training, enablement, modelling, persuasion, environmental restructuring	Yes
Automatic motivation	Education, training, enablement, environmental restructuring	Yes

These intervention functions work in tandem with the policy category of Step 6 (Table 15), with suitable behaviour change techniques (BCTs) also identified (Step 7) that begin the final considerations of the design (Stage 3 *Identify content and implementation options*). The focused actions of this research were to design, implement, and explore the feasibility of a NF1 BCA intervention for young women with NF1 and their associates. Therefore, the policy category of communication/marketing was deemed as most suitable to reach as many individuals as possible, and to again meet the APEASE criteria.

Table 15

Policy Category

Policy Category	Intervention functions acted upon	Does the policy category meet the APEASE criteria?
Communication/marketing	Education, training, enablement, modelling, persuasion, environmental restructuring.	Yes

With the identification of suitable intervention functions under the relevant policy category, BCTs that can deliver the intended outcomes were identified. A comprehensive list of all BCTs with individual details can be found within the BCT Taxonomy (v1) (Appendix F), providing a standardised language of 93 items, categorised into 16 groups (Michie et al., 2014). The below BCTs (Table 16) were selected as the most compatible for the proposed change mechanisms that concurrently met the APEASE criteria.

Table 16

Identification of BCTs

Intervention function	BCT	Does the BCT meet the APEASE criteria?
Education	**4.1** Instruction on how to perform the behaviour. **5.1** Information about health consequences.	Yes
Persuasion	**5.1** Information about health consequences. **9.1** Credible source. **13.2** Framing/reframing. **15.1** Verbal persuasion about capability.	Yes
Training	**4.1** Instruction on how to perform the behaviour. **6.1** Demonstration of the behaviour. **8.1** Behavioural practice and rehearsal.	Yes
Environmental restructuring	**7.1** Prompts and cues. **12.5** Adding objects to the environment.	Yes
Modelling	**6.1** Demonstration of the behaviour.	Yes
Enablement	**1.4** Action planning. **3.1** Social support (unspecified – Childhood Tumour Trust website/social media). **3.3** Social support (emotional). **4.1** Instruction on how to perform the behaviour. **8.1** Behavioural practice and rehearsal. **12.5** Adding objects to the environment (website with intervention and other materials).	Yes

4.12 Identifying the mode of delivery

The most suitable mode of delivery is determined by examining various dimensions to ascertain which method best meets the intervention requirements (Michie et al., 2014). It also allows for a robust clarity of what the intervention itself will be, providing for a well-defined plan that cogitates aspects such as recipients, provider, and setting, for example. These considerations are detailed within Table 17 below.

Table 17

Considerations Within the Identification of the Mode of Delivery

Considerations within mode of delivery	Proposed design implementations within research and after data collection
Content	NF1 BCA animation and information leaflet.
Provider	Content designed by principal investigator of Manchester Metropolitan University and provided by Childhood Tumour Trust.
Setting	Initially, online through Qualtrics. Once data collection has been completed this may be delivered online through the Childhood Tumour Trust's social media platforms.
Recipient	Young women with NF1 and their associates. Once publicly available, recipients may also be considered as the public, HPs, charities etc.
Intensity	Feasibility of the intervention is examined in two contacts. One via Qualtrics to collect pre- and post- test data predominantly quantitative in nature. Second contact is via telephone/Microsoft Teams for interviews for qualitative data collection. Once public, the animation may be watched in one contact.
Duration	Up to 6-month period of data collection to ascertain changes in BCA.
Fidelity	Maintained by delivery without deviations detailed within the research project's ethics application.

Acknowledging from the intervention functions that education is essential in increasing NF1 BCA knowledge, whilst training may aid in building self-efficacy to know what to be aware of when checking breasts, it is important to consider how these will be delivered, as detailed within Step 8 (*Identify mode of delivery*). It is intended that the mode aids in the persuasion of the content, enabling individuals to feel positive in conducting the behaviour, and reduce negative connotations of cancer.

Important considerations acquired from research specific to the recipients are important when deciphering the best delivery mode. Both young women with NF1 and HPs are often susceptible to misinformation particularly online within the realm of rare diseases (Suarez-Lledo and Alvarez-Galez, 2021; Plunkett and Pilkington, 2024). In fact, anyone can be susceptible to misinformation, particularly on media sharing platforms where users can share symptoms, therapies, and medical treatments (Loeb et al., 2019), ascertaining that information is reliable by the number of 'likes' the information receives, or the number of visits to a page, and particularly if the content appears to be logically structured and expressed with a 'scientific' language style (Faase et al., 2016). This susceptibility to misinformation, therefore, includes associates that may be looking for information and advice on behalf of a young woman with NF1. Often, 'accessible information' is uncontrolled, with some information being misleading, or contradictory to important messages within interventions (Kitchens et al., 2014). With it being recognised that individuals with NF1 have low levels of health literacy and a decreased uptake of health management and monitoring (Crawford et al., 2016), it is critical that accurate and accessible information is available to educate on, and increase self-efficacy of BCA and NF1, with those with low levels of health literacy susceptible to misinformation and disengagement from positive behaviours (Rubinelli and Diviani, 2020). As discussed within Chapter Two, health literacy levels are low within the UK and ROI (Rowlands et al., 2015; HSE, 2022b). It is therefore important that the intervention is designed to be at an accessible level aimed at the common reading age level of a 11-14-year-old reading age group which is at or below Level 1 of the literacy national standard as set out by the UK government's *Skills for Life Survey* (2012). Before online information was available, individuals regarded HPs as an irrefutable source of medical advice and information, however today, trust is put on the experiences and perspectives of others (Smith, 2011), as is often found online.

With the exploration of the potential positive utilisation of objectification to aid in increasing BCA, using a cartoon or doodle woman to both deliver training on what to be aware of when checking breasts, and to act as a modelling mechanism, may aid in creating a distance to allow for the objectification of the figure and therefore self-objectification of the breasts. This subsequently acts on increasing efficacy of becoming breast cancer aware, including its related components of screening, and statistical risk which are also important for associates. Figoureux and Van Gorp (2021) found that using cartoons within sensitive subjects such as radicalisation positively elicited conversation, and diminished power relations between the researcher and the participant. Utilising a cartoon form within this intervention may also act in a similar way, with the identification that there are clear placements of power and responsibility with HPs. It is important that women with NF1 are empowered to develop self-efficacy and take on this duty of care onto themselves. Witnessing a woman with NF1 and the breasts in cartoon form may aid in eliciting a distance, therefore allowing a better focus on what to be aware of when looking for any breast changes. It may create an association of breasts as cartoons when checking the breasts for any changes, which may also provide a protective distance from the normally associated 'creatureliness' of the breasts (Courtney and Goldenberg, 2021).

It is imperative that accurate online information and resources are made available that adopt methods that encourage positive utilisation. From examining Michie et al.'s (2014) taxonomy of modes of delivery for intervention functions that involve communications, two are deemed most suitable. The NF1 BCA intervention content will be an animated digital media format within the Internet (differences in NF1 BCA levels to be measured), with a print media format of an information leaflet with key points and images from the animation initially provided with debrief information (differences in NF1 BCA levels not measured). Rubinelli and Diviani (2020) highlight the importance of ensuring that committed efforts are made to identify the most trusted sources of health information within a target group to successfully communicate a message. From the evidence presented, online resources that are available on sites that young women with NF1 and their associates interact with for support and advice, such as the Childhood Tumour Trust, are deemed to be the most feasible. Therefore, the Childhood Tumour Trust is the provider within the mode of delivery. By adding the intervention online to this platform and their social media sites, it also restructures these environments, whereby they now also act as a source and setting of evidence-based resources.

It is recognised that the dimensions of intensity, fidelity, and duration are considered two-fold; firstly, within the data collection period of the research, and then after when the animation becomes publicly available. Intensity varies, with two points of contact required to explore intervention feasibility; one via Qualtrics to collect pre- and post- test data predominantly quantitative in nature, and the second for qualitative purposes via telephone/Microsoft Teams interviews. Once public, the animation can be watched in one contact. Fidelity is maintained by ensuring no deviations of permissions granted within the research project's ethics application.

To conclude this process, a detailed summary is provided within the final APEASE criteria assessment as outlined in Table 18. While not within this chapter but through the methodology, analysis and discussion sections, the MRC framework component of evaluation is accomplished.

Table 18

Identify Mode of Delivery

Mode of delivery	Detailed summary of final APEASE criteria check
An NF1 BCA intervention in the form of: A. An animation B. Information leaflet with summary points and images from the animation (provided with debrief material – not within analyses). C. After data collection resources to be made available online via Childhood Tumour Trust.	
	***Affordability*: YES** A) By advertising the animation project through Rise at Manchester Metropolitan University there is no monetary cost for employing a team to animate and design a leaflet. B) No new website set up costs are involved. Platforms such as the Childhood Tumour Trust website are available. C) Qualtrics is free when downloaded through the university.
	***Practicability:* YES** Young women with NF1 and HPs were found to use online searches for information pertaining to NF1 and breast cancer risk.
	***Effectiveness and cost-effectiveness:* YES** Potentially a large effect size of intervention in relation to the desired objective in the real-world context. From a cost-

effectiveness perspective, it is suitable with only a short timescale required for the design.

Acceptability: **YES**

A) From the information obtained from PPI, it is evident that developing NF1 BCA is deemed as important and necessary, and therefore acceptable.

B) With online resources being found to be commonly used by women with NF1 and HPs and noted as preferred when speaking to women with NF1 (Plunkett and Pilkington, 2024), the proposed design of an animation and information leaflet available online is judged to be appropriate.

Side-effects/safety: **YES**

A) This intervention is considered predominantly safe. However, accepting that this is a potentially sensitive subject for some, it is important that key resources that offer support are also provided when in the data collection phase through participant information sheets and debrief sheets (e.g., Macmillan Cancer Support, Breast Cancer Now, and practical advice such as actively encouraging individuals to attend a HP if there are breast concerns).

B) It is recognised that from viewing the animation and/or information leaflet, a breast cancer symptom may be found or suspected. It is communicated that if the person is not happy with anything concerning their breasts, they should contact a HP.

Equity: **YES**

92% of adults in the UK and ROI were recent internet users in 2020, and almost all adults aged 16-44 years in the UK were recent internet users (99%) (Office of National Statistics, 2021). These online resources may aid in reducing knowledge acquisition disparities and build self-efficacy in the target population of young women with NF1 (18-40 years), and their associates, by being placed on a platform that individuals have access to and utilise frequently.

4.13 Conclusion and overall evaluation of PPI involvement

Through the application of theoretical framework components of both the BCW guide to designing interventions, and the MRC's framework for developing and evaluating complex interventions, a robust strategy has been formulated to take forward within this research. It has been ascertained through these frameworks that the NF1 BCA intervention will be delivered by a novel animation. An information leaflet will also be produced, but to be utilised solely as a summary of key points for participants after intervention completion and will be provided as part of debrief material. It will not be included within the intervention analyses. PPI was critical in the development of this intervention to gain an understanding of contextual factors that may otherwise have been omitted. It is therefore prudent to evaluate PPI involvement for not only transparency, but for addressing issues to aid in proposing recommendations in future studies. However, PPI reporting in research is often partial and inconsistent, with fragmented evidence of what works, for whom, why, and in what context with limited consideration of process, and impact (Mockford et al., 2012; Staniszewska et al., 2017). The GRIPP2 reporting checklist (Appendix G) was referred to as a guide to consider levels of PPI at this stage of the research to improve consistency, quality, and transparency (Staniszewska et al., 2017).

While the research strived to ensure *governance,* and *inclusive opportunities* within the UK Standards for Public Involvement (2019) by gathering PPI experience and insight, within this initial intervention design planning phase only two young women with NF1 were involved. It was anticipated that more would have desired to have been involved, and therefore PPI within this cohort is limited. There was a balance to be struck with having greater numbers from this cohort and not expending potential research participant numbers, with recruitment difficulties reported within rare disease research (Whicher et al., 2018). However, it is recommended that future studies aim to recruit from a wider pool, and to ensure that a greater involvement of young women with NF1 is achieved for accurate relevance of intervention information. Greater PPI numbers may be garnered from incentivisation to be involved. PPIs were not offered compensation such as cash or vouchers within this research. However, ethical considerations are important to consider such as perceived undue influence, or unjust inducement (Largent et al., 2023). However, Halpern et al. (2004) reported no occurrence of these, with individuals generally personally motivated to partake in research (Largent et al., 2023).

This research experienced difficulties with recruiting for traditional focus groups, with one supposition of this being the alignment of timing of recruitment for PPI involvement for intervention design with the reduction or removal of COVID-19 restrictions heralding a societal shift back to normalcy. The motivation to be involved within PPI may therefore not have been present. Recruitment of HPs within PPI may also have been affected during this time, with HPs continue to experience research embargos and an increased workload with COVID-19, making it difficult to partake (Bratan et al., 2021). Instead, Padlet was employed as a novel and creative approach to support *working together, communications,* and *support and learning* within the UK Standards for Public Involvement (2019). However, future applications would benefit from a more cautious approach to allow for better monitoring and communication of numbers of PPI contributors, with Padlet unable to ascertain exact numbers of respondents (Mehta et al., 2021) making it difficult to establish whether responses are communicated from all, or from a select few that may offer several responses for one question. This was a particular challenge with the number of associate responses. As a period has now elapsed, reconsideration of including traditional focus groups may be warranted within subsequent research phases.

Utilising the behaviour change wheel (Michie et al., 2014) alongside the Medical Research Council's framework for developing and evaluating complex interventions (Skivington et al., 2021) for guidance aided in facilitating *impact* by its emphasis of exploration of PPI feedback. Through the observation of PPI comments within Padlets, it became apparent that young women with NF1 and their associates believed that BCA should be the responsibility of HPs. This presented the question of where was the 'self' within 'self-efficacy'? PPI therefore greatly impacted the trajectory of the intervention design, and application of theoretical models for behaviour change by highlighting the importance of instilling self-efficacy to be breast cancer aware, rather than merely BCA knowledge acquisition.

Readability and acceptability of any materials employed involved PPI. These included those for research advertisement, PIS, and debrief materials (supervisory team, the Childhood Tumour Trust), Padlet questions (supervisory team, the Childhood Tumour Trust, Nurse Researcher), and pre- and post-test items (supervisory team, the Childhood Tumour Trust). While patient and public involvement at charity level is important, the research also included involvement from targeted HPs such as an expert in rare disease genetics, a breast cancer specialist nurse, and HPs employed within a cancer centre. It is recommended that these are also involved in any subsequent related research to ensure accuracy of information. Wider involvement of NF charities, and NF clinics may also aid in improving diversity of PPI involvement, with PPI of young women with NF1 and associates advertised only by The Childhood Tumour Trust. While the animation design process (drawing and sound) involved the supervisory team and the Childhood Tumour Trust, on reflection it would have benefited from wider PPI involvement, particularly with young women with NF1. Returning to the importance of garnering a collective understanding of what works, for whom, why, and in what context as communicated by Staniszewska et al. (2017), it is conceded therefore that further pertinent and applicable information may have been overlooked when exploring the feasibility of this novel breast cancer awareness intervention.

4.14 Summary of the key points in this chapter

- Health behaviour is an act that an individual engages in to attain, maintain, or regain good health, but additionally to prevent illness. BCA, or the act of being breast cancer aware is also a health behaviour that involves breast awareness of having the knowledge and confidence to ‘look and feel’ breasts to become familiar with what is normal.
- Michie et al. (2011) summarise that behaviour change occurs by the modification of capability, opportunity, and motivation which is the foundation of the BCW that aids in understanding the problem in behavioural terms and explores intervention and implementation options.
- The NF1 BCA intervention is designed by the BCW guidance across its three stages of understanding the behaviour, identifying intervention options, and identifying content and implementation options.
- The MRC framework for developing and evaluating complex interventions is also incorporated to ensure a thorough evaluation of intervention design options is considered.
- PPI of clinical, academic, and personal experiences was gathered within Padlets.
- It was determined that the NF1 BCA intervention would be delivered in an animated form, with an information leaflet designed as supplementary material.

- With the BCW not comprising a comprehensive guide to intervention evaluation, the MRC framework's guidance on evaluation is followed by utilising the most appropriate method to address the research question.
- Applying the GRIPP2 for reporting PPI involvement allowed for the consideration that wider PPI involvement may aid in providing further insights into intervention design and delivery. Future research may benefit from including greater numbers of young women with NF1 within the intervention design stage.

4.15 The next stage of the research

With objectives now defined to take forward in designing the intervention, the next stage provides a detailed discussion pertaining to the design, and therefore application of psychological literature, of both the NF1 BCA animation and the information leaflet. The requirement to source creative professionals that are sensitive to the required novel approach of the animation is imperative. The following chapter explores how the successful recruitment of a sound engineer, animators, and voice actors allowed for a theoretically based NF1 BCA intervention to come to life.

Chapter Five

The design of a theoretically based NF1 breast cancer awareness animation

Please click here or visit

https://mmutube.mmu.ac.uk/media/NF1+Breast+Cancer+Awareness+/1_luz3zvps

to watch the animation (closed captions available).

5.1 Introduction

A novel animated intervention was designed with the objective of increasing BCA in young women with NF1 and their associates and encourage prompt medical consultation for a breast concern. A supplementary information leaflet was also designed with key points from the animation. It was provided alongside the debrief sheet and not used for measuring differences in NF1 BCA levels. An animated format initiates both an instructive and engaging experience, employing a sequence of graphically detailed and dynamic elements that epitomise real-world experiences, and depict complex ideas to aid in multimedia learning (Mayer and Moreno, 2002). Compared with text-based resources and static images, animations can simplify complex phenomena, and communicate important information by employing colour, symbols, modification of speech including speed and stress of words, and sound effects (Yue et al., 2013). The animation skills of Carly Smith and Rebecca Horswill were utilised, who were at the time of the design undertaking an MA in Animation within the School of Digital Arts (SODA) at Manchester Metropolitan University. They were recruited through the Rise programme, a platform where university students and staff can learn new skills, get involved with projects, and for students to gain experience within internship programmes and earn credits toward their degree. Both animators received 300 Rise points and transcript recognition. Voice actors, and Charlotte Proctor, a student sound engineer and composer were recruited through the animators. Proctor, a SODA MA student, received 250 Rise points and transcript recognition. The inclusion of professional talents arguably adopts a multidisciplinary team approach; one that goes beyond that of the commonly used HPs and patients for other perspectives to convey important health behaviour messages. During the animation design process, meetings were held with the supervisory team and the Childhood Tumour Trust to ensure that pertinent aspects for accessibility and acceptability such as character conception, understanding and language level, and length and speed of animation were suitable.

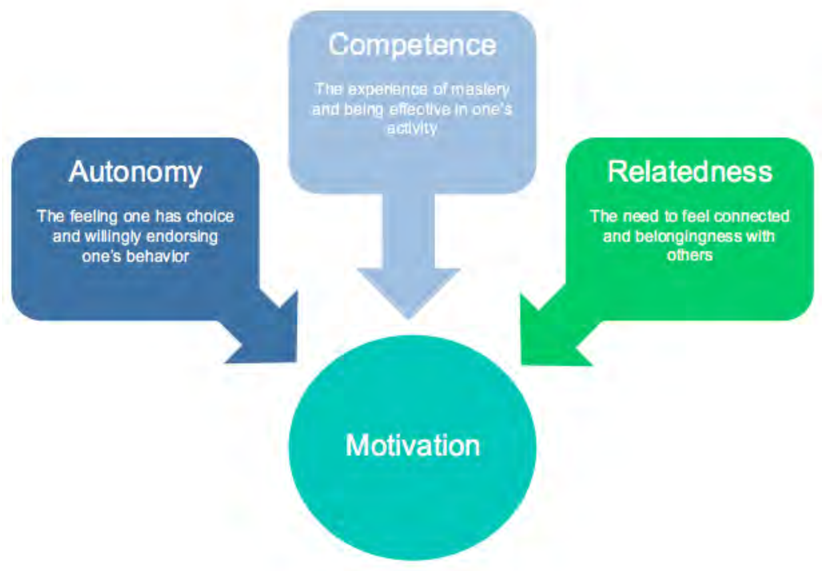
The animation script that I designed (Appendix H) is built on the theoretical components of autonomy, competence, and relatedness of self-determination theory (SDT; Deci and Ryan, 1985). BCTs that were elected within the intervention design process (Chapter Four) were also incorporated within the animation script, characters, and setting design. Evidence-based breast cancer sign and symptom information was obtained from Breast Cancer Now. With the incorporation of this source, PPI, and the application of a behaviour change theory ensures that BCT 9.1 *Credible source* is utilised. The remainder of the chapter discusses the animation development.

5.2 Self-determination theory as an animation design framework

Within the BCW intervention design (Michie et al., 2014) it was ascertained that the responsibility of NF1 BCA was placed with HPs. Therefore, the intervention needed to instil a motivation to be breast cancer aware whereby control, support, and knowledge are experienced. Within their work with individuals with learning disabilities, Heslop et al. (2020) identify key characteristics related to experiencing happiness and health which is relevant due to a high prevalence of learning difficulties within the NF1 population. These are having choice and control, feeling valued, feeling safe and secure now and in relation to the future, having self-confidence, and a feeling of self-worth. These align closely with SDT components, recognising that individual innate psychological needs and inclination to grow are the basis for self-motivation that is either intrinsic or extrinsic (Ryan and Deci, 2017). Intrinsic motivation describes the experience whereby an individual will behave in a particular way for the innate gratification, with behaviours enacted out of their interests and values, whilst extrinsic motivation is experienced by external rewards that are recognised and valued external to the self (Deci and Ryan, 2000). Motivation, both intrinsic and extrinsic, is experienced by the innate psychological needs of autonomy, competence, and relatedness to others (Figure 19) (Ryan and Deci, 2017). Relatedness refers to the sense of connection with others, competence is a belief that one can carry out required behaviours, and autonomy is an individual’s perception that they have choice and freedom from excessive external pressure of compliance to think, act, and behave a certain way (Ryan and Deci, 2017). A digital health behaviour intervention, sensibly considered to include an animated format, aims to satisfy these needs to persuade and advance engagement (Keenan and Lionarons, 2018) by aiding in disseminating information for informed decision making and self-management (competence and autonomy), and providing a process for information exchange and support (relatedness) (Kostkova, 2015; Zanaboni et al., 2018).

Figure 19

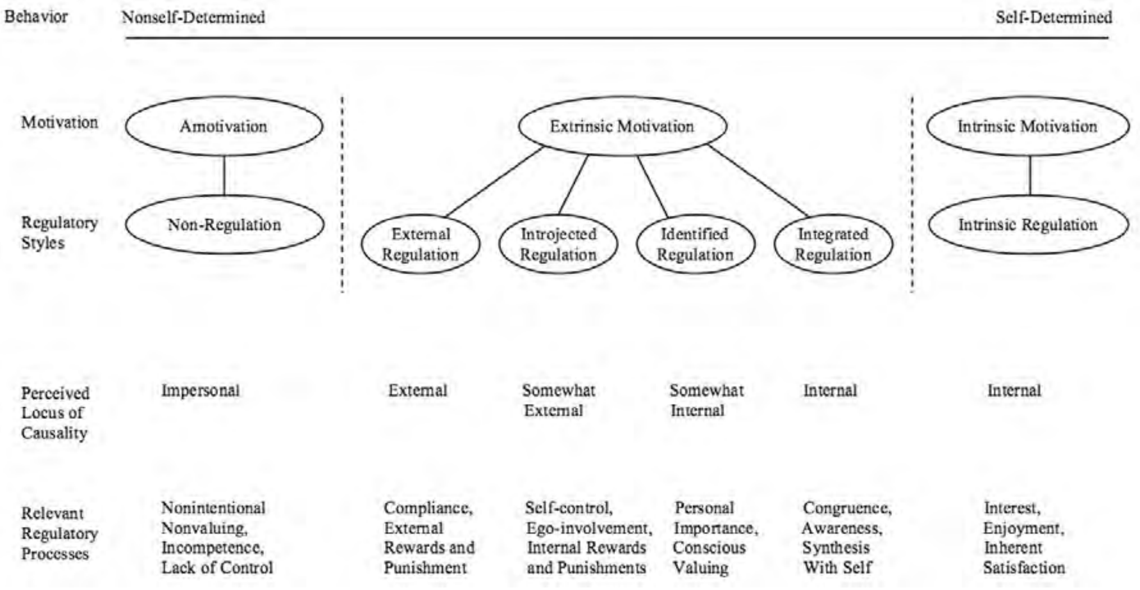
The Components of Self-Determination Theory



Within SDT extrinsic motivation varies in type with contextual factors either promoting or hindering internalisation and behaviour integration. These variations are outlined in Figure 20 within Deci and Ryan's (1985) organismic integration theory (OIT), whereby external motivation is explained as a continuum that proceeds from one end as *external regulation* of an entirely external perceived locus of causality with regulatory processes including those of compliance, and external rewards and punishments. On the other end of the continuum motivation is experienced as *integrated regulation*, whereby an individual's perceived locus of causality is internal, with a congruence and an awareness with the self when performing a behaviour.

Figure 20

Self-Determination Continuum with Regulatory Styles, Perceived Locus of Causality, and Relevant Regulatory Processes (Ryan and Deci, 2000)



While motivation is important for behaviour change, it is preferable that this motivation is intrinsic or as close as possible to this (Ajzen, 1991). However, when encouraging BCA this behaviour can often be perceived as extrinsic, with a message coming externally rather than being experienced internally, with compliance required to follow instructions of what to be aware of when checking breasts, when to check, and when to go for breast screening. Compliance refers to a particular kind of response, referred to as ‘acquiescence’, whereby the communication is a request (Cialdini and Goldstein, 2004). This is observed within OIT as an extrinsic motivation of external regulation; however, the intervention intends to foster an extrinsic motivation on the other end of the continuum of integrated regulation. Despite the behavioural change message coming from an external source where initially a level of compliance is required, by aiding in the development of an inclination to adopt BCA behaviours with a perceived internal locus of causality, and congruence with self by methodically incorporating the innate psychological needs of SDT of integrated regulation, the desired behaviour may be fostered within a congruence of needs and values (Ryan and Deci, 2017).

5.3 The effect of health message framing on competence, autonomy, and relatedness

How the health message is framed within the intervention influences motivation by affecting the innate psychological needs of competence, autonomy, and relatedness to others, and consequently the health and happiness of the individual (Heslop et al., 2020). Persuasion is a key strategy that public health advocates often use to motivate individuals to adopt healthy behaviours (Gallagher and Updegraff, 2012; Liu et al., 2019). Within the BCTs, persuasion can include verbal persuasion about capability (BCT 15.1), whereby it is communicated that the person can successfully perform the desired behaviour. BCT 13.2 of framing/reframing suggests that the deliberate adoption of a perspective or new perspective on behaviour to adapt emotions and cognitions about performing the required behaviour is also a persuasive strategy in building motivation for behaviour change adoption and maintenance.

Framing theory posits that a message can be viewed from a variety of perspectives and values placed upon them (Chong and Druckman, 2007). A health message can communicate essentially identical information; however, one message frame type may be more effective than another at promoting health behaviour change and evoking differing emotional responses (Rothman et al., 1997; Mikels et al., 2016). This originated from Tversky and Kahneman's (1981) prospect theory whereby an individual, if faced with two choices, a preference for one over the other will be influenced by how these are framed. If potential losses are emphasised, a willingness to opt for a risky option to prevent those losses is often observed. Conversely, if potential gains are highlighted, less willingness is found for risks to secure those gains. In the same reasoning, health messages can be framed to emphasise either the benefits of engaging in a behaviour (a gain-frame), or the negative outcomes of failing to engage in a behaviour (a loss-frame) (Gallagher and Updegraff, 2012).

Rothman and Salovey (1997) posited that gain-framed health messages should be more effective than loss-framed messages for promoting health behaviours that are perceived to be only minimally risky to carry out. Conversely, loss-framed messages should be more effective when health behaviours are perceived to have a higher degree of risk associated with actioning them. Behaviours that serve as an illness detection function, arguably this BCA intervention, should therefore be more likely to be perceived as involving a higher level of risk due to the possibility that a sinister breast anomaly may be found. However, Rothman and Salovey’s (1997) deduction places detection behaviours as simply risky on one degree, despite the existence of potential variables that may affect how individuals perceive the risks associated with a behaviour, and consequentially the acceptance of framed messages. Within this research, two key variables of young women with NF1 are age and risk. Message framing has been found to have differing effects on health behaviours among older (60-89 years) versus younger adults (18-32 years) (Notthoff and Carstensen, 2014), with older adults (64-86 years versus younger adults 18-23 years) often rating positively framed messages as more informative (Shamaskin et al., 2010) and responding less negatively to loss-framed messages compared to younger adults (*M* = 20.93 years versus older adults *M*= 73.77 years) (Mikels et al., 2016). This is consistent with the phenomenon coined the ‘positivity effect’, whereby older adults compared to younger adults are more likely to focus on and recall positive information (Reed et al., 2014). This is related to socioemotional selectivity theory (Carstensen et al., 1999) whereby priorities for social, emotional, and information seeking goals are set within a temporal acknowledgment that time left is less than time passed. Emotionally meaningful goals and a present-orientated mindset therefore become the dominant position (Carstensen and Mikels, 2005).

Risk is important to consider, with the increased risk of developing breast cancer at a younger age among women with NF1 noted as a central requirement for education. Gallagher et al. (2011) reported a loss-frame advantage among women who considered themselves to be at substantial risk for breast cancer, however, no advantage was found from either frame perspective for women who perceived that they had little or no risk for breast cancer. While the evidence of age and risk present an argument for the adoption of a negative framing style for the communication within the intervention, interviews conducted within the target population (Plunkett and Pilkington, 2024) contribute a different perspective. While it is established in the medical literature that there is an increased risk of developing breast cancer at a younger age among women with NF1, these interviews indicated confusion in what was the exact increased risk, and what age group this risk was associated with. This demonstrates that while the NF1 and breast cancer risk is firmly established in literature, this should not automatically signify an understanding in those with NF1, or among their associates. In this regard, it can be assumed that a negative-framed message would therefore not be beneficial. Considering research that suggests that negative framed messages may be more impactful on younger women, such as those at increased risk of developing breast cancer associated with NF1, it is important to consider another important factor before opting for a specific frame based merely on age. Fear was highlighted as a significant impact on self-esteem and competence (Plunkett and Pilkington, 2024). It is, therefore, pertinent to explore the impact of fear on this cohort, and the effect of this on message framing.

5.4 The consideration of fear on message framing

Achar et al. (2020) suggest that detection health behaviours are associated with fear as they involve the possibility of discovering a negative outcome in relation to one's health. Fear is a reaction to the contemplation of an unpleasant and uncertain situation and includes a low perception of personal control (Smith and Ellsworth, 1985). Behaviours intended to prevent or minimise breast cancer are associated with the perception of control (Rothman et al., 1993). Individuals are more likely to engage in a health behaviour through an enhanced perception of self-efficacy within illness prevention as they have a sense of control (Achar et al., 2020). However, for detection behaviours, the fear of finding something that may lead to a cancer diagnosis may also contribute to a loss of perceived self-efficacy. Fear is associated with avoidance behaviours (Achar et al., 2020), creating a barrier to encouraging individuals to carry out important health behaviours. This is a pertinent consideration within this research, as BCA is deemed a health detection behaviour, compared to that of a health behaviour that is undertaken to help prevent or minimise the occurrence of breast cancer. Arguably, fear has a negative effect on establishing an integrated regulation level of extrinsic motivation, with competence impacted with the loss of self-efficacy, and autonomy to be breast aware impaired if an avoidance behaviour is assumed rather than that of a self-determination to check breasts and seek prompt consultation from a HP if required.

It is, therefore, important that positive attitudes are fostered within this intervention to aid women with NF1 to develop a confident competence of self-efficacy in being breast cancer aware. Considering these points, it is deemed more appropriate to impart a positive frame throughout the animation and within the information leaflet. Individuals should be encouraged that they have the competence, and autonomy to be breast aware. It is also important that a sense of support and relatedness is developed to enhance an integrated level of extrinsic motivation as reasoned within SDT.

5.5 Social stories and narratives

Individuals often rely on narratives to comprehend complex issues by relatedness to others, vicariously experiencing others' emotions for sense making (Vafeiadis and Shen, 2021). Narratives that describe social situations and provide cues and behavioural expectations have been found to be more effective in changing attitudes and behaviours than traditional advocacy messages (Dal Cin et al., 2004). Murphy et al. (2013) found the utilisation of narratives to be successful in encouraging positive attitudes toward cervical cancer screening. This is important within this research, as negative attitudes specifically pertaining to fear can often act as a barrier to attending HPs and screening services when they are required or recommended.

Narratives is an umbrella term that encompasses a method known as social stories. A social story (Gray and Garand, 1993) utilises pictures and/or objects of reference, and a character experiencing a particular situation of unanswered questions or unresolved conflict, with the social story ending with a resolution (Hinyard and Kreuter, 2007). This method is an inclusive tool that aids individuals, including those with learning difficulties, to understand situations and learn new information within a coherent story with a beginning, middle, and end. A created character intended to be like the viewer also cultivates a sense of relatedness to others, as described within SDT (Ryan and Deci, 2017).

Previous exploration within Chapter Four argued a potential positive utilisation of objectification by the design of a cartoon woman with NF1, rather than a human woman to aid in creating relatedness to others and cultivate BCA by educating on breast checking (BCT 4.1 *Instruction on how to perform the behaviour*), and modelling of expected behaviour by the *Demonstration of the behaviour* (BCT 6.1). It correspondingly creates a sense of distance to allow for the viewer to objectify the animated figure to aid self-efficacy of competence and autonomy to be breast cancer aware. The perceived distance of the viewing of an animated character that can still be related to despite it not being human, may also aid in developing positive attitudes towards health behaviours and lessen fear by promoting an experience of transportation. This occurs when immersion into a storyline is experienced to induce a temporal, physical, and psychological disconnection from the real world (Green and Brock, 2000). Transportation enhances the perceived vividness and realism of story-related events, aiding in generating positive attitudes and feelings toward characters (Vafeiadis and Shen, 2021) therefore affecting behaviours and attitudes (Gebbers et al., 2017; Shen et al., 2017). Viewers that experience transportation become less attentive to counterarguments through identification with the storyline characters aiding in reducing perceived feelings of threat and fear and increasing message persuasiveness (Mazzocco et al., 2010; Gardner and Leshner, 2016).

5.6 Setting the scene of the NF1 breast cancer awareness animation

Transportation is created by scenes and characters. Animated characters create a protective distance to the viewer within the social story and consist of women with NF1 aged 18-40 years within scenes that portray these individuals within the flow of their daily activities depending on their own stages and responsibilities. Examples of these activities are having coffee (Figure 21), at work (Figure 22), and at university (Figure 23). To encourage transportation, these women are portrayed as ‘just like’ the women that the intervention is aimed at. Arguably, however, anyone that watches the animation can experience an intrinsic sense of relatedness to others and transportation, whether it is a young woman with NF1, a person associated with a young woman with NF1, or a person who is not familiar with the genetic condition of NF1 as they witness these animated individuals going about their daily lives like them.

Figure 21

Animation Screenshot of Woman Having Coffee

Figure 22

Animation Screenshot of Young Woman at Work

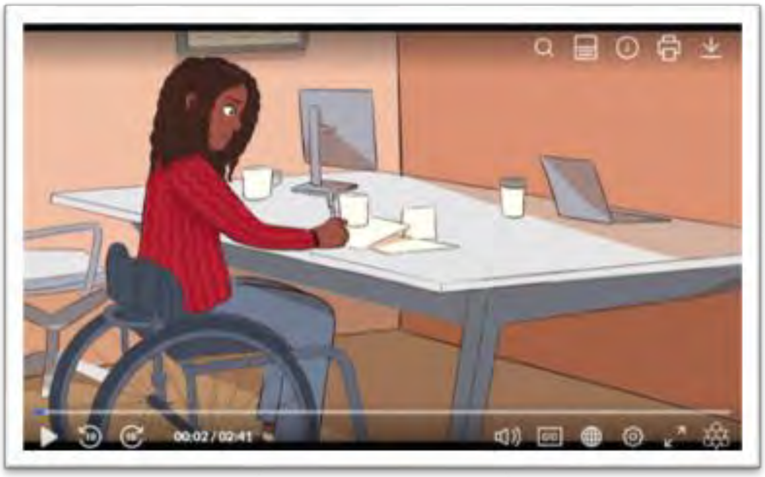


Figure 23

Animation Screenshot of Young Woman at University

We then meet "Bea" (B.E.A.; Breast Examination Awareness) the protagonist of this 'story' and the communicator of NF1 BCA facts. Bea is a young woman with NF1 with visible manifestations of café-au-lait macules (Figure 24), again designed in a way that builds relatedness to those with NF1 and makes these individuals visible to anyone who watches, whether they have NF1 or not.

Figure 24

B.E.A. - NF1 BCA Animation Protagonist

Visible manifestations are further described to particularly benefit those that may not be familiar with the condition, by explaining about NF1 and making a comparison of café-au-lait macules to milky coffee to aid in remembering this information (Figure 25).

Bea: Hi, I’m Bea. I have a genetic condition called neurofibromatosis type 1 or NF1 for short. Having NF1 increases my chances of developing a number of things, like neurofibromas that are the lumps and bumps on my skin, and café-au-lait marks, kind of coloured like milky coffee.

(Focus changes quickly to inside the cup of the woman drinking coffee.)

Figure 25

Animation Screenshot of Comparison of Café-au-Lait Macules to Milky Coffee

kind of coloured like milky coffee.

Bea: 6 or more of these are usually found on individuals with NF1.

Bea communicates in an approachable and friendly manner with a gentle smile, and a warm tone that conveys a sense of approachableness and competence in their instructions on how to be breast cancer aware, rather than utilising fear or negative framing. While the intervention requires compliance for carrying out BCA actions, a social story with Bea and development of self-determination, it can be considered with an increased integrated regulation and an internal perceived locus of causality (Ryan and Deci, 2017). It shifts from an externally controlled motivation, to one that builds and sustains confidence to not only undertake the behaviour, but to persist, increase self-esteem, and wellbeing (Deci and Ryan, 1991).

5.7 Increased competence

Animations designed for education are grounded in the cognitive theory of multimedia learning (CTML; Mayer, 2008). CTML is built on established theories such as cognitive load theory (CLT; Sweller et al., 1998) and dual coding theory (DCT; Paivio, 1986). CLT is concerned with the learner's cognitive capacity, with three types of cognitive load processing occurring of essential, extraneous, and generative (Mayer, 2010). Essential processing concerns the intrinsic load which is an innate cognitive processing that forms a mental representation of the learning content. Extraneous processing involves mental activities whereby the learner encounters redundant situations such as a distracting sound effect that does not match the learning context. The coherence principle posits that only necessary visual or verbal data should be included to ensure minimal disruption for essential information focus (Moreno and Mayer, 2000). Generative processing occurs when the learner formulates a coherent mental model for understanding. An animation designed for learning therefore aims to achieve essential processing, minimise extraneous processing, and enable generative processing (Mayer, 2010). Within DCT, words and images are separately processed within the limited capacity working memory channels which are then integrated into a mental model of the taught subject matter (Paivio, 1986). Both images and verbal elements contribute to mental models, with verbal parts contributing theory-based data, and images providing visual representations to strengthen the verbal components (Bartholomé and Bromme, 2009).

For awareness campaigns that communicate messages that require compliance such as a BCA intervention of checking breasts a certain way and at a particular frequency, this can often be experienced at an external regulation point within the extrinsic motivation continuum, acting on the external gain of rewards and punishments (Deci and Ryan, 1985). While this may meet the sense of increased competence with being able to carry out the behaviours, it lacks autonomy and relatedness to others, jeopardising behaviour continuation. Certain factors may also become a barrier to meeting increased competence. As recognised previously, there is a high prevalence of learning difficulties among individuals with NF1. If the intervention is not designed at an inclusive level, the motivation for competence is decreased, and arguably the motivation to adopt a health behaviour.

This BCA animated intervention and information leaflet are designed at a level that attempts to be inclusive for competency to be developed. Literacy and health literacy levels are important to consider when designing materials for this intervention. As discussed within Chapter Two, learning difficulties are prevalent within the NF1 population and 43% of adults aged 18 – 65 years in England do not have adequate literacy skills to understand health information, with many of these adults classified within the 11-14-year-old reading age group (Rowlands et al., 2015). Irish research communicates similar findings, with 38.8% of the adult population having limited health literacy (HSE, 2022b). Recognising these points, the health intervention is aimed at an average reading age of an 11-year-old, and therefore positioned within the literacy national standard of Entry 3 as set out by the government's *Skills for Life Survey* (2012) whereby adults can read more accurately and independently, obtaining information from everyday sources, and communicating (oral and written) information and opinions. Employing both an animation and an information leaflet designed at this level also appreciates the findings from Raynor et al. (2007) that individuals obtaining health information do not want written information as an alternative for spoken information, and that good communication is not simply using one method *or* another, but instead adopting multiple methods.

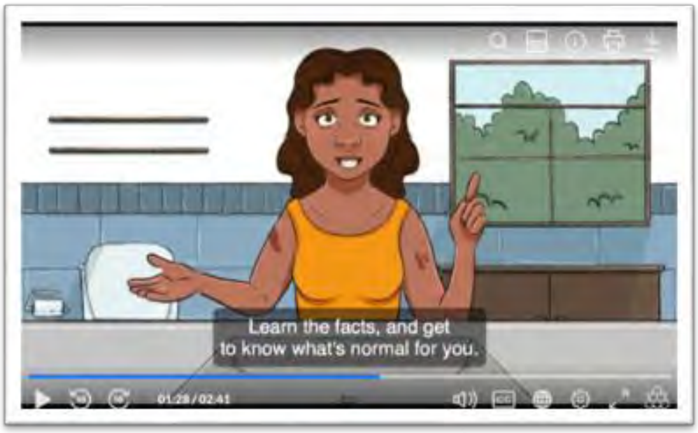
It is estimated that 50-90% of individuals with learning disabilities also have communication difficulties (Jones, 2002). This encompasses a range of issues including expressing themselves, understanding others, and complex verbal and non-verbal information that allows individuals to connect with others, and traverse social situations (Bradley et al., 2020). Within these, there are two main factors to consider, these being communication and comprehension. Communication can be described as the method in how we convey information from one person to another, using systems that both parties can understand (e.g., talking, listening, reading, writing, pictures, objects, facial expressions, and behaviours). Comprehension denotes 'understanding' whereby an individual has the means to pay attention when another is communicating by whatever means and can appropriately understand and interpret. To develop competence in understanding, and self-efficacy to carry out the intended breast awareness behaviours, the intervention adopts a 'total communication approach,' whereby several aspects of communication are utilised to increase comprehension and retention, with the avoidance of complicated grammatical structures, the utilisation of shorter sentences and familiar vocabulary, and information presented in an order that things are expected to happen (Bradley et al., 2020). This is in line with the Accessible Information Standard (NHS, 2017) which necessitates that information is produced in an easy read format, audio, or video to meet the needs of individuals with disabilities.

Speech is often considered as the most valued form of communication, but it can often be the most difficult to understand, and transiently available, necessitating a sufficient auditory memory to both retain and process (Bradley et al., 2020). Misinterpretation may occur with the use of non-concrete language such as metaphors or idioms, e.g., ‘it’s raining cats and dogs’ (Bradley et al., 2020). It is therefore important to ensure that individuals who engage with this intervention have a sense of competence maintained through the provision of clear messages. Within the total communication approach, the consideration of the impact of images utilised on competence is also included. The concrete image of female breasts is important to utilise, recognising that it is easier to process and understand instead of an abstract representation that may require more evidence to be understood (Bradley et al., 2020). Text combined with clear images engage the audience more than graphics *or* text alone (Houts et al., 2006). These considerations are incorporated by employing closed captions, short sentences that are matched to the animated parts, and a clear use of anatomical features pertinent to BCA. The inclusion of an active voice is also important (Rudd, 2019), with short informational segments delivered by Bea. All these components work in tandem to provide education and training (BCTs 4.1 *Instruction on how to perform the behaviour* and BCT 6.1 *Demonstration of the behaviour*). The various animation shots of breast cancer warning signs also provide the viewer an opportunity to mentally rehearse BCA (BCT 8.1 *Behavioural practice and rehearsal*), and to be able to develop a self-efficacy to begin to create a plan to become breast cancer aware (BCT 1.4 *Action planning*).

Bea: Learn the facts and get to know what’s normal for *you.* (Figure 26)

Figure 26

Animation Screenshot of Bea Communicating the Importance of Getting to Know What is Normal within BCA



Learn the facts, and get to know what's normal for you.

The signalling principle suggests that pertinent information within multimedia learning materials should be highlighted using well-defined structural indicators which are cues that aid learners focus their attention. The contiguity principle suggests that aural and visual elements should correspond with each other (Mayer, 2008). Within the intervention these are aligned for improved learning focus with verbal communication and imaging of the letters of N-F-1, and details of each letter headed and succinctly explained with sound effects for audio cues (Mayer, 2014).

Bea: N - F – 1
N - *New changes.*
Does your breast or nipple look different in any way such as a change in size or shape? Is your nipple pulled or flattened, is there discharge, like a liquid coming from it? (Figure 27)

Figure 27

Animation Screenshot Demonstrating Abnormal Discharge from the Breast

Is there discharge, like a liquid coming from it?

Bea: F – *Feels* different (Figure 28).
Is there a new lump or thickening of the skin in the breast, or a swelling in the armpit or around your collarbone?

Figure 28

Animation Screenshot of Application of Text Headings Before Moving to Breast Images

Bea: 1 - *One* time a month.

Pick a time that's going to work for you. Why not set a reminder! Checking once a month will help you learn what's normal for *you* and spot any changes (Figure 29).

This monthly reminder delivered verbally by Bea, with an image of a mobile phone calendar reminder and the audio of a reminder bell are positioned to act on BCT 7.1 *Prompts and cues.*

Figure 29

Animation Screenshot of Setting a Reminder

5.8 Developing autonomy

To experience an integrated regulation, the meaning of the behaviour must be comprehended, and that meaning should amalgamate with the individual's goals and values. Autonomy is fostered by ensuring that choice, and freedom from excessive external pressure of compliance to think, act, and behave a certain way are experienced

(Ryan and Deci, 2017) whereby a consistency or coherence between the behaviour and the internal state is experienced (Koestner et al., 1992). Autonomy, and therefore integration, is further created within SDT by the occurrence of the following three contextual acts; providing a meaningful rationale, acknowledging the behaver's perspective, and conveying choice rather than control (Deci et al., 1994).

A rationale that is personally meaningful to the target person can assist in the comprehension of why the behaviour would have a personal and therefore autonomous use. However, and particularly in this instance, encouraging BCA is not an action that often stems from intrinsic motivation, even when a meaningful rationale is supplied. Acknowledging this internal conflict between extrinsic and intrinsic motivation of the required compliance and the innate desire, demonstrates a respect for the individual's right to choose and can therefore aid in alleviating this tension by legitimising the person's concerns of a perceived inconsistency with values and normative behaviours (Deci et al., 1994). Suggesting that the individual has choice and control also creates an internalisation of motivation. While monthly breast checking is recommended, the decision and control of when and where this is undertaken is encouraged to be made by the woman, where possible. The Social Care Institute for Excellence (2020) also suggests that having choice and control is a principal factor that promotes dignity which directly contributes to an individual's empowerment, self-worth, and feeling valued. Self-esteem and the active BCT component of 15.1 *Verbal persuasion about capability* is created within the animation by the viewer receiving acknowledgment that they have achieved an important milestone in checking their breasts. This is conveyed within the animation by the communicated message of, 'NF1? Look. Feel. Learn. Done.' (Figures 30 and 31). This also positively impacts on the viewers self-confidence of believing in themselves (Bénabou and Tirole, 2002), therefore experiencing self-efficacy to be breast aware.

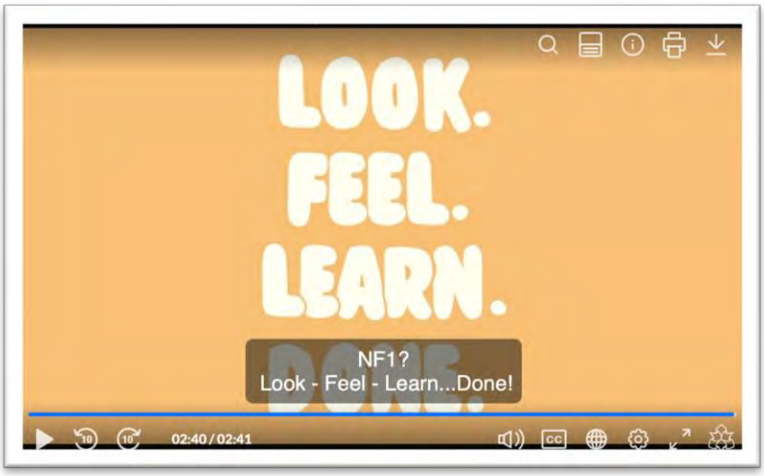
Figure 30

Animation Screenshot of NF1? Look. Feel. Learn. Done. (Part 1)

NF1?
Look - Feel - Learn...Done!

Figure 31

Animation Screenshot of NF1? Look. Feel. Learn. Done. (Part 2)



NF1?
Look - Feel - Learn...Done!

The avoidance of authoritative words and phrases that create behaviours to be carried out through external regulation of extrinsic motivation, such as ‘should,’ ‘must,’ and ‘have to,’ acknowledges that control and choice is for the individual to procure, with Bea communicating NF1 BCA information in a friendly yet competent manner as portrayed in tone, open body language, and friendly facial features. Examples of the three contextual acts of providing a meaningful rationale (Figure 32), acknowledging the behaver’s perspectives (Figures 33, 34, and 35), and conveying choice rather than control (Figure

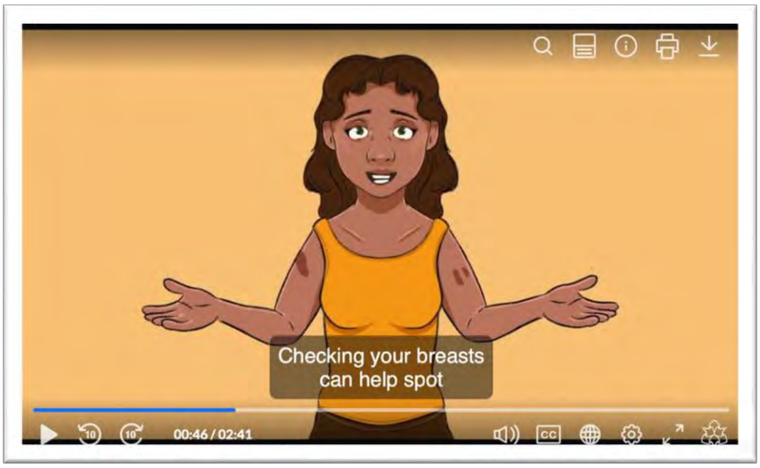
36) are communicated in the following ways (BCT 5.1 *Information about health consequences*):

Providing a meaningful rationale

Bea: Getting to know what is normal for your breasts is important. Checking your breasts can help spot any changes and help catch breast cancer early. Catching breast cancer early can mean better outcomes.

Figure 32

Animation Screenshot Demonstrating Provision of a Meaningful Rationale



Checking your breasts can help spot

Acknowledging the behaver's perspective

Bea: Checking breasts may make you anxious...

Side Character 1: What if I find something? Oh, what's that?

Figure 33

Animation Screenshot of Checking Breasts Creating Anxiety

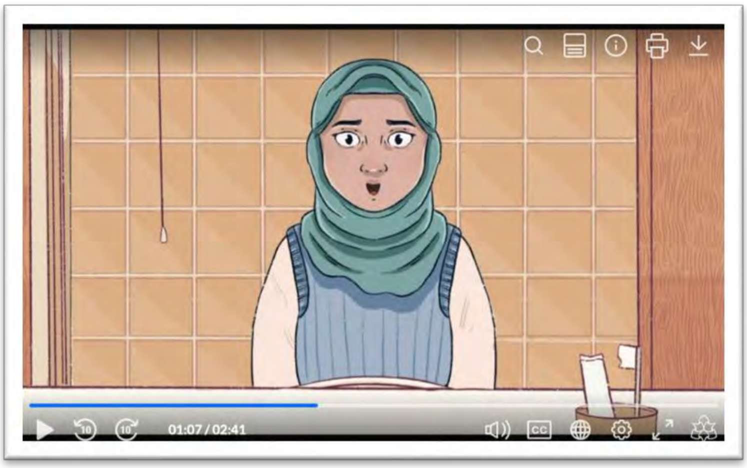

What if I find something?

Bea: Or it may just be boring…

Side Character 2: (Bored sigh)

Figure 34

Animation Screenshot of Checking Breasts Being Boring



Bea: Or maybe you feel a bit embarrassed?

Side Character 3: Well, *this* is weird!

Figure 35

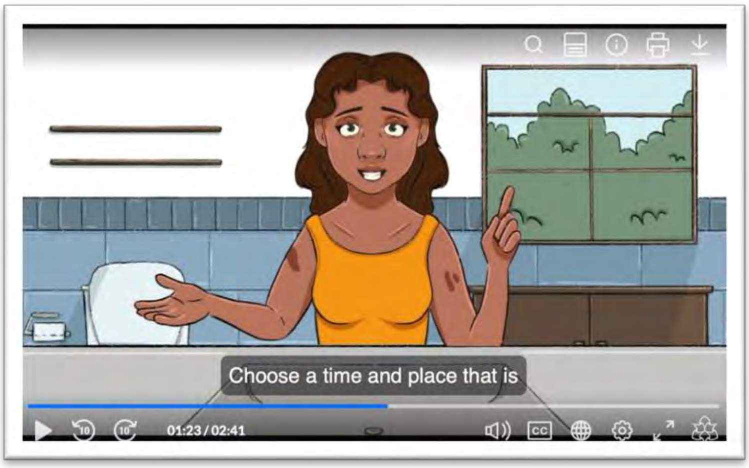
Animation Screenshot of Checking Breasts being Embarrassing

Conveying choice rather than control

Bea: Choose a time and place that is best for you to check your breasts.

Figure 36

Animation Screenshot of Bea in Control of Time and Place for Checking Breasts



5.9 Developing relatedness to others

Within SDT, Deci et al. (1994) recognise that human beings are proactive with a natural or intrinsic function that is either facilitated or impeded by the social context, which therefore includes social groups in which they are situated within. Individuals are more likely to adopt activities that have perceived relevant social groups value (Tajfel and

Turner, 2004). This relatedness to others also acts as a presence of support for self-determination, with this increasing the level of integration and therefore the level of internal locus of causality experienced (Deci et al., 1994). The perception of relevant social groups that aid in developing relatedness closely aligns with the components of social identity theory (SIT; Tajfel and Turner, 1986). SIT posits that individuals engage in social comparison and social categorisation to help shape values, beliefs, and behaviours, all of which are important to experience an integrated motivation. Groups that individuals create a relatedness to are referred to as reference groups. Individuals are most persuaded by their reference groups as they act as a reference point to ensure that standards of values and behaviours are aligned with others in the group. These can be described as social norms and can either guide or restrain behaviours (Cialdini and Trost, 1998) by the perceived social incentivisation to engage or not engage in certain behaviours (Ajzen, 1991). These social norms are therefore important health behaviour determinants (Dempsey et al., 2018). Individuals also develop in-group and out-group attitudes and behaviours that further instil their own beliefs, attitudes, and behaviours of what is personally relevant. There is the comparison against the out-group of young women in the general population that do not have NF1 and an increased risk of breast cancer by the making of the animation itself and the communication of NF1 specific information. There is also the social categorisation amongst the NF1 group that allows for the recognition of similarities that go beyond the medical condition, and reach out to the shared values, beliefs, and behaviours that being breast cancer aware is the expected norm. The development of a social norm of undertaking BCA behaviours is therefore encouraged, with an innate understanding of positionality of being within the NF1 in-group through the portrayal of the animation characters that contributes to building relatedness as outlined within SDT to move towards an intrinsic motivation.

The positioning of the animation online on the Childhood Tumour Trust's website and its relevant social media platforms (Instagram, Facebook, and X) after completion of data collection reinforces the in-group, and aids in contributing to the establishment of required social norms through relatedness to others. This action incorporates the BCTs of 12.5 *Adding objects to the environment* (adding BCA information to the website)*,* 3.1 *Social support (unspecified* – Childhood Tumour Trust website/social media*),* and 3.3 *Social support (emotional).* Social media can be an information source to what the perceived social norms of a group are (Fournier et al., 2013), with the online world recognised as not only a social place but additionally as an influential place (Yocco, 2016) whereby the behaviour of being breast cancer aware may be promoted to emanate from oneself as self-determined and integrated within the individual (Deci and Ryan, 1991). These social supports are also popular with associates of those with NF1, which strengthen these individuals' own in-group through their links with young women with NF1. There is a formulation of a social norm that recognises the importance of knowing what to be aware of for NF1 BCA, and of supporting those with the condition.

Relatedness to others also aligns with the central component of involvement within the elaboration likelihood model (ELM; Petty and Cacioppo, 1986) whereby it relates to the extent the information being communicated is relevant and related to an individual or group. Within ELM, two routes to persuasion exist, these being the peripheral and the central routes. When choosing a central route, an individual often prefers messages that contain aggregate data that allows them to analyse what is being communicated, rather than being exposed to a personal story. Conversely, individuals who prefer a peripheral route exhibit a reliance on heuristic cues rather than analysis, and therefore experience stories as more persuasive for health messaging (Gray, 2009). However, risk perceptions may affect which route an individual will favour, with those that consider themselves as having a low-involvement within the situation preferring story-based messages, and those that deem themselves as highly involved favouring informational messages (So et al., 2017). Recognising that there was inconsistency and confusion communicated by young women with NF1 surrounding risk perception of breast cancer (Plunkett and Pilkington, 2024), a mixture of both routes to persuasion within ELM is utilised. Therefore, a story line with colourful images and characters that encourage relatedness is created alongside the incorporation of informational data on risk and screening communicated by Bea (Figure 37).

Bea: Women with neurofibromatosis type 1 are at increased risk of developing breast cancer, with those under the age of 50 having an up to five-fold increased risk of developing the disease.

Bea: Don't forget that if you are a woman with NF1, it is recommended that you attend earlier annual breast screening from when you are 40 years old.

Figure 37

Animation Screenshot of 40th Birthday Cake with Party Sounds to Communicate Screening Age

from when you are 40 years old.

This approach is also applied to the design and content of the information leaflet which was provided within the debrief sheet (Figure 38) containing summary points of screening age, and specific breast cancer risk for young women with NF1.

Figure 38

Information Leaflet for NF1 Breast Cancer Awareness Intervention

NF1?

LOOK. FEEL. LEARN. DONE.

N - New changes?

- Change in size or shape of the breast.
- Nipple pulled or flattened, or discharge coming from it.

F – Feels different?

- New lump or thickening of the skin in the breast.
- Swelling in the armpit or around your collarbone.

1 - One time a month.

- Pick a time that's going to work for you

Why not set a reminder!

Checking once a month will help you learn what's normal for you, and spot any changes

Women with NF1 are at an increased risk of developing breast cancer, with those under the age of 50 having an up to five-fold increased risk of developing the disease.

If you are a woman with NF1, it is recommended that you attend earlier annual breast screening from when you are 40 years old.

Getting to know what is normal for your breasts is important. Checking your breasts can help spot any changes and catch breast cancer early. Catching breast cancer early can mean better outcomes.

If you notice any changes that you are not happy with, get them checked out with a healthcare professional.

5.10 Conclusion: Reflexivity on the transformation of psychological theory to animation

The animation script and scene ideas were derived from findings from Plunkett and Pilkington (2024), and from information gathered via Padlets within the previous chapter. I hold a BA (Hons) in English literature and Spanish and am comfortable with, and continue to enjoy creative writing processes despite having graduated over 20 years ago. The design process was therefore a positive experience. It was important that viewers could relate to the characters as having NF1, with Bea designed with the common manifestation of café-au-lait macules. The name of the character was important to get right. I wanted something that sounded friendly and approachable, but that also meant something. I went through short names and accidently stumbled on Bea, wondering what significance I could bring to a name that I liked the sound of. The first letter was easy as B stood out as signifying *Breast*, and then E and A signified two other important contributions to BCA which is *Examination* of the breasts, but within the context of having increased *Awareness.* I shared it with the team, and it was positively received which was lovely. With regular meetings with the Childhood Tumour Trust, supervisory, and animation team before the animation design, there were some, but not many refinements before presenting to participants. The greatest was ensuring that the café-au-lait macules on Bea were more visible. Choice of clothing to allow these to be clearly seen, and enhancement against skin tone were modified to aid in this. It was important that these could be clearly seen to enhance learning of this important manifestation of NF1, but also to accurately portray the condition. The importance of demonstrating a diversity of skin colour and ethnicity to communicate that NF1 can affect anyone was highlighted. This was considered among characters then placed in various scenarios as the animation was developed (e.g., student, mum, worker).

Recruitment for animators went as smoothly as it possibly could, with great support offered by the Rise team. It was advertised as needing two animators to undertake this project. This was because of the workload, and the short timeframe to design and deliver the animation (October 2022 to January 2023). There were only three applicants, however, two of them stood out for their experience, and their clear enthusiasm to be part of a project that raises awareness. I do think that even if there were more applicants, ultimately, we (Dr Melissa Pilkington and I) would have selected Carly and Rebecca or 'Becca'. I have lead teams in previous roles, but this was my favourite one, probably due to the intended outcome of the project and the passion that was evident within the team. I really did think that we had hit ‘the jackpot’ when Becca casually mentioned that she had contacts for voice actors and a sound engineer. Again, the luck kept rolling with the high calibre of actors, and a sound engineer that was fastidious, and also happened to be a music composer! Another casual comment within a meeting with Charlotte, our sound engineer, was, ‘oh, I also compose. I could compose some background music...if you’d like?’ It’s strange how these things happen. When I started thinking about the possibility of designing an animation, from very early on I had an idea of a catchy little ‘ditty’ with an almost sparkly sound to highlight ‘*N-F-1*', and of course the takeaway message of *‘NF1? Look. Feel. Learn. Done*’. As it materialised within a fantastic animation that brought to life psychological theory that I had previously only experienced as a sterile inanimate object within books and journals, it now emerged breathing as I pressed play for the first time on the finished product...while I continued to hold my breath throughout.

The finished animation while only 3 minutes 10 seconds in duration, took time to consider, put together, and edit. I gave each SDT component a page of paper, laying them out flat on my desk as I brainstormed ideas for each. The competence part was the easiest as this the educational information that needed to be communicated. However, I really wanted to instil self-efficacy within those that watched this animation. Having knowledge is one thing, but actually believing in yourself in that *you* have the knowledge, and *you* have the power, well that’s very different. A belief and confidence in being able to go to a HP and speak up and ask for further action if needed is what I wanted to be experienced. It’s hard. I know. I remember feeling embarrassed, as if I was wasting my GP’s time, the day I went about the lump I found in my breast. How differently I feel now. How thankful I am that I was lucky in that my GP wasn’t taking any chances and despite being only in my thirties at the time, he took me seriously and didn’t ‘fob me off’ as being too young for breast cancer. This animation was designed to instil autonomy to pick the time, the date, and the place to check breasts. Bea, while only a cartoon character, played the most important role within this research. This (animated) person had to create that protective sense of distance to not instil fear, to look friendly yet be someone that you are going to listen to, and trust. The animators did a fantastic job of this, and the actor’s voice tone for Bea, and delivery of lines were perfect. Creating relatedness was also an easy one, in that I pictured Bea having other characters around her, and therefore anyone who watches the animation may also feel surrounded and supported. They may have a rare disease or be an associate of someone with NF1, but feeling seen and heard should never be a rarity.

5.11 Summary of key points in this chapter

- A novel animated intervention was designed with the objective of increasing BCA in young women with NF1 and their associates and encourage prompt medical consultation for a breast concern.
- Two animators and a sound engineer/composer were recruited through Rise to bring to life the intervention utilising self-determination theory (Deci and Ryan, 1985), applying its components of competence, relatedness, and autonomy to directly affect levels of BCA motivation.
- SDT applies well to Heslop et al.'s (2020) key characteristics of experiencing happiness and health within their work with individuals with learning disabilities of having choice and control, feeling valued, feeling safe and secure now and in relation to the future, having self-confidence, and a feeling of self-worth.
- Fear and negative framing can affect how messages are received. With the increased risk of developing breast cancer at a younger age, and previously conveyed fear among women with NF1, it was deemed more appropriate to utilise a positive frame within the animation and information leaflet.
- The narrative is created by animated characters that both tell a social story and impart educational facts whilst also creating distance through the objectification of an animated character with the form of a woman's body.
- Competence is developed through the main character (Bea), imparting information pertaining to risk, screening, and breast awareness.
- Relatedness is instilled through the portrayal of characters with NF1, with the protagonist having visible café-au-lait macules.
- Autonomy is conveyed by communicating that the viewer chooses when, and where to check their breasts.

5.12 The next stage of the research

With the design of a novel NF1 BCA animation and information leaflet completed, it is now important to consider how this intervention will be examined to explore the feasibility of an NF1 BCA intervention among young women with NF1, and their associates. The next stage of this research explores the methodologies adopted within a mixed method approach with a qualitative emphasis, of how these were elected and applied to gather preliminary evaluations of this intervention.

Chapter Six

Methodology: A mixed method approach

6.1 Introduction

Recognising the Medical Research Council's guidance on evaluation of assessing the intervention by utilising the most appropriate method to address research questions, this chapter details the theoretical basis that has been employed in informing the research design, the data collection process, the decision for sample size, and justifications for, and details of, the qualitative and quantitative approaches elected within this mixed method research. The British Psychological Society's Codes of Ethics and Conduct (BPS; 2021a), and Human Research Ethics (BPS; 2021b) outlines recommendations to ensure high research ethical standards. Actions taken to fulfil these are also considered within this chapter.

This research aimed to explore the development and feasibility of a novel NF1 breast cancer awareness (BCA) animation intervention for young women with NF1 and their associates. The objective of this intervention was to increase BCA in young women with NF1 and their associates and encourage prompt medical consultation for a breast concern. It addressed this by asking the following research question:

To what extent is a novel animation feasible for increasing NF1 specific breast cancer awareness in young women with NF1 and their associates?

A feasibility study is an initial phase of examination of intervention development and implementation, and a preliminary examination of participant responses to the intervention (Dobkin, 2009). This differs to a pilot study, whereby there is a focus on outcomes, and a more controlled evaluation of participant responses to the intervention. From a literature review of feasibility and pilot studies, Orsmond and Cohn (2015) identified five main objectives of a feasibility study that addresses the overarching question of: *Can it work?:*

1. Evaluation of recruitment capability and resulting sample characteristics
2. Evaluation and refinement of data collection procedures and outcome measures

3. Evaluation of the acceptability and suitability of intervention and study procedures
4. Evaluation of resources and ability to manage and implement study and intervention
5. Preliminary evaluation of participant responses to intervention

Addressing these objectives aids researchers in identify strategies to address issues and required revision of components before undertaking a more formal evaluation of intervention outcomes such as within a pilot study (Orsmond and Cohn, 2015). However, undertaking feasibility studies can carry limitations, whereby later stages of the research may experience contamination of the study samples because of modification to study methods after a feasibility and/or pilot study is carried out (Lancaster, 2015; Leon et al., 2011). Participants in later research stages may already have been exposed to the intervention, becoming more proficient or less compliant with the protocol as the intervention has already been completed (Cope, 2015), or because of selection bias caused by unrepresentative pilot sampling (Van Teijlingen et al., 2001). Participant recruitment may become a particular issue within this study, as rare disease research highlights the difficulties in recruiting due to small numbers with specific conditions (Whicher et al., 2018). Therefore, there is a potential risk of limiting participant numbers within subsequent studies. As the feasibility study only explores an initial examination, it is important to note that it therefore does not aim to provide a definitive conclusion of intervention effectiveness and does not guarantee that the feasibility study will be developed or employed further. While the objectives of a feasibility study will be evaluated throughout the thesis, Chapter Ten offers a comprehensive reporting on each of the objectives as set out by Orsmond and Cohn (2015) and presents future recommendations.

6.2 Ontological and epistemological positions

Research design should have ‘methodological integrity’ (Levitt et al., 2017) whereby it is both coherent and considered (Willig, 2013) to ensure that research aims, philosophy, and methodology are incorporated into each other (Chamberlain et al., 2011). From taking these components into consideration, the research question posed within this thesis was addressed by adopting a mixed method approach with a qualitative emphasis. This was ascertained to be the most suitable based on the epistemological and ontological positions that were applied to this research.

Ontology is concerned with reality or the knowable (Guba, 1990). Reality and ‘being in the world’ are often expressed in behaviours, shared meanings, and practices (Titchen and Ajjawi, 2010). Epistemology is related to knowing or knowledge through cognitive description (Titchen and Ajjawi, 2010). Ontologies and epistemologies are connected, with ontological positions often giving rise to specific epistemological positions, with the paradigm being the overarching belief and value system consisting of ontology, epistemology, and methodology that should demonstrate a coherent fit when placed together (Braun and Clarke, 2022).

While evidenced-based BCA material is accessible within the UK and ROI with pertinent information suitable for all persons such as breast cancer warning signs, other important aspects specifically communicate general population risk, and screening eligibility. There are differing contextual factors for women with NF1 such as the increased risk of developing breast cancer at a younger age, and earlier screening eligibility. This may affect BCA perspectives, representations, and interpretations among these women, their associates and from a wider perspective HPs, arguing that there is no realist perspective of a singular truth within this area (Braun and Clarke, 2022). Reality, therefore, is not simply a reflection or even reducible to simply that of a natural or biological world, but also that of human emotions, experiences, and meanings (Maxwell, 2012). My positionality within this research also affects ontology and epistemology. While I am familiar with the oncology field as a researcher and therefore with an outsider perspective, I have also undergone treatment for breast cancer as a young woman and therefore have an insider position with a personal motivation and knowledge of the importance of being diagnosed early and receiving prompt care and treatment. Like young women with NF1, I am also at an increased risk requiring annual screening. However, it remains that I only have partial access into the participants’ realities as I do not have NF1 which may affect interpretations. My positions are part of this domain that is to be examined and understood, with it being unachievable to remove myself from both the social and human reality that is observed (Braun and Clarke, 2022). An ontological critical realist, and epistemological contextualist position were therefore taken within this research to reflect both knowledge and reality.

Taking an ontological critical realist position understands that the data does not provide an exact reflection of reality, instead what is accessed is the participant’s perception of their reality that is influenced by and rooted within their cultural context, language, or a particular representation of reality (Willig, 2013). In this instance it is the perceived reality of BCA within the contextual factors of NF1 including self-efficacy, breast screening eligibility, and breast cancer risk. Braun and Clarke (2022) assert that within this ontological position the aim is to provide a logical and convincing interpretation of the data that is continually anchored by participants' situated reality accounts that differ from one person to the next.

An epistemological contextualist position retains a sense of truth whilst recognising a context-conditional nature of meaning and language (Alvesson and Sköldberg, 2017). A probability of multiple accounts of reality and therefore knowledge is acknowledged, whereby one account from a participant that conflicts with another is not untrue and consequently unacceptable within the data analysis (Braun and Clarke, 2022). Therefore, it is understood that it is not possible for knowledge to be detached from the knower, and that the researcher's experiences, practices, and values will also inexorably influence the production of knowledge, actioning a co-production of meaning (Braun and Clarke, 2022).

The epistemological approach adopted shapes whether this evaluation will be reflective or reflexive (Willig, 2013). These can be conceptualised as existing on a continuum instead of a split between the two, with reflection being described as general thoughts that relate to process and verification to represent participants accurately, and reflexivity described as including an evaluation of the self (Shaw, 2010). Epistemological reflexivity considers how assumptions and values that are based within the researcher's personal theoretical and methodological commitments shape the knowledge produced (Willig, 2013) by a methodological process of self-consciousness observation (Lazard and McAvoy, 2020). Tebes (2005) asserts that contextualism requires a reflexive researcher to consider influence, and to make these transparent to the reader.

6.3 Research design

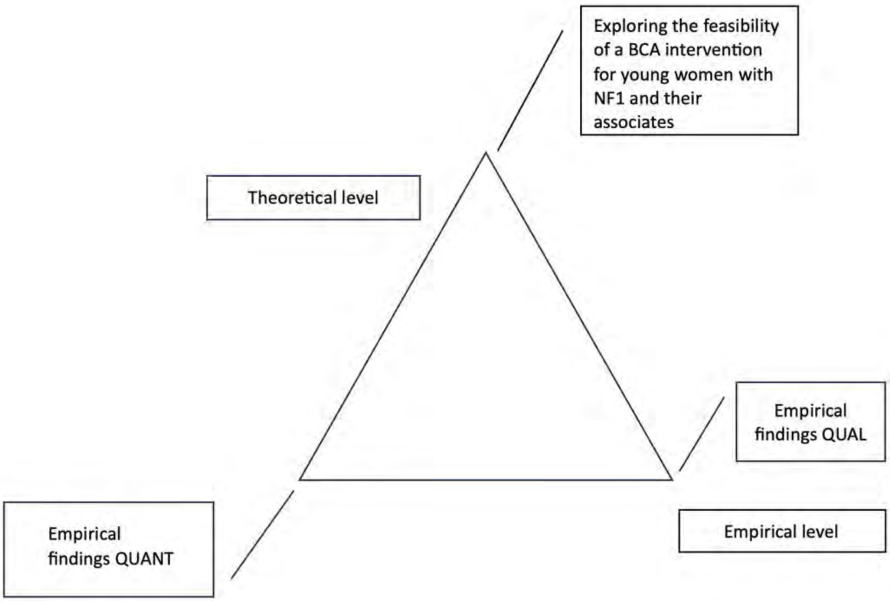
Recognising both the ontological and epistemological positions within this research, a mixed method approach is most suitable to address the research question. Both the critical realist ontological and the contextual epistemological positions recognise that participants may already be familiar with applicable general BCA warning signs. Within the research aim of evaluating the feasibility of the development of a novel intervention, it examines BCA components specific to NF1 of risk and screening age eligibility. Quantitative analyses of pre- and post- test data is therefore required to capture changes (if any) of these. However, with behaviour assumed to have multiple causes that is often affected by differing perceptions of an environment (Waszak and Sines, 2003), and the acknowledgment that the development and feasibility of this NF1 BCA intervention is novel, it is also important to employ a qualitative method to understand participants' experiences (Ashworth, 2015), including facilitators and barriers of the intervention design and accessibility, and to BCA within an NF1 context for future applications.

The concept of mixing methods was primarily presented by Jick (1979) to intersect both qualitative and quantitative techniques within the social sciences. This process emphasises similarities and differences of certain facets of a phenomenon (Bernardi et al., 2007). A mixed method approach or design is practical within implementation research due to the recognition that innovative interventions can be adequately complex to warrant a single methodological approach (Palinkas et al., 2015). Within healthcare research, it has been noted that the design allows for the provision of a more developed understanding of issues across settings and situations that may be limited if an either/or approach is adopted (Foss and Ellefsen, 2002; Palinkas et al., 2011), simultaneously answering confirmatory and exploratory questions (Erzberger and Kelle, 2003; Teddlie and Tashakkori, 2003). Despite some such as Smith and Heshusius (1986) arguing that mixed method designs are not compatible or complementary, others such as Greene et al. (1989) argue that because these paradigm characteristics are independent, they can therefore be mixed with other methods to achieve the combination most appropriate for a given inquiry to satisfy the five principles of mixed methods evaluations of: (a) triangulation (the convergence and confirmation of results from varying methods examining the same phenomena), (b) complementarity (elaboration, illustration, enhancement, and elucidation of results from one method with the results from the other), (c) development (utilising the results from one method to help inform another method), (d) initiation (discerning inconsistencies that can assist with the reframing of a research question), and e) expansion (expanding the inquiry by employing different methods).

When qualitative and quantitative methods are mixed within research, it is characteristic that one method is typically given precedence over the other (Östlund et al., 2011), however even in research that offers equal weight within the differences of approach, all should facilitate a distinct identification of the connections between theory, epistemology, and methodology, resulting in a visualisation of a triangulation of methods (Erzberger and Kelle, 2003). This research's triangle of methods is outlined within Figure 39.

Figure 39

The Research Triangle



6.4 Research flow

The research flow within the thesis is presented as sequential in its approach (see Figure 40) and is presented as quant → QUAL within the Morse (1991) notational system to denote the quantitative - qualitative sequential collection of data with a qualitative emphasis, whilst satisfying triangulation within a mixed methods approach (Erzberger and Kelle, 2003).

Figure 40

Flow of Research Process

6.5 The adaptation of the Breast-CAM to the Breast-CAM-NF1

The Breast Module of the Cancer Awareness Measure (Breast-CAM; Linsell, 2010) (Appendix I) was developed by Cancer Research UK, King's College London, and University College London. It was validated with the support of Breast Cancer Care and Breakthrough Breast Cancer. This measurement explores risk factors for poor breast cancer awareness, and aids in the development and evaluation of interventions that promote awareness. Within its psychometric test analysis (Linsell et al., 2010), test-retest reliability was moderate to good ($\kappa = 0.42$-0.70). Construct validity was completed by 18 cancer experts and 13 non-medical academics, with cancer specialists obtaining significantly higher scores than non-medical academics demonstrating capability of discriminating between high and low levels of BCA. A Flesch Reading score of 87.9, indicated that it is easier to read than standard adult reading material. 91% of participants found the questions easy to understand, with 96% reporting that they did not find the questions upsetting. This is particularly important to consider within this research, with a prevalence of learning difficulties among the NF1 population (Antônio et al., 2013) and an appreciation that many individuals in adulthood do not have suitable literacy skills to comprehend health information (Rowlands et al., 2015).

Within the terms of use outlined within the Breast-CAM, it states that some flexibility is allowed for decreasing the number of items due to time, or to better suit the research aim. As a minimum, researchers must examine knowledge of breast symptoms, knowledge of age-related risk, and frequency of breast checking. It was also specified that all respondents must complete the following demographic information as a minimum; age, ethnicity, and at least one indicator of deprivation. For this research the highest level of education qualification obtained was selected to highlight if education levels affect health literacy as has been found within previous literature (e.g., Berkman et al., 2011; Jansen et al., 2018; Okan et al., 2019). These, and further demographics are reported within Chapter Seven. Despite the flexibility offered, the Breast-CAM carries limitations. Firstly, it is unsuitable in its original guise for assessing the research's novel NF1 BCA intervention, with age-related risk and screening eligibility items targeted towards general population statistics, which differ to women with NF1. Permission was sought and granted (Appendix J) from Cancer Research UK in November 2020 to adapt items pertaining to knowledge of age-related risk, and screening age eligibility. Secondly, there are other pertinent aspects to critically consider, both within the Breast-CAM and in the Breast-

CAM-NF1. While the Breast-CAM is a validated measure and is widely used, from examining the Linsell et al. (2010) paper, only items of breast cancer warning signs, risk, and breast checking frequency have been assessed. The Breast-CAM that is advertised for public use as a measure explores additional facets such as promptness to attend a HP, and reasons for putting off going to a doctor. Aspects such as readability, acceptability, construct validity, and test-retest reliability of additional items may not have been as comprehensively examined. While amendments were made within the Breast-CAM-NF1 to allow for more accurate assessment of risk and screening specific to NF1, the 'five-fold increased risk' of developing breast cancer at a younger age among women with NF1 was not examined within the measure. As previously stated, while the Breast-CAM allows for some flexibility such as not having to include all items, the terms of use advise that the Breast-CAM should not be altered. While permission was granted for amending Breast-CAM risk and screening items to align with NF1 information, the testing of the 'five-fold increased risk' would have required an item addition and therefore altering the Breast-CAM outside of its current scope. However, this specific risk is explored within interviews. Subsequently, both measures lack the ability to provide a deeper exploration of BCA within an NF1 context, or social and cultural contexts that may affect behaviour (Afaya et al., 2024) and may inhibit participants from disclosing important concerns about BCA (Ridley-Merriweather, 2023). A qualitative approach such as one that is used within this feasibility study is beneficial in contributing to a more in-depth exploration (Braun and Clarke, 2013).

It was important to assess the Breast-CAM-NF1 items to ensure that participants would not experience any that demanded too much, or any incomplete or ambiguous items, and that questionnaire layout was coherent (Giles, 2002). This was done by performing a read-through of items with the supervisory team, and the Chair of the Childhood Tumour Trust, recognising that experts are important (within this regard academics and an individual with knowledge and experience of NF1) for cross-checking and suitability (Ruel et al., 2016). From reading through each item of the Breast-CAM-NF1, and in consultation with the supervisory team and Childhood Tumour Trust, it was also agreed that some items were unsuitable in their standard form to administer to associates and were amended to allow for appropriate responses from this cohort. For example, breast checking would not be suitable to ask associates in its form designed for young women with NF1 and was adapted to; '*From watching the animation, how often do you think a woman with NF1* *should check their breasts?' One item was omitted for associates; 'Are you confident that you would notice a change in your breasts?'*, as this question was important to examine levels of self-efficacy in breast checking of young women with NF1, and any changes that may be demonstrated from undertaking the animation. Principally, questions were asked to associates to examine important aspects such as knowledge levels on symptoms, screening eligibility, and risk, as in certain cases they may be better placed to educate a young woman with NF1 about BCA, make medical appointments, and also understand aspects such as barriers to attending a HP, or as examined within the Breast-CAM-NF1, to explore aspects of avoidant health-seeking behaviours, e.g.; '*After viewing the animation, could any of these reasons still put a young woman with NF1 off going to the doctor if they had a breast concern*'. BCA components measured within the Breast-CAM and its items, and Breast-CAM-NF1 items for young women with NF1 and associates (in italics) including scoring, can be found in Table 19. Higher scoring within the Breast-CAM-NF1 indicates positive behaviour changes and knowledge. Appendix K contains the Breast-CAM-NF1 as presented online.

Table 19

Breast-CAM and Breast-CAM-NF1 Components

Breast-CAM		Breast-CAM items	Breast-CAM-NF1 items	
			Pre-animation	Post-animation[b]
Knowledge of symptoms				
Question		Can you tell me whether you think any of these are warning signs of breast cancer or not?	Do you think any of these could be warning signs of breast cancer or not?	
	Scoring	Yes (1)	Yes (2)	
		No (2)	No (0)	
		Don't know (-99)	Don't know (1)	
	Responses	Do you think a change in the position of your nipple could be a sign of breast cancer?	Change in position of your nipple	
		Do you think pulling in of your nipple could be a sign of breast cancer?	Pulling in of your nipple	
		Do you think pain in one of your breasts or armpit could be a sign of breast cancer?	Pain in one of your breasts or armpit	
		Do you think puckering or dimpling of your breast skin could be a sign of breast cancer?	Puckering or dimpling of your breast skin	
		Do you think discharge or bleeding from your nipple could be a sign of breast cancer?	Discharge or bleeding from your nipple	
		Do you think a lump or thickening in your breast could be a sign of breast cancer?	A lump or thickening in your breast	
		Do you think a nipple rash could be a sign of breast cancer?	Nipple rash	

	Do you think redness of your breast skin could be a sign of breast cancer?	Redness of your breast skin	
	Do you think a lump or thickening under your armpit could be a sign of breast cancer?	A lump or thickening under your armpit	
	Do you think changes in the size of your breast or nipple could be signs of breast cancer?	Changes in the size of your breast or nipple	
	Do you think changes in the shape of your breast or nipple could be signs of breast cancer?	Changes in the shape of your breast or nipple	
Confidence, skills and behaviour in relation to detecting breast changes			
Question	How often do you check your breasts?	How often do you check your breasts?	From watching the animation, how often do you think you will check your breasts now?
		How often should young women with NF1 check their breasts?[a]	*From watching the animation, how often do you think a woman with NF1 should check their breasts?*[a]
Scoring	Rarely or never (4)	Rarely or never (1)	Rarely or never (1)
	At least once every 6 months (3)	At least once every 6 months (3)	Once a week (2)
	At least once a month (2)	At least once a month (4)	Every 6 months (3)
	At least once a week (1)	At least once a week (2)	Once a month (4)
	Don't know (-99)	Don't know (0)	Don't know (0)
			(Placed in this order considering that too frequent may increase anxiety contributing to missing signs (Moore, 1999). Rarely/never may contribute to poorer prognosis).
Question	Are you confident you would notice a change in your breasts?	Are you confident you would notice a change in your breasts?	From watching the animation, are you confident you would notice a change in your breasts?
		Not asked to associates[a]	
Scoring	Not at all confident (4)	Not at all confident (1)	
	Slightly confident (3)	Slightly confident (2)	
	Fairly confident (2)	Fairly confident (3)	
	Very confident (1)	Very confident (4)	
	Don't know (-99)	Don't know (0)	
Anticipated delay in contacting the doctor			
Question	If you found a change in your breast, how soon would you contact your doctor? Write how soon you contact your doctor here	If you found a change in your breast, how soon would you contact your doctor? Write how soon you would contact your doctor here (if you are unsure you can write 'Don't know')	Now that you have watched the animation, if you found a change in your breast, how soon would you contact a doctor?
		If a young woman with NF1 found a change in their breast, how soon should they contact a doctor? Write how soon they should contact a doctor here (if you are unsure you can write 'Don't know')[a]	*Now that you have watched the animation, if a young woman with NF1 found a change in their breast, how soon should a doctor be contacted?*[a]
Scoring	Verbatim response (not scored)	Verbatim response (not scored)	
Barriers to seeking medical help			
Question	Sometimes people put off going to see the doctor, even when they have a symptom that they think might be serious. Could you say if these might put you off going to the doctor?	Sometimes people put off going to see the doctor, even when they have a symptom that they think might be serious. Could you say if these might put you off going to the doctor?	After viewing the animation, could any of these reasons still put off going to the doctor if you had a breast concern?
		Sometimes people put off going to see the doctor, even when they have a symptom that they think might be serious. Could you say if any of these might put a young woman with NF1 going to the doctor?[a]	*After viewing the animation, could any of these reasons still put a young woman with NF1 off going to the doctor if they had a breast concern?*[a]
Scoring	Yes often (1)	Yes often (1)	
	Yes sometimes (2)	Yes sometimes (2)	
	No (3)	No (3)	

		Don’t know (-99)	Don’t know (0)	
	Responses	Too embarrassed to go and see the doctor	Too embarrassed to go and see the doctor	
		Too scared to go and see the doctor	Too scared to go and see the doctor	
		Worried about wasting the doctor’s time	Worried about wasting the doctor’s time	
		My doctor is difficult to talk to	My doctor is difficult to talk to	
		Difficult to make an appointment with the doctor	Difficult to make an appointment with the doctor	
		Too busy to make time to go to the doctor	Too busy to make time to go to the doctor	
		Too many other things to worry about	Too many other things to worry about	
		Difficult to arrange transport to the doctor’s surgery	Difficult to arrange transport to the doctor’s surgery	
		Worrying about what the doctor might find may stop me from going to the doctor	Worrying about what the doctor might find may stop me from going to the doctor	
		Not feeling confident talking about my symptom with the doctor	Not feeling confident talking about my symptom with the doctor	
Question		Is there anything else that you can think of that might put you off going to the doctor? (not scored)	Is there anything else that you can think of that might put you off going to the doctor?	
			Is there anything else that you can think of that might put a young woman with NF1 off going to the doctor?[a]	
	Scoring	Verbatim response (not scored)	Verbatim response (not scored)	
Knowledge of age-related and lifetime risk				
Question		In the next year, who is most likely to get breast cancer?	In the next year who is most likely to develop breast cancer if they have NF1 (in comparison to general population risk)?	
	Scoring	A 30-year-old woman (4)	A 40-year-old woman (1)	
		A 50-year-old woman (3)	A 60-year-old woman (0)	
		A 70-year-old woman (2)	An 80-year-old woman (0)	
		A woman of any age (1)	A woman of any age (0)	
		Don’t know (-99)	Don’t know (0)	
			(Dichotomous variable)	
Breast screening knowledge				
Question		At what age are women first invited in the NHS Breast Screening Programme?	At what age are women with NF1 eligible for breast screening in the UK and Ireland?	
	Scoring	Age in years (no score)	20 years (0)	
		Don’t know (-99)	30 years (0)	
			40 years (1)	
			50 years (0)	
			Don’t know (0)	
	Range	Verbatim response (not scored)	(Dichotomous variable)	
Risk factors				
Question		How much do you agree that each of these can increase the chance of getting breast cancer? (Not utilised in Breast-CAM-NF1).	Specific five-fold increased risk for women with NF1 explored within interviews	
	Scoring	N/A	Verbatim response (not scored)	
Further comments				
		N/A	How was your experience of watching the NF1 breast cancer awareness intervention? (e.g. How has it changed your awareness and attitudes, if at all? How has it made you feel?). Please feel free to share anything about your experience.	

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[a] *Text in italics are those asked to associates and were altered for suitability*

[b] greyed out boxes indicate questions, scoring, and responses are identical to pre-animation

A within-subjects (repeated-measures) design was employed to measure differences of pre- and post-test knowledge from watching a novel NF1 BCA animation, with one independent variable of time with two levels (pre- and post-animation). Data collected from the Qualtrics questionnaire was uploaded to SPSS (V.28) and analysed using Wilcoxon signed rank tests, and McNemar's tests to investigate if there were any changes in levels of BCA components as listed previously in Table 19. A McNemar test was conducted to determine if there were differences on dichotomous dependent variables of either correct or incorrect answers of screening age eligibility for women with NF1, and to ascertain knowledge of age-related risk of developing breast cancer among young women with NF1. A non-parametric Wilcoxon signed rank test was employed to compare sets of scores within pre- and post-animation analyses on BCA components. Instead of comparing means by a paired-samples t-test that is employed when assumptions are met to perform parametric tests, the Wilcoxon test instead converts scores to ranks (Pallant, 2020). A parametric t-test was deemed unsuitable as assumptions were violated on two levels. Firstly, many of the ratings within the Qualtrics questionnaire can be deemed as ordinal. Traditionally, intervals between value ratings are assumed to be unequal and therefore should be analysed non-parametrically (Jamieson, 2004). Secondly, recognising the small sample size, violation of normal distribution can occur. Whilst the parametric t-test is more powerful than non-parametric tests in correctly identifying whether there is a difference between groups, the small sample size is recognised as affecting power which carries the risk that a non-significant result may be due to insufficient power (Pallant, 2020).

6.6 Reflexive thematic analysis

The process of sense-making and interpretation occurs within the philosophy of hermeneutics, differing in its method depending on whether the approach is experiential or critical (Byrne, 2001). Experiential research is driven by a position that language is a tool that transparently communicates meaning of the psychological worlds of what is 'inside the head', or the social worlds, that are 'out there', striving to remain close to the participants' meanings (Braun and Clarke, 2022). Critical qualitative research is informed by Ricoeur's hermeneutic of suspicion, taking an inquiring interpretative orientation by critical questioning of data meaning (Hay, 1999). The approach also focuses on theoretical resources for sense-making, rather than solely relying on the reported experiences of participants (Braun and Clarke, 2022) and recognises that researchers cannot evade their own involvement and understandings within the research (Finlay, 2002). This aligns with the critical realist ontological and the contextualist epistemological positions within this research. It is through these positionings that reflexive thematic analysis (RTA) is deemed the most suitable method to employ.

RTA acknowledges both the participants' and the researcher's positions, whereby the position and assumptions of the researcher are openly demonstrated within the active production of knowledge within the research (Braun and Clarke, 2019a; Braun and Clarke, 2023). It recognises the importance of critical reflection on the role, research process, and practice of interpreting patterns (Braun and Clarke, 2021; Braun and Clarke, 2022), and values a subjective, situated, aware, and questioning researcher (Braun and Clarke, 2019a). Researchers do not approach a topic in a void, instead it is approached with a distinct schema to seek an answer to the proposed research question (Hamdan, 2009). It is not exceptional that many researchers have a sense of necessity to study matters that have some sort of personal association or interest to them (Hill and Dao, 2021), however, reflexive scrutiny displays the identity of the researcher that guides the epistemology within the research (Hamdan, 2009). It is a process that communicates what contextual factors have aided in the development of the research process and the production of knowledge (Lazard and McAvoy, 2020), commanding the researcher to challenge their power, privilege, positionality, and biases (Stoudt et al., 2012; Sherry, 2013). Frisby et al. (2005) assert that these are inherently within research. The inclusion of reflexive accounts gathered at the end of the Breast-CAM-NF1 from participants is also considered important from an ethics of representation perspective. It establishes the co-construction of meaning within socially positioned situations of not only the participant but also of the researcher (Shaw, 2010).

The most appropriate orientation to data and focus of meaning is decided by what is required from the research (Braun and Clarke, 2022). As established within this chapter, BCA information is already accessible within the UK and ROI, with breast cancer warning signs applicable to all. However, there are differing NF1 factors such as the increased risk, and earlier screening eligibility. In this regard, this research's orientation to data was considered both deductive and inductive. Within a deductive orientation to data, analysis is shaped by existing knowledge and theoretical constructs that aid in providing a focus through which to read and code data and develop themes. However, semi-structured interviews allow for an inductive orientation, with coding and theme development resulting from the content of data itself (Braun and Clarke, 2022). The focus of meaning therefore employed a mixed approach of a latent level whereby meaning is explored through the analysis at an underlying or implicit level, and a semantic level with analysis at a more surface or explicit level (Braun and Clarke, 2022). While RTA is described as a method, it is better described as an analytic process (Braun and Clarke, 2022). Thematic analysis is a theoretically flexible method that is commonly utilised to develop, analyse, and interpret patterns across a dataset, and involves a systematic coding process for the purpose of theme development (Braun and Clarke, 2022). Within RTA, there are six phases consisting of dataset familiarisation, data coding, initial theme generation, theme development and review, theme refining, defining, and naming, and writing up. These are applied and developed within RTA analyses in Chapter Eight and Chapter Nine.

6.7 Informing interview questions within a theoretical basis

The interview questions were predominantly based on the Breast-CAM-NF1 to ascertain if any changes of NF1 BCA occurred from watching the animation. The interview provided an opportunity to further explore areas within the questionnaire and allowed for an examination into facilitators and barriers to being breast cancer aware within an NF1 context for both young women with NF1, and associates. Self-determination theory (SDT; Deci and Ryan, 1985) has been an important anchor within the animation design, and the interview questions have also been aligned to SDT components to provide clarity on changes to these through exposure to the intervention. Interview questions shared similarities across both young women with NF1 (Table 20), and associates (Table 21), however, there were phraseology differences within questions pertaining to breast checking.

Table 20

Semi-Structured Interview Questions for Young Women with NF1

Interview Question	SDT Component
Rapport building: When were you diagnosed with NF1? Tell me a little bit about how NF1 affects you specifically, if at all?	**RELATEDNESS**

From watching the video, how do you feel your knowledge of breast cancer specific to NF1, including risk, has changed, if at all?	**COMPETENCE**
How do you feel your level of confidence has changed in relation to detecting any breast changes, if at all?	**COMPETENCE**
How have your feelings changed, if at all, about contacting your doctor or a HP if you were concerned about something to do with your breast?	**AUTONOMY**
How has your knowledge of your eligibility for screening changed, if at all, since watching the video? Tell me a little bit more about this change/no change.	**COMPETENCE**
Exploration of facilitators and barriers: What can prevent a woman with NF1 being breast cancer aware?	**COMPETENCE/AUTONOMY/ RELATEDNESS** (Dependent on participant answer)
How do you feel the video helped, if at all, with encouraging breast cancer awareness?	
Questions to focus further on intervention experience: How did the video, being in animation format help, if at all, with learning about this topic?	**COMPETENCE/AUTONOMY/ RELATEDNESS** (Dependent on participant answer)
Overall, how has taking part in this research about NF1 and breast cancer awareness made you feel?	
What, if anything, will you do or feel differently about after watching the animation?	

Table 21

Semi-Structured Interview Questions for Associates

Interview Question	SDT Component
Rapport building:	**RELATEDNESS**

Thank you for taking part in this research. You have indicated that you are taking part as you wish to support somebody with NF1. What is your connection with this person?	
What do you know about NF1?	
From watching the video, how do you feel your knowledge of breast cancer specific to NF1, including risk, has changed, if at all?	**COMPETENCE**
How have your feelings changed, if at all, about encouraging a woman with NF1 to contact their doctor or a HP if they had a breast concern?	**AUTONOMY** (To instil autonomy in young women with NF1)
How has your knowledge of NF1 breast screening eligibility changed, if at all, since watching the video? Tell me a little bit more about this change/no change.	**COMPETENCE**
Exploration of facilitators and barriers: What can prevent a woman with NF1 being breast cancer aware?	**COMPETENCE/AUTONOMY/ RELATEDNESS** (Dependent on participant answer)
How do you feel the video helped, if at all, with encouraging breast cancer awareness?	
How did the video, being in animation format help, if at all, with learning about this topic?	**COMPETENCE/AUTONOMY/ RELATEDNESS:** (Dependent on participant answer)
Overall, how has taking part in this research about NF1 and BCA made you feel?	
What, if anything, will you do or feel differently about after watching the animation?	

Within the post-test questionnaire, the final question was a participant reflexive section which was analysed qualitatively by RTA that asked participants; *'How was your experience of watching the NF1 breast cancer awareness intervention? (e.g. How has it changed your awareness and attitudes, if at all? How has it made you feel?). Please feel* *free to share anything about your experience'.* This provided participants a space to voice their thoughts within an online environment instead of directly to me as researcher, to aid in reducing power dimensions whereby they do not feel that they must answer favourably about the research. This builds a sense of autonomy as per SDT. While RTA argues to incorporate both the researcher and the participant with a transparency of contextual factors (Braun and Clarke, 2022), and co-constituted outcomes (Finlay, 2002), there is a danger particularly within the field of medical practice, education, and interaction with marginalised individuals that as researchers we may speak *for* them claiming to fully understand their position, which consequently transfers power to the researcher (Garden, 2015). This, while not a deliberate act to create another power dimension barrier within a process that tries to equilibrise this, it can negatively impact on research integrity and therefore rigour, with Garden (2015) asserting that the only way that we can speak for another is in a flawed way.

Participation within research occurs within a situation of power relationships that may develop and emerge within three aspects. These are *power over* which is a demonstration of a hierarchical relationship where one individual dominates over another; *power with* that demonstrates the sharing of resources and strengths to become collectively stronger; and *power to* which is best described as transformative power of PPI that work together for a better practice (Tew, 2006). Within person-centred research, it is *power with* that is developed, and should be witnessed throughout, for example the inclusion of a participant reflexive section within the post-test to gain a better understanding of intervention experiences without the direct presence of the researcher.

6.8 Maintaining rigour within qualitative research

Qualitative research has received criticism as a method that lacks scientific rigour compared to quantitative approaches that utilise objective experimental methods (Mays and Pope, 1995). Rigour is how integrity, competence, and legitimacy are demonstrated within the research process (Tobin and Begley, 2004). However, qualitative methods have been critiqued due to the lack of consensus for quality assessment within this field (Leung, 2015). Whilst some have challenged the concept of rigour as not fitting within interpretive approaches due to its empirical analytical term (Denzin and Lincoln, 2005), rigour should not be considered only within an empiricist-positivist paradigm but instead as a process of how integrity and competence is demonstrated within research (Tobin and

Begley, 2004). Rigour was maintained throughout the qualitative application of RTA by various means.

Firstly, the Critical Appraisal Skills Programme (CASP; 2018) checklist was referred to and completed (see Appendix L). This aided in the consideration of results, validity, and research value by ensuring criticality was maintained by scrutinising my application of research as if I were appraising another qualitative research paper. Secondly, the reflexive process that was adopted throughout this research aids in upholding research integrity, with Teh and Lek (2018) arguing that reflexivity is the gold standard for determining trustworthiness within qualitative research. Finlay (2002) also observes that reflexivity demonstrates a level of integrity, whereby it exposes the research process to the public eye for scrutiny, and while this process does not prove anything, it validates an act on the researcher’s part that they are employed in a systematic and extensive self-evaluation of the effects on research. Thirdly, validity evaluations taken within quantitative research that utilise a rationalistic paradigm is mapped onto qualitative research as trustworthiness (Cope, 2014). Lincoln and Guba (2011) present four criteria of credibility, dependability, confirmability, and transferability to evaluate this.

Credibility

Comparable to internal validity, credibility addresses the ‘truth’ (Polit and Beck, 2010) which within this research is from both the researcher and the researched. Methods to demonstrate credibility within qualitative research include engagement, which is a process by which trust, and rapport are built (Cope, 2014), a description of methods of observation, and audit trails, whereby the researcher’s descriptions of experiences within the research process, and a thorough detailing of the research findings are demonstrated (Koch, 1994; Braun and Clarke, 2013; Cope, 2014). Within this research this includes the provision of interview transcripts, data analyses, and reflexivity within chapters and post interview logs. The transparency of the role of the researcher with self-monitoring of the impact of selected theories, beliefs, personal experiences, and biases aid in maintaining an equilibrium within research by addressing three fundamental matters of, ‘what I did’, ‘how I did it’, and ‘why I did it’ (Seale, 1999; Creswell and Miller, 2000; Berger, 2015; Tuval-Mashiach, 2017).

Lincoln and Guba (1985) recommend the process of member checking. However, due to the accepted incorporation of the researcher's position throughout the process and influence on interpretation, this process is not recommended (Braun and Clarke, 2013). Member checking operates within a realist framework of the truth being learnt from the participant, however this method conflicts with the critical realist framework employed (Braun and Clarke, 2022).

Dependability

This is akin to the reliability of the data over comparable situations and can be realised when other researchers agree with the decision process trails within the research process (Koch, 1994). Within other methods of thematic analysis, the adoption of coding books is useful in this regard for increasing dependability (Thomas and Magilvy, 2011). However, this is inconsistent with the process of RTA, as the incorporation of reflexive accounts from my perspective is utilised to demonstrate the decision processes, and it is therefore not possible or required to provide precise coding accounts and agreement among others (Byrne, 2021). However, adding the ability for participants to add their reflexive accounts within the questionnaire increases dependability by better highlighting their own opinions of the intervention process.

Confirmability

This is the researcher's ability to demonstrate that the data is representational of the participants' responses (Tobin and Begley, 2004; Cope, 2014). This is demonstrated by the inclusion of quotes from participants within the analysis section, with a description of how interpretations and conclusions were established by utilising data extracts illustratively, with the analytic narrative delivering a description and interpretation of themes (Braun and Clarke, 2013).

Transferability

To determine this aspect, the context of the research must be sufficiently described (Houghton et al., 2013). The entire methodology, analyses and discussion sections of this research have been thoroughly presented (Thomas and Magilvy, 2011).

6.9 Participants and recruitment

Whilst participant number calculations are often important to diminish the likelihood of errors, with these being negatively associated with economic, health, and ethical aspects within research (Martínez-Mesa et al., 2014), calculation and recruitment of 'N' is difficult within this research for three reasons. Firstly, with current estimates indicating approximately 7,000 rare diseases (Orphanet, 2023), individually each rare disease impacts a small population which negatively affects the number of individuals who will be eligible to participate in any given study, subsequently affecting the study design, power, and sample size (Whicher et al., 2018). It is estimated that there are only 25,000 individuals with NF1 in the UK (Nerve Tumours UK, n.d.). There is a significantly smaller number of individuals with NF1 in Ireland, with approximately 2,500 individuals diagnosed with NF as a set of genetic conditions including NF1, NF2-related schwannomatosis, and schwannomatosis (NF Association of Ireland, n.d.). Secondly, with learning difficulties prevalent within the NF1 population, some individuals may have levels that may make partaking in research difficult, negatively affecting participant numbers. Including associates of young women with NF1 to aid in delivering BCA information particularly to those with learning difficulties widens the participation pool whilst maintaining the specifity of the research area.

G*Power (Faul et al., 2009) for a Wilcoxon signed-rank test was undertaken to determine a sufficient sample size using alpha of 0.05, a power of 0.80, a large effect size ($dz = 0.8$), and two-tails. A desired sample size of 15 was reported (Appendix M). When calculating participant numbers, it is generally accepted that errors of rejecting the null hypothesis when it is true (α) and errors that fail to reject the null hypothesis even though it is false (power) are set at values of 0.05 and 0.8 respectively (Field, 2018). With no previous studies on NF1 BCA conducted it was not possible to ascertain employed effect sizes (Lakens, 2022). However, recognising recruitment difficulties particularly within rare disease research that often results in diminished participant numbers, the smallest suitable number was found by applying a large effect size of $d = 0.8$ (Cohen, 1988). This was therefore utilised to aid in deciding recruitment numbers. A large effect size demonstrates a greater difference between groups, making it more probable to detect a significant result with a smaller sample size, whereas a smaller effect size would require larger participant numbers (Sullivan and Feinn, 2012). Lakens (2022), in considering if a study will consequently be informative, advises that a mixed method approach is employed to provide prominence to interview data to augment collected statistical data with small numbers that may fall below a desired sample size.

Thirdly, within qualitative research and particularly within RTA, there is no simple way to determine the correct data set size, with sample size a positivist-empiricist aim that is inconsistent to the values and assumptions of RTA (Braun and Clarke, 2022). 'Data saturation' is often touted within qualitative research for validity, whereby there is 'no new' theme development (Braun and Clarke, 2019b), however within RTA there are always new theoretical insights to be garnered while data collection continues (Low, 2019). Instead, the research was guided by 'information power' to ascertain final participant numbers, whereby study aim, sample specificity, use of established theory, quality of dialogue, and analysis strategy informed the final participant number (Malterud et al., 2016).

Study aim

A broad study aim will require a larger sample size than a narrow aim, as the phenomenon is more wide-ranging that necessitates more experiences and opinions (Malterud et al., 2016). The study aim within this research is considerably narrow, in that it aims to explore the development and feasibility of a novel NF1 BCA intervention. There are set pre- and post-test analysis questions based on an already well-directed measure, with only an exploration being made among participants of their experiences of watching the animation.

Sample specificity

For an appropriate information power to occur, a precise sample is required within the study aim, with specific participant characteristics, regarded as participants that belong to a particular target cohort that can also demonstrate some variation within explored experiences (Malterud et al., 2016). In this instance, homogeneous purposeful sampling was employed to recruit young women with NF1 and their associates as it aids in the identification of shared common patterns within a sample specificity (Palinkas et al., 2015). Specifically, women with NF1 aged 18-40 years were targeted as earlier screening is recommended from 40 years of age. It was recognised that women with NF1 over the age of 40 years may already be attending screening and subsequently have increased NF1 BCA knowledge. Associates were recruited, recognising that learning difficulties are prevalent among individuals with NF1 (Vogel et al., 2017), and may be better placed to deliver BCA information to young women with NF1 that may not be eligible to take part in this research due to higher levels of learning difficulties, or age, for example.

Recruitment was undertaken through specific gatekeepers connected to general NF and NF1 specific charities of both Nerve Tumours UK and the Childhood Tumour Trust, and only advertised within their chosen platforms including Facebook, Instagram, and X. The inclusion and exclusion criteria for this research for both young women with NF1 and their associates included:

Young women with NF1 - Inclusion criteria

- Women with a diagnosis of NF1, aged 18-40 years that are resident in the UK or ROI.
- Good command of English due to the qualitative nature of interviews and questions asked on the Breast-CAM-NF1 survey.
- Not attending regular breast screening.
- Not previously diagnosed with breast cancer.
- In possession of technology to allow for interviews to be conducted via Microsoft Teams or telephone.

Young women with NF1 - Exclusion criteria

- Unable or unwilling to participate via the required data collection methods of online Qualtrics survey, Microsoft Teams, or telephone.

Associates - Inclusion criteria

- An individual of any gender who has a close relation or connection with a young woman with NF1 (e.g., relative, friend, or a carer).
- Aged 18 years or over and are resident in the UK or ROI.
- Good command of English due to the qualitative nature of interviews and questions asked on the Breast-CAM-NF1 survey.
- In possession of technology to allow for interviews to be conducted via Microsoft Teams or telephone.

Associates - Exclusion criteria

- Have received a previous diagnosis of breast cancer.
- Unable or unwilling to participate via the required data collection methods of online Qualtrics survey, Microsoft Teams, or telephone.

Established theory

Malterud et al. (2016) also argue that information power and therefore sample size is associated with the study's level of theoretical background. Research that is bolstered by theory particularly within the planning and analysis stages normally necessitate a smaller sample for information power. Employing a theoretical perspective acknowledges that existing knowledge can be fused with new learnings to extend understanding within a subject area. In this regard, BCA resources are readily available, however, this extends knowledge within the field of BCA by focusing on a specificity of NF1. This research is also supported by theoretical application with semi-structured interview questions based on the Breast-CAM-NF1 that were mapped onto SDT. The intervention is also built on the BCW and MRC frameworks.

Quality of dialogue

A smaller number of participants is required to reach information power when there is a rich and clear communication between the participant and the researcher (Malterud et al., 2016). I am comfortable broaching BCA topics based on my own personal experience of having gone through breast cancer, and through a volunteering role offering survivor support within a charity in the ROI. Previous employment roles have also necessitated clear communication which helped with communicating in a confident yet warm manner with participants. I am also in my 40s, with an increased ease that has grown within me to talk to everyone and anyone, particularly on topics that I feel strongly about such as BCA. Conducting semi-structured interviews offered me opportunities to explore participants' interesting and pertinent points deeper. While specific questions were mapped onto SDT, semi-structured interviews also allowed for a freedom to delve deeper into areas that were important to the participant, aiding in considering a variety of experiences within a specific sample and study aim. This was also my second research project working specifically on the topic of NF1 and BCA, and therefore I was familiar with interviewing within this area. Building networks among rare disease charities, medical professionals, and importantly speaking with those with NF1 and their associates also aided in growing my knowledge for a greater dialogue quality.

Analysis strategy

Employing RTA and adopting a critical realist ontology and contextualist epistemology that recognise both deductive and inductive orientations to data, and semantic and latent foci of meaning aids in increasing the information power with smaller participant numbers.

Based on these considerations, my original estimate was 15 participants. However, information power was deemed to have been met at 19 interviews based on the frequent consideration of the above points. I started to perceive information power from about the 14th interview, however, I wished to perform further interviews in case the shared data would lack quality and richness. I was happy to have conducted more, and then through referring to my own familiarisation and reflexivity logs, and in discussion with my supervisory team, I was confident in stopping data collection after the 19th interview.

6.10 Data collection and handling

Vanessa Martin, Chair of the Childhood Tumour Trust, and Professor Gareth Evans and Professor Rosalie Ferner, both medical advisors to Nerve Tumours UK acted as gatekeepers and advertised the research on the social media platforms of the charities to recruit potential participants of young women with NF1, and associates of young women with NF1 during the period of February 2023 – June 2023. However, for transparency, Nerve Tumours UK advertised the research on only one occasion, with recruitment predominantly undertaken through a significantly smaller charity, The Childhood Tumour Trust. To ensure minimal risk of coercion, no family members, or friends of mine were recruited. Digital posters were employed for recruitment of young women with NF1 (Appendix N), and associates (Appendix O).

Participant information sheets (PIS) (one for young women with NF1, and one for associates) (Appendices P and Q), and consent forms (Appendix R) were provided via Qualtrics. The PIS could be accessed via the link or QR code that was available on the posters. This allowed potential participants to read the PIS relevant to them as many times as they wished. Participants could also download the PIS for their own keeping. If participants decided to partake, they moved ahead via the Qualtrics platform where they formulated their own unique participant identification code (PIC). Instructions were provided on this page, asking for the date of the participant's birthday, first and last letters of their birth month, and first and last letters of their favourite colour e.g., 28th of May, Purple is a PIC of 28MYPE. This PIC, along with the date auto filled into the next page which was the consent form within the anonymous Qualtrics questionnaire part.

Participants then completed the pre-Breast-CAM-NF1, watched the NF1 BCA animation (also within Qualtrics), and then answered the post-CAM-NF1 to ascertain if there were any differences in NF1 BCA from watching the animation. Participants then provided interview availability. This Qualtrics questionnaire was a separate Qualtrics platform to ensure that the first part of the research was kept anonymous, with only the PIC used to identify participants to me as the researcher. Within this second Qualtrics questionnaire participants were instructed to provide an email address if they wished to be informed of the research outcomes. This Qualtrics questionnaire also provided a section for participants to provide email contact details for a Microsoft Teams interview, or a telephone number if they preferred a telephone interview.

On receiving contact details and suitable interview times, I directly contacted participants to confirm the date and time with them and to check if they had any questions or concerns. Immediately before interviews, consent was sought within a separate recording to the interview recording via Dictaphone (SONY ICD-UX570) following the considerations of the COVID-19 pandemic to secure consent for interviews via telephone or Microsoft Teams (Manchester Metropolitan University, 2020). Firstly, I stated my name as the interviewer, the project title and interview date. Secondly, the participants were reminded that the conversation was being recorded. I waited for confirmation that this was acceptable. Thirdly, the interviewee's name and their PIC were stated for the record. Fourthly, audio consent was collected by reading the consent form aloud with the version number and date being used (v1.2 dated 26th January 2023). Once audio consent was obtained, the recording was stopped, and a new separate recording was started to record the interview. Participants were asked to create a pseudonym to be referred to during the interview, with these used within research outputs instead of participants' real names to protect their identities. 19 interviews were conducted, ranging from 12 minutes to 38 minutes. Once participants completed the interview, a debrief sheet (young women with NF1, Appendix S; associates, Appendix T) was emailed to them with the information leaflet to solely act as a reference sheet to what was covered in the intervention rather than being part of any pre-post-test analyses (Figure 38, Chapter Five).

Collected data was stored within folders within my university password protected Microsoft OneDrive account. Data was shared only within the supervisory team, who also held university password protected accounts with all individuals within this group handling data in line with GDPR, with no personal data sharing occurring with third parties. No data was transferred outside of the European Union. Data collection was only used for the purpose of the research, and not for any commercial purposes. Recordings of interviews were deleted once these were transcribed. The Principal Supervisor held the position of data custodian. Identifiable personal data was stored in a separate folder to any other collected data within the OneDrive account which can be held for 10 years from the end of the research project as per the university's retention and disposal schedule 2023/4. Manchester Metropolitan University acted as the data controller within the research, including any personal data that was provided by participants, with the university also registered with the Information Commissioner’s Office ensuring that personal data is managed in line with the General Data Protection Regulation and the university's own Data Protection Policy. It is aimed that anonymous data collected from the Breast-CAM-NF1 pre- and post-tests will be shared within the UK Data Archive as per Cancer Research UK’s terms of use of the Breast-CAM once this research has been passed, aiding in future analyses. No third party was used for transcribing or analysing of data. Interview transcripts were printed out for aiding in the qualitative analysis process; however, these were filed in a lockable cabinet within my own personal office, and only contained the pseudonyms of participants and their unique PIC. Once finished with analysis these transcripts were scanned and stored within my own personal university OneDrive. The physical transcripts were shredded.

6.11 Ethical considerations

Ethical approval (EthOS: 45560) was granted by Manchester Metropolitan University's Health and Education Research Ethics and Governance Committee on the 8th of February 2023 (Appendix U). An amendment was granted on the 21st of February 2023 for additional gatekeepers to increase study exposure for recruitment (Appendix V).

The BPS Code of Human Research Ethics (2021b) was employed for ethical guidance when conducting research with human participants (Oates et al., 2021). Within this, four principles of respect: a) the autonomy, privacy, and dignity of individuals, groups, and communities, b) scientific integrity, c) social responsibility, and d) maximising benefit and minimising harm were upheld. Alongside these, the BPS Code of Ethics and Conduct (2021a) was also followed of: a) respect, b) competence, c) responsibility, and d) integrity.

Informed consent allowed for autonomy or self-determination to take part in the research (Fouka and Mantzorou, 2011). Both PIS documents provided my university contact information as Principal Investigator and contact information of the Principal Supervisor for answering any questions. Informed consent was ensured through research transparency within the PIS outlining full research information, its purpose, what it involved, its benefits and risks, information pertaining to data handling and protection, and an explanation that participation was voluntary. These actions also reflect scientific integrity within the Code of Human Research Ethics. Recognising the prevalence of learning difficulties within the NF1 population, care was taken to ensure that complex terminology was either clearly explained or removed, with sentences formatted in easy-to-read short structures to enable participants understand what they were consenting to.

PIS and debrief sheets also supplied information on how to withdraw from the research if required. Demonstrating responsibility within the Code of Ethics and Conduct, it is important to include the right to withdraw. If a participant wished to withdraw or to have their identifiable data withdrawn before the end of the retention period, they were to contact me directly and provide their PIC to identify their data. Participants were informed that they had a two-week period to withdraw on completion, after which data would be analysed and writing up would commence. In circumstances whereby the participant only completed the pre- and post-test questionnaires, this data was included for analysis, unless participants explicitly requested that this data was withdrawn. Participants' identities were protected while also demonstrating respect, and self-determination by asking them to elect a pseudonym to be referred to during interviews.

Due to the potential risk of the topic of breast cancer and the associated risk of developing breast cancer at a younger age among women with NF1 creating distress among participants, the Manchester Metropolitan University distress protocol (Haigh and Witham, 2015) was followed (Appendix W). This ensures that in situations where a participant displays signs of distress or voiced these, interviews are paused, and immediate support is offered. Any participants that do become distressed are encouraged to contact a trusted HP. A follow-up courtesy call is made a few days later to ensure the wellbeing of the participant. However, no participants became distressed during the research process. In cases of loss of capacity during interview, participants would automatically be withdrawn. However, this was not experienced.

Participants were provided with contact details for both breast cancer and NF1 support organisations, with these being made available on both the PIS documents and the debrief sheets. These included contact details for Breast Cancer Now, Macmillan Cancer Support, Childhood Tumour Trust, and Nerve Tumours UK. It was explicitly stated that if any participants were concerned about any breast symptoms that they discuss these with their doctor or with a trusted HP. Details were provided within the PIS and debrief sheets for any complaints or concerns associated with this research. However, no complaints were submitted.

Considering my own personal experience of having undergone breast cancer treatment, it was also important to include myself in minimising potential distress. Firstly, there were regular supervisory meetings which allowed for discussions on any challenges and developmental opportunities. Secondly, journaling throughout the process also provided a personal reflective space. Thirdly, Manchester Metropolitan University provides counselling and mental health services if required. I also attended a registered psychotherapist every couple of months during the research period. This individual provided psychological support throughout my breast cancer treatment and was therefore best placed to ensure that any issues relating to the BCA topic were discussed, with these sessions also providing a positive opportunity for personal development, and exploration. No details pertaining to research participants were discussed, with these sessions solely based on my personal emotions and cognitions that I experienced during the research process.

6.12 Summary of the key points in this chapter

- An ontological critical realist, and an epistemological contextualist position was employed within this mixed method research. This allows for the recognition of the positions and influences of both the participants and the researcher.

- A mixed method design allows for the provision of a more developed understanding of issues across settings and situations that may be limited if an either/or approach is adopted.
- A qualitative emphasis utilising RTA was employed with a quantitative pre-post intervention analysis of an adapted version of the Breast-CAM.
- Reflexivity communicates what contextual factors have aided in the development of the research process and the production of knowledge, with the researcher considering their power, privilege, positionality, and biases.
- The research was guided by ‘information power’ to ascertain final participant numbers, whereby study aim, sample specificity, use of established theory, quality of dialogue, and analysis strategy informed the final number of participants.

6.13 The next stage of the research

The following chapters provide both qualitative and quantitative studies to aid in exploring the feasibility of the novel animation. The aim of both approaches is to aid in providing a preliminary evaluation of participant responses to the NF1 BCA intervention development. The analyses from the mixed method design allows for addressing whether the intervention shows promise of being successful within the intended cohorts.

Chapter Seven

(Study 1) Preliminary evaluation of pre- and post-test responses to a novel breast cancer awareness intervention for young women with NF1, and their associates.

7.1 Introduction

This chapter provides a preliminary evaluation of pre- and post-test responses to a novel NF1 animation of components of breast cancer awareness (BCA), as primarily conceptualised within the Breast-CAM (Linsell et al., 2010) and adapted to the Breast-CAM-NF1 to align with NF1 breast cancer risk, and breast screening eligibility. Changes in BCA levels for young women with NF1 and their associates were examined by Wilcoxon signed rank tests and McNemar's tests. Full details of SPSS Descriptive and Inferential Outputs can be found in Appendix X.

7.2 Sociodemographic characteristics of participants

Young women with NF1 aged between 18-40 years were recruited (Table 22), with this range encompassed by participants (*M* = 27.92 years). As the sole age-related criteria for associates required participants being aged 18 years or over at the time of survey, the age range of this group was 21-57 years (*M* = 41.64 years). All participants identified their ethnicity as English/Welsh/Scottish/Northern Irish/British.

Most participants reported a qualification at undergraduate level (Certificate/Diploma/Degree) or working towards this level (84.6% young women with NF1; 72.7% associates).

Table 22

Sociodemographic Characteristics of Participants

Characteristic	Young women with NF1	Associates
Age		
Min	18	21
Max	40	57
M	27.92	41.64
SD	6.42	12.58

Ethnicity n(%)		
English/Welsh/Scottish/Northern Irish/British	13(100%)	11(100%)
Highest Educational Qualification* n(%)		
Post primary/Secondary	0 (0%)	1(9.1%)
Undergraduate	11(84.6%)	8(72.7%)
Postgraduate	2(15.4%)	2(18.2%)
Currently in part-time/full-time education	4(30.8%)	1(9.1%)

*highest level of education obtained or currently working towards

7.3 Completion rates

N = 81 engaged with the questionnaire at some level (N = 51 young women with NF1; N = 30 associates), with most exiting at the PIS stage, particularly those identified as young women with NF1 (56.9% young women with NF1; 26.7% associates) (Table 23). Only participant data of fully completed pre- and post-test questionnaires were included for analyses. 24 participants fully completed both pre- and post-test questionnaires (N = 13 young women with NF1; 11 associates), indicating an overall completion rate of 29.6%, (25.5% young women with NF1; 36.7%-associates).

Completion times were similar for both cohorts (*M* = 12 minutes 41 seconds young women with NF1; *M* = 14 minutes 9 seconds associates). Most participants accessed the study via link/web address (88.2% young women with NF1; 86.7% associates) to access the questionnaire compared to the QR Code (11.8% young women with NF1; 13.3% associates).

Table 23

Completion Rates and Access Type of Intervention

Item	Young women with NF1	Associates
Completion rate N(%)		
Some interaction	51(100%)	30(100%)
Exited at PIS	29(56.9%)	8(26.7%)
Exited post-animation	6(11.8%)	4(13.3%)
Full completion	13(25.5%)	11(36.7%)
Completion Time (mm:ss)		
Partially completed[a]		
Min	00:04	00:08

Max	47:12	13:45
Mean	03:43	03:02
Fully completed		
Min	08:30	06:50
Max	23:56	34:06
Mean	12:41	14:09
Method of access n(%)		
QR Code	6(11.8%)	4(13.3%)
Link/web address	45(88.2%)	26(86.7%)

[a] Two outliers of 24h46m09s and 1h25m10s excluded from associates

7.4 Preliminary evaluation of pre-post-test analyses

Breast-CAM-NF1 scores demonstrated positive changes in means in all categories (see Table 24).

Table 24

Scoring Range of Breast-CAM-NF1 Components

Question	Scoring range		Pre-animation				Post-animation			
	Min	Max	Min	Max	*M*	*SD*	Min	Max	*M*	*SD*
Knowledge of symptoms (warning signs)										
Young women and associates	0	22	15	22	20.54	2.36	10	22	20.88	2.74
Barriers to seeking medical help (put off going to doctor)										
Young women	0	30	17	26	22.00	3.39	17	30	23.69	4.57
Associates	0	30	10	22	16.36	4.48	10	26	19.18	5.51
Confidence, skills and behaviour in relation to detecting breast changes (how often check)										
Young women	0	4	0	4	2.4	1.39	0	4	3.20	1.54
Associates	0	4	2	4	3.40	.92	4	4	4.00	.00
Confidence, skills and behaviour in relation to detecting breast changes (notice a change)										
Young women	0	4	1	4	2.00	1.00	2	3	2.50	.52

Evaluation of the Wilcoxon-signed rank test (Table 25) indicated a non-significant increase in knowledge of symptoms of breast cancer (warning signs) in 7 participants, with 3 participants showing a decrease in knowledge levels (p = .505). 14 participants experienced no changes in knowledge levels, achieving the maximum score of 22.00 both pre- and post-animation. Reasons for putting off going to the doctor with a breast symptom for young women with NF1 yielded a statistically significant result (p = .036). 8

participants indicated a reduction, and 2 participants exhibited an increase in the reasons for putting off going to the doctor, with 3 participants achieving a no change tied score. For associates a non-significant reduction in perceived reasons for young women with NF1 putting off going to the doctor with a breast concern was reported (*p* = .065), with 9 participants reducing reasons, 1 participant showing an increase in reasons, and 1 participant experienced no change in response levels.

A non-significant change in levels of confidence, skills and behaviour in relation to detecting breast changes by measuring *breast checking frequency* was reported post-animation (*p* = .139). 10 participants selected the ideal frequency answering 'once a month' post animation versus 7 participants 'at least once a month' pre-animation.

A positive but non-significant post-animation change was reported in 4 associates of how often women with NF1 should check their breasts (*p* = .059). 7 participants demonstrated no changes answering comparably 'at least once a month' pre-animation and 'once a month' post-animation, with all associates correctly answering 'once a month' post-animation.

A significant change was reported among young women with NF1 in levels of confidence, skills and behaviour in relation to detecting breast changes by measuring variation in *noticing a breast change* (*p* = .020), with 8 participants increasing in levels of confidence in noticing a breast change. 4 participants demonstrated no change of confidence levels, with 1 participant indicating a decrease.

Table 25

Wilcoxon-Signed Rank Test Results

Question	*n*	*Mdn*			*z*	*p*	*r*
		pre-test	post-test	change			
Knowledge of symptoms (warning signs)							
Young women and associates	24	22.00	22.00	0.00	0.67	.505	0.10
Barriers to seeking medical help (put off going to doctor)							
Young women	13	22.00	25.00	2.00	2.10	.036*	0.42
Associates	11	18.00	20.00	4.00	1.84	.065	0.39

Confidence, skills and behaviour in relation to detecting breast changes (how often check)							
Young women	13	2.00	4.00	0.00	1.48	.139	0.30
Associates	11	4.00	4.00	0.00	1.89	.059	0.40
Confidence, skills and behaviour in relation to detecting breast changes (notice a change)							
Young women	13	2.00	3.00	1.00	2.33	.020*	0.46

**p* < .05.*

A non-significant result was found by McNemar test (Table 26) for knowledge of age-related and lifetime risk (*p* = .125). Post intervention 13 participants (54.2%) reported the correct age (40-year-old woman) of who is most likely to develop breast cancer if they have NF1 (compared to general population risk), 11 participants (45.8%) provided incorrect answers, with an increase in 5 participants providing a correct answer.

Table 26

McNemar Test Results

Question	Correct answers		Change	*p*
	pre-test	post-test		
Knowledge of age-related and lifetime risk n(%)	8(33.3%)	13(54.2%)	5	.125
Breast screening knowledge n(%)	11(45.8)	21(87.5%)	10	.006*

**p* < .05.*

A significant result was reported for breast screening knowledge (*p* = .006). Post-intervention, 21 participants (87.5%) recognised the correct screening eligibility age (40 years) for women with NF1 in the UK and Ireland with 3 participants (12.5%) answering incorrectly.

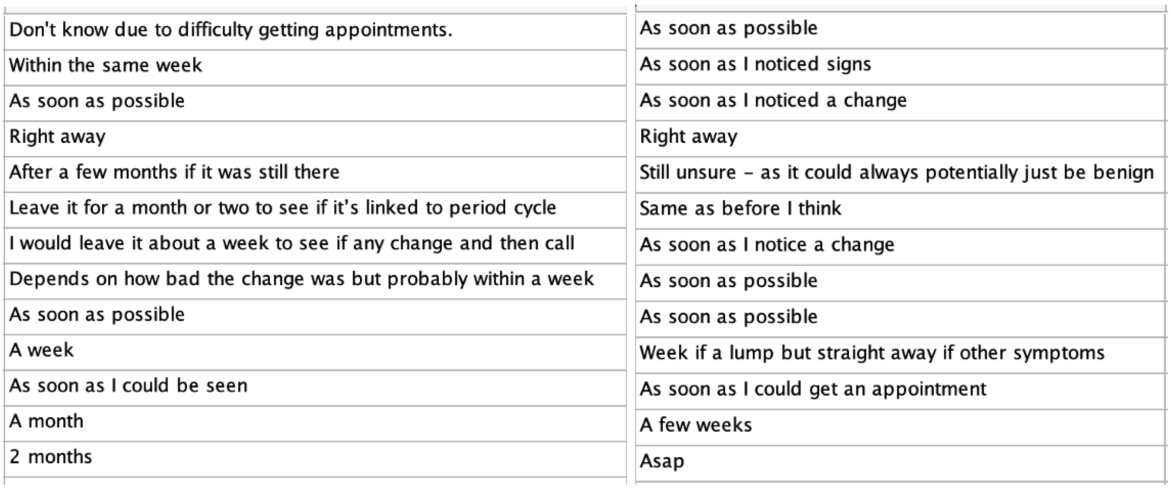
7.5 Pre- post-test textbox evaluation

Reported time taken to contact a doctor for a breast concern

Tables 27 and 28 display aligned responses as provided within the SPSS output from young women with NF1 and associates pre- (left column) and post-animation (right column).

Table 27

Young Women with NF1's Responses for Time Taken to Contact a Doctor Pre- (Left Column) and Post-Animation (Right Column)

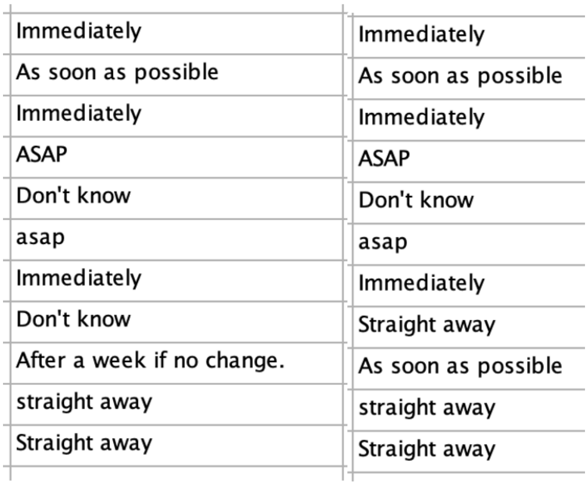


Don't know due to difficulty getting appointments.	As soon as possible
Within the same week	As soon as I noticed signs
As soon as possible	As soon as I noticed a change
Right away	Right away
After a few months if it was still there	Still unsure – as it could always potentially just be benign
Leave it for a month or two to see if it's linked to period cycle	Same as before I think
I would leave it about a week to see if any change and then call	As soon as I notice a change
Depends on how bad the change was but probably within a week	As soon as possible
As soon as possible	As soon as possible
A week	Week if a lump but straight away if other symptoms
As soon as I could be seen	As soon as I could get an appointment
A month	A few weeks
2 months	Asap

Overall, young women with NF1 demonstrated an assertiveness to contact their medical doctor promptly even before watching the animation (N = 8). This is based on the medical advice that anyone with a breast lump that has remained after a period of 2 weeks should seek medical advice from a HP (Patient, 2018). However, most women that would have put off going to the doctor for a longer period demonstrated a change post-animation whereby they would be more prompt with presenting (N = 10). One respondent changed from 'a month' to 'a few weeks', however, it is uncertain whether this translates as to mean shorter than a month or longer. One participant conveyed that from watching the animation they would not change how quickly they would attend, answered previously as 'leave it for a month or two to see if it's linked to period cycle'. The confusion of recognising whether the change is benign or malignant also remained for another, which may create a delay in presenting with a breast concern. It is also noted that at a surface level, a response of 'as soon as I could get an appointment' may be understood as promptness to attend, however, it may also convey the difficulties of obtaining an appointment quickly within the healthcare system.

Table 28

Associates' Responses for Time Taken to Contact a Doctor Pre- (Left Column) and Post-Animation (Right Column)



Immediately	Immediately
As soon as possible	As soon as possible
Immediately	Immediately
ASAP	ASAP
Don't know	Don't know
asap	asap
Immediately	Immediately
Don't know	Straight away
After a week if no change.	As soon as possible
straight away	straight away
Straight away	Straight away

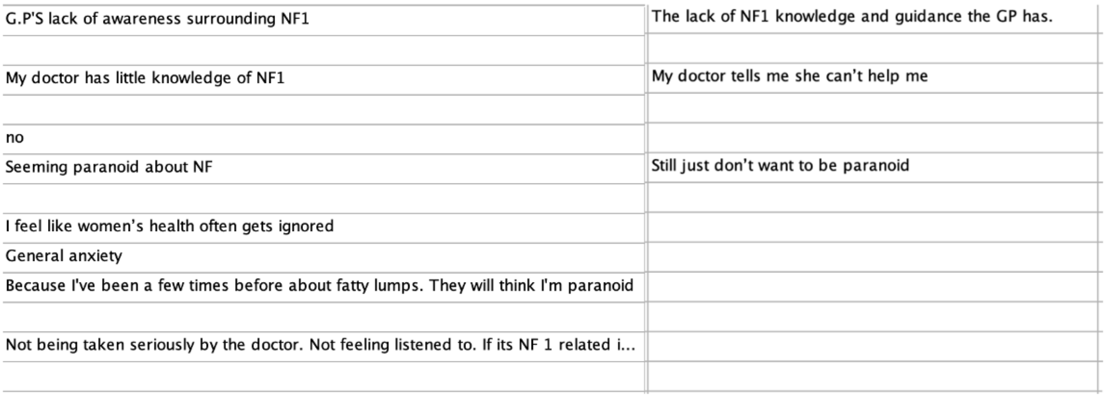
Most associates demonstrated the opinion both before and after the animation that young women with NF1 should contact a doctor promptly. Pre-animation, this was conveyed by N = 9. Post animation, N = 10 conveyed a sense of urgency, with responses such as 'immediately', 'as soon as possible', 'ASAP', and 'straight away'. One associate remained unsure, providing the response 'don't know' both pre- and post-test.

Other reasons for putting off attending a doctor for a breast concern

Table 29 and Table 30 provide responses of those that elected to respond from young woman with NF1, and associates. Participants were not forced to give an answer if they did not have anything to add.

Table 29

Other Reasons from Young Women with NF1 for Putting off Attending a Doctor for a Breast Concern Pre- (Left Column) and Post-Animation (Right Column)



G.P'S lack of awareness surrounding NF1	The lack of NF1 knowledge and guidance the GP has.
My doctor has little knowledge of NF1	My doctor tells me she can't help me
no	
Seeming paranoid about NF	Still just don't want to be paranoid
I feel like women's health often gets ignored	
General anxiety	
Because I've been a few times before about fatty lumps. They will think I'm paranoid	
Not being taken seriously by the doctor. Not feeling listened to. If its NF 1 related i...	

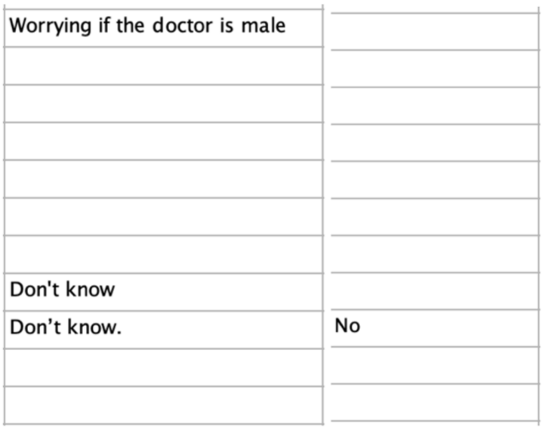
One woman's response pre-animation was considerably long and therefore the full text answer has been provided:

> *'Not being taken seriously by the doctor. Not feeling listened to. If its an NF1 related issue they don't often know what it is or how it can be causing the issue your [sic] visiting for. Having to get past the receptionist can be difficult, sometimes it feels like they try their hardest to not let you see a doctor. If your [sic] visiting for an ongoing issue and the doctor is out of ideas they just pass the buck on to someone else only for them to draw the same conclusion of not knowing and you end up going round in circles. Being a young woman [sic] they always come to the conclusion of "are you pregnant" for a lot of symptoms you go for and then ask "are you sure" when you say no.'*

Before watching the animation, the young women with NF1 that elected to offer further reasons, expressed that the lack of NF1 knowledge among HPs was a barrier to attending if there was a breast concern, with this in turn also being experienced as not being taken seriously. Other issues such as general anxiety, and the perception that women's health gets ignored, also create barriers to seeking medical help. Most of these participants expressed their concerns before watching the animation, with one participant communicating a lack of NF1 knowledge as creating a 'pass the buck' attitude, with difficulties in getting an appointment with the receptionist. A reductionist approach to women's health is conveyed by this participant, with doctors 'always come to the conclusion of are you pregnant for a lot of symptoms'. There were fewer responses post-intervention, however, the sentiment remained of NF1 not being understood by HPs, with this being perceived as these professionals not caring or wanting to help, and the women themselves left to feel negative emotions for example, ‘still just don’t want to be paranoid’.

Table 30

Other Reasons from Associates for Putting off Attending a Doctor for a Breast Concern Pre- (Left Column) and Post-Animation (Right Column)



Worrying if the doctor is male	
Don't know	
Don’t know.	No

As demonstrated, associates did not offer as many potential reasons that might put a young woman with NF1 off going to the doctor. No further reasons were provided post-animation. Only one associate provided a reason of ‘worrying if the doctor is male’ pre-animation. Two other associates provided answers of ‘don’t know’.

7.6 Discussion

Pre-post intervention analyses utilizing an adapted version of the Breast-CAM (Linsell et al., 2010), the Breast-CAM-NF1, was employed to measure differences of NF1 BCA levels of young women with NF1, and associates. This was undertaken to contribute to a preliminary evaluation of the feasibility of a novel NF1 BCA intervention for young women with NF1, and their associates. Education of breast cancer, early detection, and screening is critical for improving prognosis and survival rates (Labrague et al., 2021). A plethora of approaches have been utilised for raising BCA including breast health education conducted by trained breast cancer survivors (Yi and Park, 2012), and nurses (Secginli and Nahcivan, 2011), for example. Other methods such as mobile technology (Labrague et al., 2021) have been employed to increase accessibility. The design of a digital NF1 BCA animation encompasses BCA knowledge and self-efficacy to notice breast changes and to attend promptly for a breast concern.

From preliminary evaluation, the data tentatively suggests that the animation may aid in reducing reasons that young women with NF1 would put off going to their doctor with a breast symptom, may support increasing confidence among young women with NF1 in noticing breast changes, and may positively aid in increasing knowledge of screening eligibility age for breast screening for young women with NF1 in the UK and Ireland. This is congruent with O'Mahony et al. (2017) within their systematic review of interventions for raising BCA in women, whereby it is confirmed that it is important that women are not only breast cancer aware in that they have the knowledge, but also the confidence, and skills to detect breast changes and promptly present to a HP. A delay to help-seeking has been found to be associated with women's lack of knowledge of non-lump breast symptoms (O'Mahony, 2013; O'Mahony et al., 2017). The suggested increase in participants' knowledge of when women with NF1 are recommended to attend for breast screening is also pertinent, with screening being the most widely utilized and best available means for detecting breast cancer (MacBride, 2012), with early detection aiding in earlier access to treatment for a better prognosis (Ginsburg et al., 2020).

However, no significant differences were found in knowledge levels of breast cancer warning symptoms, nor the number of reasons that young women with NF1 would put off going to the doctor with a breast symptom as perceived by associates, breast checking frequency knowledge, breast checking frequency knowledge (associates), or in knowledge of the age a woman is most likely to develop breast cancer if they have NF1. Despite the analysis providing a non-significant result for differences in knowledge of breast cancer warning symptoms, it was evident that there were very little changes in levels overall, with 14 participants aware of all warning signs both pre- and post-intervention potentially demonstrating high levels of pre-existing knowledge of breast cancer warning signs. However, the provision of boxes of *yes, no,* and *don't know* for the warning signs may have created different forms of response biases, including acquiescence bias, and extreme responding. The former refers to the tendency to agree with all the questions in a measure which can sometimes be driven by demand characteristics whereby participants will respond in a way to questions that they perceive to be the correct responses based on the experiment that they are partaking in (Watson, 1992). Another potential reason may be posited towards extreme responding whereby respondents may have selected the most extreme answers, with this response style found to be prevalent within individuals with lower levels of intelligence and education (Meisenberg and Williams, 2008). However, participants within this research demonstrated a high level of education attainment. Another consideration is that the true effect size may have been too small (Visentin et al., 2020), with the sample size providing insufficient statistical power to address the research question (Andrade, 2020). This may also be a contributory factor of the non-significant results among young women with NF1 for differences in breast checking frequency knowledge, and associates for breast checking frequency knowledge, despite it evident that there was a positive impact within responses. Orsmond and Cohn (2015) also provide cautionary statements regarding effect sizes in feasibility studies, suggesting a combination of methods (qualitative and quantitative) that best suit the feasibility study design and measured outcomes to interpret preliminary findings, and present recommendations.

While sample size is also considered within the non-significant result of increasing the likelihood of correctly answering what age a woman is most likely to develop breast cancer if they have NF1, the results may have demonstrated a confusion despite having watched the animation. For transparency, the animation communicates that women under the age of 50 years have an increased risk of breast cancer. As this is not directly asked within the question, this may have contributed to uncertainty. A non-significant result found for a difference in the number of reasons that a young women with NF1 would put off going to the doctor from watching the animation as perceived by associates may provide evidence that despite family and friends providing emotional and self-management support, and facilitation of healthy behaviours (Rosland et al., 2013) which in this instance includes BCA behaviours, only the patients themselves can truly communicate important information pertaining to such knowledge and understanding of what are such key reasons. It demonstrates that without the patient’s perspective, it creates a difficulty of being able to understand the lived experiences of those that experience a condition such as NF1 unless they experience this themselves. This validates the importance of ensuring that explorations within feasibility include those experiencing a condition, with young women with NF1 offering reasons for an important question like this, and in some cases quite detailed responses. These were also explored further within the interviews. Without young women with NF1, these barriers to attending a doctor may have been missed or would not have been described in such detail.

The small sample size reflects experienced recruitment challenges. Despite best efforts, particularly from the Childhood Tumour Trust, with advertising and sharing the research with various NF/rare disease charities, and advertising via various online platforms, recruitment numbers promptly slowed after 2 months, and then stopped after four months. In discussion with the supervisory team and Childhood Tumour Trust, data collection was therefore stopped. This parallels already reported recruitment challenges, and subsequently small participant numbers within rare disease research (Whicher et al., 2018). Despite 81 individuals engaging with the questionnaire at some level (51 of young women with NF1; 30 of associates), only 24 participants (30%) fully completed this. The highest drop-out rate came at the PIS stage (65%) before accessing consent. There are several reasons suggested for this. Firstly, on seeing the link advertised, individuals may have clicked on the link out of curiosity to find out more about the research without the intention to complete it at that time, or indeed at any point. However, the length of the PIS itself (7-pages) may have deterred individuals from moving forward, with participants less likely to read longer information (Sharp, 2004). Longer information sheets can also result in poorer comprehension and retention of key details compared to briefer versions (Ennis and Wykes, 2016). At the time for applying for ethical approval, feedback from the ethics committee was provided that more information was required to ensure that full communication of research information and protocols were fully addressed. This resulted in a substantially lengthy document. Despite acting to employ easy to understand language with this checked by the Childhood Tumour Trust, comprehension may have been negatively affected because of the PIS length. This may somewhat explain why there was a high level of education attainment in all participants that completed the Breast-CAM-NF1 indicating a lack of diversity in this regard, despite the high prevalence of learning difficulties within the NF1 population well documented (Acosta et al., 2012; Lehtonen et al., 2015; Vogel et al., 2017). The length and format of the PIS therefore may not have been acceptable and accessible to all individuals with varying levels of learning difficulties. Similarly, insufficient diversity of ethnicity was found. Despite NF1 being a condition that can affect an individual regardless of gender, race, or ethnicity (Children's Tumor Foundation, n.d.), all young women with NF1 and associates identified themselves as English/Welsh/Scottish/Northern Irish/British. With no participants from other ethnicities, there are potential omissions of information that may be pertinent to the feasibility of an inclusive NF1 BCA intervention. Despite this research open to participants in the UK and ROI, no participants identified themselves as being of Irish ethnicity. However, it cannot be ascertained whether any of the participants were residing in Ireland and therefore receiving care or supporting someone with NF1 within the state. Although a QR Code and Link/web address were offered as access methods for increasing accessibility, the majority utilised the link/web address. As the research was shared primarily by the Childhood Tumour Trust, it was reported by this charity that providing a link was easier to share via social media platforms and was therefore utilised more than the QR Code, reducing the promotion of this.

Despite tentative indications that the animation demonstrates feasibility, caution is advised with interpreting findings. With participants conducting a post-test questionnaire immediately after watching the animation, improvements in NF1 BCA levels may have resulted from the test questionnaire itself rather than the intervention, with participants remembering questions or the questions aiding in raising awareness and triggering learning after the pre-test (Marsden and Torgerson, 2012). It is also possible therefore, that initial results of knowledge or attitude may be reported as high, particularly as the animation was only approximately 3 minutes in length allowing for a quick transition from pre-test to post-test. With no further time point within the research, it cannot be ascertained if knowledge or attitude 'decay' may be experienced (Stratton, 2019) if a longer period between the pre- and post-test was employed. This is particularly pertinent for behaviour change interventions, whereby health-promoting behaviours must be repeated over the long-term to have a meaningful impact (Gardner et al., 2023) to avoid lapsing into previous behavioural patterns (Kwasnicka et al., 2016). Other confounding variables may have contributed to score changes which were unable to be controlled and accounted for such as participants' environment of when and where they completed the questionnaire and watched the animation (Thiese, 2014).

7.7 Summary of the key points in this chapter

- Preliminary evaluation of NF1 BCA components of the Breast-CAM-NF1 was analysed utilising Wilcoxon signed rank tests, and McNemar tests.
- Significant results from the Breast-CAM-NF1 suggest increased levels of NF1 BCA knowledge of eligibility for breast screening for young women with NF1 *(p* = .006)*,* reduction in reasons for putting off going to a doctor for a breast concern (*p* = .036), and for increased levels of confidence to spot breast changes (*p* = .020).
- Overall, there are some tentative indications that the animation demonstrates feasibility, however caution is advised with interpreting findings. The true effect size may have been too small, with the small sample size providing insufficient statistical power to adequately address the research question.
- The lack of a longer period between pre- and post-test measures, and the inability to control for other cofounding variables may also have affected scores.

7.8 The next stage of the research

Recognising the importance of rigour for integrity, competence, and legitimacy within the research process, and acknowledging how qualitative methods are often critiqued for lacking a shared consensus on how this is employed, the next chapter provides an exploration of the influence of the researcher's position on the research through an analysis of the reflexive logs with the incorporated stage of the familiarisation of data within RTA. This provides an increased transparency, and within Lincoln and Guba's (1985) evaluation of trustworthiness, it also offers increased credibility by demonstrating the thought process and therefore construction of meaning from not only the participants' data, but also from the researcher's interpretations of such data.

Chapter Eight

(Study 2) A reflexive thematic analysis exploring positionality influences on meaning making: When the researcher and the woman who had breast cancer are one and the same.

8.1 Introduction

Recognising that critical qualitative research espouses the hermeneutic of suspicion of an inquiring interpretative orientation by the critical questioning of the data meaning (Hay, 1999), this suspicion arguably extends to that of the researcher's interpretative position as they cannot eschew their own involvement (Finlay, 2002). It is therefore pertinent to add transparency to the RTA of interviews by examining my influence as a researcher and as a woman who went through breast cancer at a younger age on the analysis and theme development.

There can be a lack of transparency that makes visible not merely a statement of positionality (*I am* a researcher and a woman with personal experience of breast cancer), but a transparency that requires a reflexive researcher to consider their own influence and influential contextual factors (Tebes, 2005). The process of reflexive scrutiny identifies the researcher's position that guides both the epistemologies and the knowledge production within the research (Hamdan, 2009). Reflexivity in this regard concerns an analytic, yet thoughtful self-awareness of experience, reasoning, and impact on the research process (Råheim et al., 2016).

It is evident that there were my own personal experiences, and considerations within this research. This is not uncommon or inappropriate. As discussed within the previous chapter, researchers can undertake research with a sense of necessity when there is a personal interest or association (Hill and Dao, 2021). Analysing the reflexivity logs by RTA furthers transparency of my role, the selection of theories, potential biases, and influences of personal experiences, increasing sense-making of the analytic process (Berger, 2015; Tuval-Mashiach, 2017). This is a pertinent action, with the position (and subsequently influence) of the researcher being a recurrent concern particularly within methodology literature (Råheim et al., 2016). This transparency augments Lincoln and Guba's (1985) evaluation of trustworthiness, by advancing credibility, comparable to internal validity within quantitative research. By conducting this analysis, it aims to address the research question:

From my reflexivity logs that have incorporated the familiarisation of the dataset within them, what influences within the research are experienced through my positions as both a researcher and as an individual who has gone through treatment for breast cancer as a young woman?

8.2 Ontological and epistemological positions

An ontological critical realist and an epistemological contextualist position are taken, recognising that there are shared realities or similarities of experiences of both PhD researchers and those that have gone through breast cancer. However, there is also *my* reality that exists independently (Braun and Clarke, 2022).

Considering these positions, the orientation to data will be both inductive and deductive. However, it is recognised that it is predominantly deductive in that there is an explicit exploration for evidence of influence from the positions of both researcher and as a person who has had breast cancer which is a research component that has been explored. Furthermore, an inductive approach allows for coding and theme development to develop from the data content itself. Subsequently, these orientations establish both a semantic and latent approach to the focus of meaning.

8.3 Data analysis

Familiarisation of the dataset involved reading through each of the reflexive logs that incorporated the familiarisation of each interview. This was done twice to immerse myself further. Notes were added if required, however, these were brief and less frequent in nature than carrying out this process during familiarisation of participant interviews due to the explicit reflections that I had undertaken already. While this analysis involves my own reflexive accounts, it was nonetheless approached in a systematic manner when coding to ensure data relevant to the research question were captured. Coding was performed on both semantic and latent levels, with code labels applied to best convey meaningful descriptions through words or succinct phrases e.g., *BCA is personal to me!* (semantic) with this being abundantly evident throughout my reflexivity accounts that intertwine with participants' interviews, and *mom guilt* (latent) with this being a surprising observation of how my own position of being a mother allowed for a more acute awareness of other mothers' challenges, and strengths within the research.

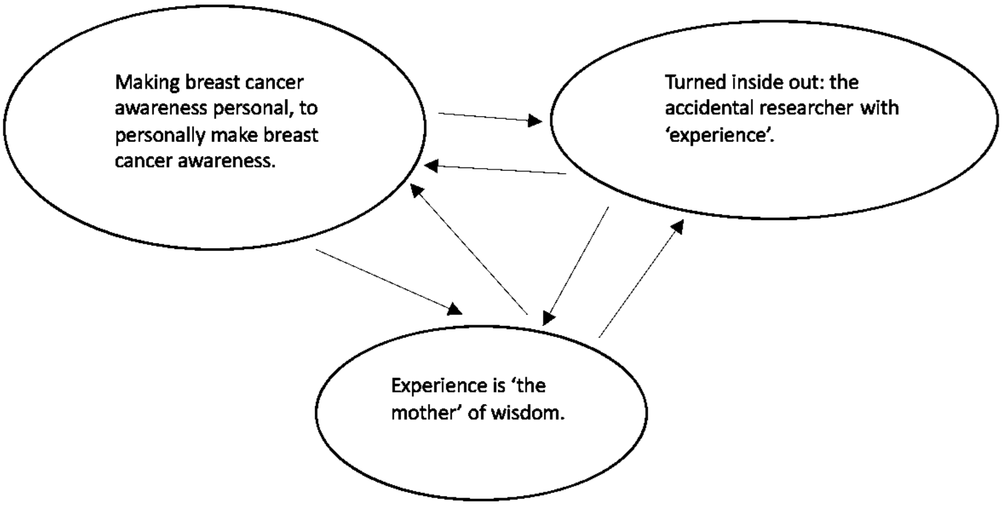
Demonstrating the iterative process, some coding labels evolved during each reading, ensuring that they best captured both meaning and a focus towards the research question. Code labels were collated, and relevant segments of data were applied to each code, with Appendix Y detailing coding and thematic development. There were shared patterns of meaning across the dataset as the codes clustered to begin providing an insight into answering the research question. These aided in the development of what were believed to be initial themes such as *working with researcher imposter syndrome,* and *my position as an outsider.* However, these did not offer enough as separate entities. Instead, coding clusters such as *my inside-out position,* and *the accidental researcher by experience* carried a shared meaning of an identity and therefore became a theme within this research of *turned inside out: the accidental researcher with 'experience'.* This better conveyed my position as an 'outsider' of being a PhD researcher, personally perceived as accidental in how I became one through a forged motivation to make a positive difference of having gone through cancer, with an 'insider' breast cancer experience that allows me to hear gaps from a patient perspective. Overlapping in initial themes was also evident within *breast cancer awareness is personal,* and *getting people talking about the facts.* These were incorporated to convey a greater sense of meaning to become *taking/making things personally may cause ~~offense~~ sense*. However, as the naming of a theme is important to convey meaning, I was not happy with this and it was changed to *making breast cancer awareness personal, to personally make breast cancer awareness.* Likewise, *the mother connection* was renamed to *experience is 'the mother' of wisdom.* The development and reviewing of themes ensured that each final theme had a central organising concept, but also had a direct relationship between each other to provide a clear focus on addressing the research question. Appendix Y also demonstrates the evolution of themes including theme name development, with names conveying not only information of what the theme addresses, but also my own preference for a play on words, and proverbs that add to the understanding of not only my positionality, but also the influences through *who I am.*

8.4 Analysis and discussion

From the analysis, three themes demonstrate common patterns that have been developed to focus on the research question. These are; *making breast cancer awareness personal, to personally make breast cancer awareness*, *turned inside out: the accidental researcher with 'experience'*, and *experience is 'the mother' of wisdom* as shown with Figure 41's thematic map.

Figure 41

Final Thematic Map (Positionality Influences)



Theme 1: Making breast cancer awareness personal, to personally make breast cancer awareness.

Throughout the reflexive logs, there is a resonant sense of my own memories back to when I underwent breast cancer treatment. The motivation to 'make' BCA is intrinsically set, as I recognise that being able to promptly spot a lump and go to the doctor saved my life. Therefore, through this personal experience comes the motivation to help others spot cancer early and be empowered to seek help to aid in a better prognosis. In this case it is helping young women with NF1. This is evident within my reflexivity after speaking with Saffie on how her new motivation to take her health more seriously, reflects my motivation too. This drive is further depicted by my use of the raising hands emoji to reflect a moment of pride or victorious personal moment (Dictionary.com, 2018) from hearing this:

> *‘For Saffie the animation has also made her realise that she should take her health more seriously. I do feel happy about this. It’s all about catching breast cancer early. For me, it’s the listening out for the taking ownership, the real power. And I found it within Saffie’s last sentence, ‘...I need to stop brushing everything -, it might be normal, it could just be nothing, but it’s not a waste of time to find out it’s nothing...’ 🙌 ’*

The motivation to undertake this research may also be part of my ’re-entry’ phase of returning to living after treatment, which is often a time of both physical and emotional challenges (Allen et al., 2009). Coping mechanisms can assist with moving forward within this phase to determine the response to a challenge or threat (in this case the threat of cancer often remains) and reduce the associated distress by cognitive and behavioural responses (Ghanem et al., 2020). Active coping strategies (rather than avoidant) are often characterised by actions that help reduce these threats (Perez-Tejada et al., 2019). Perhaps, unconsciously, there is an action to confront the natural fear of recurrence that is experienced by those navigating the survivorship period (Allen et al., 2009) by undertaking the PhD as my way of dealing with the worry and fear of recurrence that are often connected with cancer. Worry and fear were thoughts that I considered after speaking with Willow:

> *‘That’s what is needed for everyone here, to really learn and reinforce that learning. Ongoing conversations with accessible and evidence-based resources to start the conversation. Willow mentioned worry and fear. I think that’s very common. It’s not great that we do experience this, but I do think that having conversations more about this will help with reducing this worry and fear so much.’* 🙌

Within a review conducted by Lashbrook et al. (2018), it was found that those who had gone through breast cancer were more likely to have coping strategies involving planning, active coping, and positive cognitive restructuring (reframing) (Manuel et al., 2007; Aguado Loi et al., 2013; Paek et al., 2016; Goyal et al., 2018; Culbertson et al., 2020). For me, these are evident in my drive to raise BCA in an evidence-based manner, to ensure appropriate sources are available instead of Google which can often be incorrect or out of date. It made me reflect upon my own negative experience with Google when I was diagnosed, as found within the reflexive accounts of Rose and Saffie:

'It made me think about how we always go to 'Dr Google', how I went to Dr Google when I got diagnosed with a type of breast cancer that I had never heard of. My stomach did a bit of a flip as Rose said this, and I remembered my own bad experiences.'

'Yep, Dr Google strikes again, which Saffie admits 'is not the best thing to do, 'cos it, Google tells everybody that they're dying...((laughs))'. Ah, yes, this always triggers a wincing within me. Dr Google had me dead too when I looked up triple negative breast cancer. Lovely. At least I had a nurse I could call to tell her about my findings from online 'research'. It's taken going back to uni as a mature student, and a proverbial beating by Dr Google's stethoscope to know that I don't trust Dr Nick Riviera ('Hi everybody!'), The Simpson's phony doctor types.'

Evidence of my active coping and reframing is clear in my taking the time during this log to re-create a meme (Figure 42).

Figure 42

Dr Nick Riviera aka Dr Google

Boyers (2000) found that early-stage breast cancer survivors (like me) who had higher active coping levels, positive reframing, and planning had significantly higher positive growth levels than women who had lower levels of these. It is evident that this research is aiding in my growth by raising BCA in young women with NF1 and their associates to promptly seek help, but also my own BCA confidence, as after Anya's interview I somewhat call myself out as 'a bit of a hypocrite'.

> *'I do agree with what she said next, '...and with things like breast cancer, you shouldn't feel hesitant to want to contact your healthcare provider if you're concerned'. This sentiment echoed with me and I did feel that little twist in the stomach. She's right, we shouldn't feel concerned about contacting a doctor if there is something that we are concerned about, but I know it's not that easy. I certainly was not beating down the door into my GP's room. I poked and I prodded that little lump that I found. I don't know why I kept doing that. Maybe I could break it and get rid of it, and then everything would be okay [...] I went to the doctor the Tuesday after for reassurance that it was nothing. Instead, I got referred to a triple assessment clinic. I still feel awkward going to the GP and can feel that sometimes my needs are not met. I recognise that I may then appear a bit of a hypocrite, but the point is I will go if I have any concerns, and as much as I hate doing it, I will make sure that I am somewhat satisfied with the outcome of the appointment or next steps.'*

There is also a realisation that designing a BCA intervention for others, was in fact an intrinsic and perhaps an unconscious process of designing my own intervention to move away from the oncology patient identity and more towards a psychosocial oncology researcher. Within a physical and psychological intervention, it was found that breast cancer survivors were motivated to take part to help them create a distance from the illness experiences (Sebri et al., 2022). I have perhaps shifted the energy of my own fears and fights towards fighting for BCA for others, such as young women with NF1:

> *'I notice that I am now even using battle language. That feeling of 'fight' is so strong within many of the interviews.'*

Reflecting on this outward shift of language after Anya's interview, there is a revelation that while I attempt to move away from the patient identity, the fight language was always there within me as I 'fought' cancer, and it will inevitably endure as a motivation within this research, and as a legacy to future work.

Theme 2: Turned inside out: The accidental researcher with 'experience'.

Within healthcare, often a binary narrative of either 'the patients' or 'the health providers' is employed to understand practices and processes (Rowland and Kuper, 2018). Expressing this within the terms of positionality, this can be better understood as being either the insider or the outsider. Arguably, these are two differing positions that may affect interpretations. From my perspective, I carry both these positions that formulate considerations, and approaches which may not be contemplated by another researcher with a different experience to mine. It is fitting to identify as ‘researcher in the middle’ (Breen, 2007). My log of Willow’s interview demonstrates this as a curious researcher with a keen interest for women’s health, alongside my own need to be cautious with hormone medication that may increase the risk of recurrence, but how this aligns with issues experienced by young women with NF1. These positions allow me to recognise a research gap:

> *‘If there is no continuation of regular services and checks past 18 years, why are these young women not being provided with important information like this? I know how important this is. I, myself, while having gone through triple negative breast cancer, am not advised to take any hormones whether it’s certain contraceptives or HRT […] if they don’t know, and their healthcare professional doesn’t know information that is pertinent to this condition, well, there’s quite a problem there. There are so many gaps! I feel that this intervention can only make a slight dent in things, if at all. I knew it was going to be complex, but these interviews are throwing up a lot more issues that can get in the way here. You get absolutely nothing about these from the questionnaire part!’*

While I consider triangulation to be beneficial, it becomes apparent that I exhibit a preference for qualitative methods, allowing questions to be asked that cannot simply be translated into numbers to understand human experience (Cleland, 2017). Reflections after interviews with Sasha and Laura also convey this preference as a researcher with ‘experience’:

> *‘You can learn something, you can go, ‘oh yes I know what to be aware of now when it comes to breast cancer awareness and NF1!’, however, the barrier is not within the confidence and self-efficacy of learning, it is within the lack of confidence in the healthcare professional. The questionnaire items neither before or after can really pick that up and convey it.’*

> *‘I really do enjoy this stage of research. Of course, I’m always nervous, but I love how you can get so much out of an interview.’*

However, whilst I have an insider experience, I also recognise that I am an outsider as I do not have NF1. Furthermore, I may be perceived as an outsider by the participants as an academic researcher. I pondered this realisation after interviewing Saffie. From speaking to my sponsor at the Childhood Tumour Trust, it became apparent that some were 'too scared to be interviewed'. This upset me as I reflected on my position as a researcher creating barriers:

> *'Vanessa let me know that some are too scared to be interviewed. They have anxiety, and being interviewed would be too much. I talk so much about power, empowerment, and power dimensions in my research. I have experience of being the patient. I've been both empowered and overpowered by healthcare professionals. My heart sank, and my stomach churned. They may be thinking I am a cold monster, one of those 'others'. Oh no, no, no. That's not what I wanted. That's not what I want. Academia does a lot of talking about inclusivity. Ethics talks a lot about inclusivity. Many of my participants have learning difficulties. They experience anxiety. They've had bad experiences with healthcare professionals that do not listen, that fob them off. Are they seeing me as just a PhD researcher in psychology, as another person that will not listen? I will listen. I am listening.'*

There is also a contrast within my position of privilege in certain circumstances pertaining to accessing health. This realisation is made after Rose's interview, where I can promptly access appointments as a private oncology patient, despite COVID-19 backlogs:

> *'Now it's back to ringing my consultant's secretary for my review scans, having a light and friendly chat and having an appointment in the post for the next month. No, this is not reality. This is privilege. This is my privilege of being a private patient, of having private health insurance. My participant today does not have this and is not in 'the system' under a team of oncology specialists. You have to be in the right 'system'.'*

I also realise my privilege of being a person that 'put up' with sickness and discomfort for a relatively short time. Many individuals with NF1, like Lilly, experience chronic pain and discomfort:

> *'I was often quite unwell after chemo sessions, often found on a couch with my head slanted to the side as I developed a strange side effect of vertigo. However, it was only a*

short journey home for me where I was able to be on the couch, wig off, and duvet on…again, I recognise how lucky I was. I am. Lilly does not have that luxury with where she lives, and this is despite the pain and depression she experiences due to her scoliosis she has because of having NF1.'

While Rowland and Kuper (2018) highlight that a dual positionality often creates a unique standpoint that potentially allows for the advancements into unexplored perceptions, it becomes apparent that I struggle with this as a researcher. I often feel that my path to research was 'accidental'. It was both curiosity and motivation to want to help raise BCA that led me to where I am. However, as I did not enter the PhD with the goal of entering academia, there is a personal doubt in my abilities. It is evident from my logs that I experience imposter syndrome, unable to internalise my own academic success, and feeling like a 'fraud' (Langford and Clance, 1993) where I turn myself 'inside out'. I therefore approach research in a tentative manner as demonstrated during Lilly's reflexive log:

'I feel much calmer knowing I have my checklist and consent script. I wonder are researchers with lots of experience just able to rock in and not be awkward and just go for it?'

Imposter syndrome exasperates the exhaustion of undertaking a PhD with a plethora of other demands, with it not uncommon to experience a deterioration in mental health (Sverdlik et al., 2020). A negative effect on mental health can also be associated with doubts in worth and competence, consequently instilling maladaptive levels of stress (Wyatt and Oswalt, 2013). While coping strategies have aided in moving me forward from breast cancer treatment by undertaking this PhD, it becomes difficult to engage in coping strategies to help alleviate the PhD stress due to its various demands (Sverdlik et al., 2020). My exhaustion is evident after Bernie's and Christina's interviews; however, my research motivation persists, with it more about raising awareness rather than attaining a PhD:

'I do find this research emotionally hard at times, it can be quite draining, and to be quite honest I'll be relieved when it's over as I put everything I have into it, but it's these

> *moments of meeting someone else with a desire to spread awareness that gives me another bit for the tank to keep pushing forward.'*

> *'I'm sure everyone that embarks on a PhD believes that their work is important, but I do think that the animation design in itself is the important bit. I'm not saying that the PhD is not important. My exhaustion, often sleepless nights, and constant thinking about it coupled with long hours working on it would also reflect that I too think my PhD is important, but for me I already feel that the most important bit has been done, in a way. I just hope that the PhD offers more credibility to it, and for me and my imposter syndrome and self-doubt, I suppose to me too.'*

Interestingly, despite undertaking a PhD exacerbating my imposter syndrome, it is also recognised as something that can help it. I recognise this pushing beyond these doubts as an action of advocacy as noted in my log after Sasha's interview:

> *'Many have sounded exasperated, and quite frankly, exhausted. There is that hope that a short little cartoon has brought some reprieve and some light into their lives, knowing that there are some out there that want better for all of them, too.'*

However, these actions are undertaken whilst maintaining academic rigour (Chapman, 2015).

Theme 3: Experience is 'the mother' of wisdom.

People have various identities, with the self-concept understood as being both flexible and multifaceted appearing at differing times. When one is considered self-relevant, it is often the one that is salient in response to situational cues (LeBoeuf et al., 2010). During the interviews, there were occasions when communicating with those that identify as a mother, either with NF1 or whose daughter has NF1, the salient identity that was perceptible from reading the accounts was that of 'mother'. This is not an uncommon phenomenon whereby there is an acknowledgement of the personal autobiography role, with feminist researchers also claiming that their own experiences of motherhood have often driven the research topic (Frost and Holt, 2014). While being a mother has not been my principal drive, the experience has aided in producing knowledge, and understanding the power of this position for raising awareness as demonstrated after Sasha's interview.

> *'This has made me reflect on my own relationship with my daughter, of wanting to help, guide, and protect her as much as I can when it comes to breast cancer awareness through my own experience with cancer. But, of how, I too, wanted the world to know that young women can get breast cancer too and wanted to share that information with everyone.'*

From my 'mother' position, this intervention is not just an educational tool, but one that establishes communication channels from mother to daughter, as I acknowledge that this is 'everything to me' after my interview with Mavis whose daughter has NF1:

> *'And just to top it all off, I thought it was really lovely, and it made me think of my own relationship with my daughter of all the chats that we have, as Mavis now from watching the animation will, 'feel more open to talk to my daughter about getting checked or talking to me if she's got any worries and hopefully having that open conversation that she can then tell me if she's got any worries as well and we can go from there then, I can help her.' This just means everything to me.'*

What is also found is a connection forged with my own mother. On reflection of Sarah's interview and her own experience of a late diagnosis of NF1 and having gone through childhood struggling with learning and describing her childhood self without the diagnosis as 'not so bright' and 'thick', it made me think of my own mother's struggles in school and how it has influenced her and subsequently me in adulthood. Andrews (2002) suggests that when a person discusses their relationships with their mother, they are conveying cultural stories whereby they are locating themselves historically, politically, and economically. The 1950s and 1960s were periods when my mother was educated. In 1967, Dublin City 11-year olds' had reading comprehension levels just over 2 years behind equivalents in England and Wales, with over 40% of the day focused on teaching Irish in excessively large class sizes at times of 45 or more (McGee, 2004).

While 1960s Ireland recognised a position for special classes in mainstream schools for those with mild general learning disabilities (McGee, 2004), my mother reports that teachers would not have the time or the ability to explain to her and instead she was often ridiculed. She left school early; however, I recognise my own mother's strengths. She learns in a different way, and other members of my family with learning difficulties have flourished when this has been respected:

> *'For the vast majority of those that I have interviewed so far, they explained how they struggled at school, with many not getting a diagnosis of NF1 until a later age, and therefore just thought as Sarah described herself as, 'not so bright', and 'thick'. That really broke my heart. Learning difficulties are prevalent on mum's side, and all my cousins have received really good support in their education. Two run their own businesses and are doing really well in their trades. Mum didn't receive the support, often shouted at, and punished by the nuns in her school, made to stand up and subjected to mockery. She left school at 15 and did very well as a hairdresser, running her own business for a while. Mum struggles with reading but she is tenacious and will stick at a book no matter how long it takes. […] There is one important thing that I have learnt with mum. She is not 'stupid' as she would refer herself to be. She is in fact very smart and has a wonderful eye for detail. Mum just learns in a different way and is definitely more visual. Animations are a visual glory.'*

Recognising my identity as the daughter of a mother that learns differently, with an awareness of the prevalence of learning difficulties with NF1, it may have affected my decision-making process on the design of the animation. Simons (2021) asserts that identity salience might influence decision making, with decisions being made in a dynamic social environment alongside attitudes, resilience, and the salient identity.

The position of me being a mother also became apparent whereby there was a feeling of conflict between raising awareness to educate but acknowledging that this could also cause upset to learn of such information, particularly as a mother learning this about her daughter. I experienced a moment of discomfort when Bernie communicated that this was the first time she was learning about the increased breast cancer risk. There is a sense of guilt on my part as a mother of having potentially upset another mother, with guilt being a constant sensation in the lives of mothers (Collins, 2021; Fielding-Singh and Cooper, 2023). However, there is also a sense that it offers empowerment to act, with patient empowerment creating an active role in the decision-making process (Castro et al., 2016).

'However, as Bernie watched the animation it was the first time that she learnt that young women with NF1 have an up to five-fold increased risk of developing breast cancer at a younger age. I thought about how it was her, a mum's first time learning that her daughter has this increased risk. It made me feel a bit uncomfortable and then very quickly it flipped to a feeling of, 'well good. I'd want to know so as to better protect my daughter'. And it was clear from speaking to Bernie, and being able to see her body language and facial expressions due to our conversation taking place via Teams that she felt this way too. She wanted to know and appreciated learning about this increased risk.'

I unconsciously consider these young women like I would my own daughter as the sense of a struggle for empowerment makes me reflect on my own struggles as a mother with my daughter's health. The experience of being a mother therefore provides a 'wisdom', as reflected upon after Laura's interview. I am concerned not only as a researcher but as a mother who will not give up on her daughter, and consequently her participants:

''I've got much better ((laughs)) for sticking up for myself, from doctors because of this, so....' I'm not hearing much about patient-centred or person-centred care. All the research says how important it is, but what's really getting in the way here? I've spoken to some lovely doctors within my own appointments and when with my kids for theirs, who have really put me and them smack bang in the middle. They've truly listened, and they've asked what I would like, however, we've also experienced the not so lovely individuals. I think the worst was the doctor that said in front of my daughter only 9 years old at the time, 'she won't be able to do certain jobs when she's older'. Disgusting. Corinne has a visual impairment. It does not have her. […] We're not giving up. She hasn't and she won't, so why would we?'

LeBoeuf et al. (2010) posited that individuals alternate among different roles and identities with preference dependent on which identity is occurring at the moment of decision. However, I observe two identities intertwining, of researcher and mother.

8.5 Concluding remarks

Identities are central to human psychology (Walker, 2022) and how we think of ourselves socially as 'we', but also of how an individual thinks of the self as an individual entity 'me' (Walker, 2022). It becomes evident from an analysis on my own reflexive logs that several identities, both at a conscious and an unconscious level are active within this research. Recognising, and making these transparent aligns with Tebes' (2005) assertion that a reflexive researcher is one whereby the researcher makes visible any influential contextual factors.

Three of my identities are found, with the first tied to my personal experience of breast cancer making it a motivation to raise BCA, the second of a dichotomous identity that exists at times in conflict of a researcher with an insider 'experience' of having had breast cancer, but one that exists as an outsider by researcher position, personal privilege, and a perceived imposter to the research domain, and thirdly as a mother and a link to motherhood whereby it becomes clear how mother dynamics are powerful, positioning narratives in a wider political, historical, and economic sense (Andrews, 2002). It is within the finding of these identities through my own analysis of my reflexive accounts that I concur that researchers cannot avoid personal involvement (Finlay, 2002), with meaning co-constructed from both the participant and the researcher (Shaw, 2010).

8.6 Summary of the key points in this chapter

- The researcher cannot eschew their own involvement, therefore placing their own understanding on data interpretation. It is therefore pertinent to add transparency by examining my influences as a researcher and as a woman who went through breast cancer at a younger age on subsequent outputs.
- Reflexive logs incorporate familiarisation of data within them to increase transparency from this stage of the analysis, to recognise my influence through my positions.
- Ontological critical realist, and epistemological contextualist positions are taken recognising that there are shared realities or similarities of experiences of both PhD researchers and those that have gone through breast cancer. However, there is also *my* reality that exists independently.
- Three themes provided common patterns and highlighted varying identities. These are; *making breast cancer awareness personal, to personally make breast cancer awareness*, *turned inside out: the accidental researcher with 'experience'*, and *experience is 'the mother' of wisdom*.

- The first identity and theme is of one who has personally experienced breast cancer making it a motivation to raise BCA, the second is of a dichotomous identity that exists at times in conflict of a researcher with an insider ‘experience’ of having had breast cancer, but one that exists as an outsider by researcher position, personal privilege, and a perceived imposter to the research domain, and thirdly as a mother whereby it becomes clear how mother dynamics are powerful, positioning narratives in a wider political, historical, and economic sense.
- From the analysis, it is evident that researchers cannot avoid personal involvement, with meaning co-constructed from both the participant and the researcher.

8.7 The next stage of the research

Both quantitative and qualitative component findings are important to identity a more holistic approach when considering the novel intervention’s feasibility. The next chapter will provide exploration into development and feasibility of the animation by reflexive thematic analysis of interviews with both young women with NF1, and associates. This aids in exploring at a deeper level BCA components as set out in the Breast-CAM-NF1, to gain a better understanding of how these are understood. The interviews also allow for a greater comprehension of what facilitates BCA, but also what inhibits it. Intervention design format suitability will also be considered.

Chapter Nine

(Study 3) Exploring the feasibility of a novel breast cancer awareness intervention for young women with NF1 and their associates by reflexive thematic analysis

9.1 Introduction

Gaining knowledge of not only levels of BCA but also individuals' understanding and perception of these is important for a comprehensive understanding of what it means to be breast cancer aware within an NF1 context. This allows for further exploration into pertinent aspects that may be beneficial for recommendations within various areas and disciplines such as at individual levels of both the patient and the Health Professional (HP), clinics, and at policy making level. As previously discussed, the design and delivery of the intervention are important aspects that can affect how the subject matter is comprehended and valued. Therefore, interviews also provide an opportunity to gain a greater insight into how participants received the intervention within an animated format, and the influence of this (if any) on learning and BCA perception.

This chapter aims to provide further insight into the research question, by exploring intervention feasibility, including the developed animated format through reflexive thematic analysis (RTA) of interviews conducted with 19 participants of 11 young women with NF1 and 8 associates (interview length ranging from 13 to 38 minutes) via Microsoft Teams and telephone to ascertain a greater understanding of NF1 BCA, and the feasibility of an animated method. As interviews aim to provide a richness of depth and detail to provide insight to phenomena that may carry highly sensitive subject material, it is vital to preserve anonymity or pseudonymity of participants (Tsai et al., 2017). Within qualitative research, it is important to not include information that may lead to participants being identified (Tilley and Woodthorpe, 2011). Recognising that power imbalances may exist between researchers and study participants, including naming participants (Wang et al., 2024), participants chose their own pseudonym. Choice of names are personal and reflect culture and identity (Lahman et al., 2023) and may reflect personal qualities and characteristics (Itzik et al., 2023). Recognising that participants were recruited from small NF charities, where it may increase the likelihood of being identified with additional information, demographic information like what was supplied within Chapter Seven's quantitative study will not be shared. Such additional information may contribute to disclosing participant identity. However, similar demographics may be inferred as the 19 participants that were interviewed were among the 24 participants that fully completed the questionnaire. Instead, Table 31 provides details of interview participants' pseudonyms and details of participant category, and interview method.

Table 31

Details of Interview Participants

Pseudonym[a]	Participant category[b]	Interview method
Alice	A	Microsoft Teams
Amy	A	Microsoft Teams
Anne	YWNF1	Telephone
Anya	YWNF1	Telephone
Bernie	A	Microsoft Teams
Brenda	A	Telephone
Bruno	A	Telephone
Christina	A	Telephone
Jessica	YWNF1	Microsoft Teams
Laura	YWNF1	Telephone
Lilly	YWNF1	Telephone
Lucy	YWNF1	Telephone
Mavis	A	Microsoft Teams
Rose	YWNF1	Telephone
Saffie	YWNF1	Microsoft Teams
Sarah	YWNF1	Microsoft Teams
Sasha	A	Telephone
Teagan	YWNF1	Telephone
Willow	YWNF1	Microsoft Teams

[a] *Alphabetical order*

[b] *A = Associate, YWNF1 = Young woman with NF1)*

9.2 Application of reflexive thematic analysis

Here follows, the application of RTA's six phases of: dataset familiarisation, data coding, initial theme generation, theme development and review, theme refining, defining and naming, and writing up.

Initially, I spent time becoming familiar with the data from each interview and the text box questions with participants' own reflexivity of the research from the Breast-CAM-NF1. These were initially analysed separately and then together. Firstly, I listened to interviews and then again whilst transcribing these orthographically, whereby transcription was done verbatim utilising typical spelling practices of the English language whilst recognising features such as pauses from both me as the interviewer, and interviewees. Whilst there is not a definite notation system for orthographic transcription, I followed the guidance provided by Braun and Clarke (2013), for example by typing ((pause)) to indicate a significant pause/silence. For further clarity, Appendix Z provides the notation key that I employed within transcriptions. This process of familiarisation endured through the reflexive logs that I kept after each interview. Immediately after each interview, I noted my own initial observations, and thoughts as any researcher would, however, I also noted points that brought up emotions, and memories of my own inward personal experiences that reflected on the outward research aim to enhance the truer sense of reflexivity. After transcribing each interview, I would then return to these notes and fully write these up with the participant excerpts that triggered these, particularly within my own personal experiences and positions as both researcher and a person who has undergone treatment for breast cancer as a young woman. This initiation of a process that jointly familiarised myself with the data whilst simultaneously engaging in a reflexive practice, greatly helped to not only familiarise myself with the data, but to also highlight my own position, privileges, sharedness, and differences that may influence the analytic process throughout the six phases of RTA. An example of dual familiarisation and reflexivity logging is demonstrated in Appendix AA.

Reading and re-reading through each transcript and Breast-CAM-NF1 participant reflexive section comments, I began to highlight pertinent information that was relevant to the research question. At the beginning of this process, many of the observations of meaning were quite semantic, where I could immediately recognise the more explicit surface meaning from responses. However, within the iterative process of RTA, refamiliarizing myself with the transcripts several times also allowed for a latent focus on meaning, allowing for the analysis to go deeper and explore meaning at an implicit level (Braun and Clarke, 2022).

Within phase two of analysis within RTA, I began to generate short descriptive labels from the familiarisation process, which became initial codes that instigated the observation of commonalities and a sharedness (Braun et al., 2022). Orientation to data was both inductive and deductive. This was because interview questions were based on the Breast-CAM-NF1 and mapped onto the theoretical construct of self-determination theory (Deci and Ryan, 1985) with answers aligning with these. Initially therefore, the orientation to data was more deductive, however, I also approached data in an inductive manner where coding and theme development were driven by other data content from participants' discussions that were based off feed-on questions from interesting observations worth developing further within the semi-structured interview process. This process of data coding is organic, and within RTA there is no requirement or recommendation to employ a coding framework (Braun and Clarke, 2022). Recognising that RTA is an iterative process, the decision of coding was changed several times during data re-familiarisations. This is to be expected and encouraged to avoid what Braun and Clarke describe as a 'quick and dirty' analysis which can result in analytic foreclosure that delivers only superficial meaning, and themes that do not fully realise the potential of data (Braun and Clarke, 2022). Examples of codes are 'disconnected system', 'power play barriers', 'healthcare professionals – lack of knowledge'. However, Appendices AB and AC demonstrate the lengthy iterative process that was taken within coding for both interview transcripts and from the Breast-CAM-NF1's participant reflexive section, with it evident the number of evolutions that occurred from numerous and immersive readings.

The codes from all transcripts were placed altogether in one document to allow a better view to see if there were shared messages across datasets. I deemed this as the best approach, with Braun and Clarke (2022) making it clear that RTA while offering guidelines, does not subscribe to rules, allowing me an element of freedom within an already helpfully clear process. From the initial document with all codes across datasets, I began grouping them into areas of shared meanings to begin the process of creating candidate themes. This is very much an active process, and I recognise my position in this action of interpreting these code relationships in forming themes (Byrne, 2021). However, despite my influence within this part, I ensured that the focus remained on the research question (Braun and Clarke, 2013). Again, highlighting the iterative process of analysis, these candidate themes were shaped and transformed several times. Despite some of these being what I considered as interesting, there were times that I had to as Braun and Clarke (2013) describe as, 'let go' of those that were not adequate to address the research question and aim (Braun and Clarke, 2013).

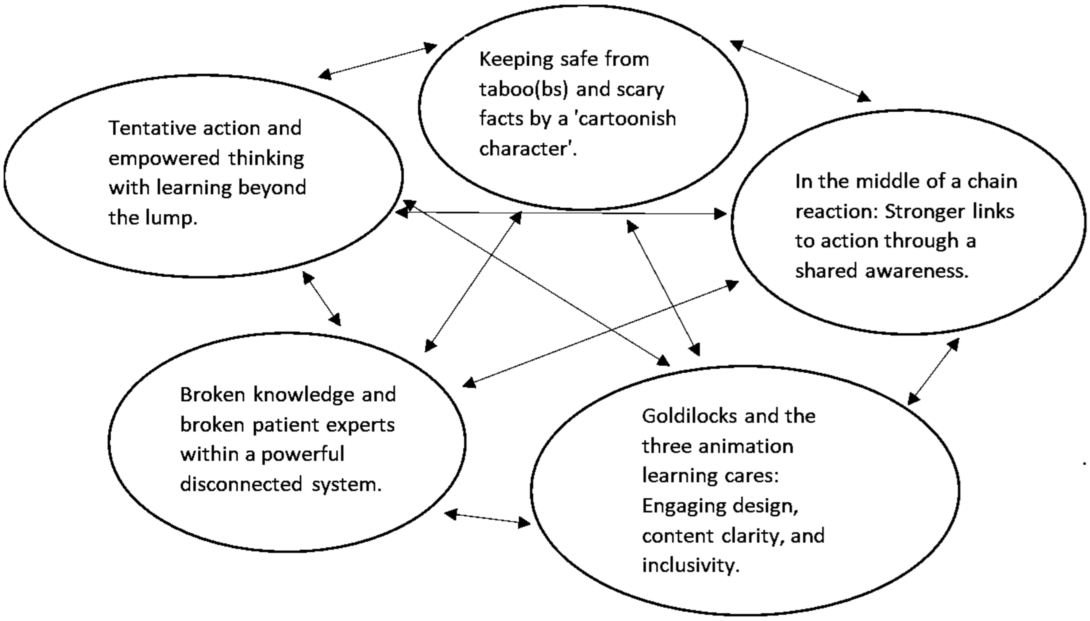
The iterative process of reviewing these potential themes continued, recognising that some of these overlapped within meaning. Therefore, some were incorporated into other themes as outlined in Appendix AD. The process of naming themes is an important one, and every effort has been undertaken to lucidly capture and communicate meaning (Braun and Clarke, 2013). Within the writing up, data extracts were used in an illustrative manner, whereby the analytic narrative provided a description and interpretation of the theme (Braun and Clarke, 2013). It is important to note that 'cleaning up' has been performed on data extracts, whereby repeated words, or the excessive use of the informal 'like', and sentence fillers of 'em' have been deleted (Braun and Clarke, 2013).

9.3 Analysis and discussion

Five themes were identified as best conveying an exploration of the intervention feasibility of a novel NF1 breast cancer awareness animation for young women with NF1 and their associates as demonstrated in Figure 43.

Figure 43

Final Thematic Map



Any pseudonyms with (A) denote that these are associates, with excerpts from the anonymous participant reflexive section of the post-animation Breast-CAM-NF1 being displayed as Breast-CAM-NF1, again with an (A) if these are from associates.

Theme 1: Tentative action and empowered thinking with learning beyond the lump.

The animation is communicated as positively impacting BCA components, with a sense of empowerment occurring predominantly among young women with NF1. Empowering patients is a goal of patient-centred education (Koekenbier et al., 2016) that supports health and wellbeing by encouraging informed decision making, responsibility of care, self-efficacy, and treatment commitment (Yeh et al., 2018). Within this intervention, this is a behavioural commitment to monthly breast checking, seeking medical help for breast concerns, and attending earlier breast screening. Many communicated a perceived increase in knowledge beyond the lump.

Sarah: *'I think it was like very good, cos like I said I didn't know what to look out for. All I thought, and knew was, honestly if you feel a lump-, but it's not just about the feeling the lump.'*

Teagan: '[...] *so checking like a bit more further up in the armpit and it's not just feeling there's lumps and stuff [...].'*

Among women with breast cancer, a lump is the most common presenting symptom (Koo et al., 2017). Whilst less frequent, other signs include nipple abnormalities, breast skin abnormalities, and breast pain (Koo et al., 2017), demonstrating the importance, particularly among those with an increased breast cancer risk, to have a robust awareness of other warning signs.

Despite not measured within the Breast-CAM-NF1, the five-fold increased risk of breast cancer was communicated as a main learning point.

> **Bernie (A):** '*So even from an early age I've talked to my daughter about the importance of, you know, checking your breasts every month […] but I didn't realise that there was an increased risk with NF1.'*

> **Brenda (A):** *'I didn't realise that there was such a huge link, that there was such an increased risk for people with NF1, that there was that connection.'*

Lack of knowledge may contribute to this perceived small or no risk (Rutherford et al., 2018). However, understanding risk is important for medical decisions including screening attendance (Joy et al., 2005).

A significant result within the Breast-CAM-NF1 was found for breast screening knowledge acquisition, with this subsequently conveyed within interviews. Earlier screening eligibility is generally accepted among younger women (< 50 years) (Meiser et al., 2000). However, participants conveyed differing opinions towards screening from 40 years. For some, it was positively received and provided reassurance.

> **Jessica:** *'It was helpful to learn I think in the animation it said you start getting checked at 40 instead of older and that was quite nice to know because I knew that you would be checked a bit younger, but I wasn't sure of the specific dates.'*

Others voiced concerns with this information, particularly among associates.

> **Bruno (A):** '*I wasn't aware of this, so I just assumed that they would have screenings on a regular basis anyway given the condition. So, when I heard about this, I was a little bit confused with it. […] So that shocked me that it was as late as 40 even with people with NF1. But that's a little bit too late, in my opinion.'*

Despite the non-significant result pertaining to differences in knowledge of monthly breast checking frequency, interviews revealed cognitive processes of new behaviours or tentative planning to implement the animation guidance of setting a reminder whereby cues within the environment can help achieve a monthly breast checking goal, establishing attitude and perceived behavioural control as per the theory of planned behaviour (Ajzen, 1991).

> **Sarah:** *'Well, I said to myself, payday, that's my reminder ((laughs)) [...] Because it's like the end of the month I get paid so then it's like bills, it's when you sort everything out. So, it's a bit like, I'll sort that out at the time, as well. That was my thinking.'*

> **Breast-CAM-NF1 (A):** '*I personally do not check my breasts as much as I should. This animation has made me think to look at them once a month either by having the same date e.g., 1st of the month or setting a reminder on the phone which was an idea I picked up from the animation.'*

> **Bernie (A):** '*I mean my daughter for example, she loves routine so she likes doing things at set times, so for her that would be perfect. It's like, choose a day of the month and do it, so I think, yeah, it's really good, and you know if you've got, you know, cos I've got everything in my calendar ((laughs)) to remind me to do things, put it in your calendar and it will pop up and remind you to do it, so I think it is a good idea to have that regular slot for that.'*

This demonstrates an ability to form a habit from watching an animation associated with a cue (Neal et al., 2012), with routine involving an action that is habitually followed (Lally et al., 2010; Arlinghaus and Johnston, 2019). However, these participant reports may indicate social desirability bias, where an over report of more desirable attributes (Edwards, 1959), in this case reporting a change to the recommended monthly checking may have occurred.

The animation also provides an opportunity to change previous harmful behaviours such as checking breasts too frequently. Too frequent checking may increase anxiety levels which may contribute to missing warning signs (Moore, 1999). Habits, including creating new ones and breaking old ones, are closely related to self-control processes which is a component of self-regulation (Duckworth et al., 2019).

> **Laura:** *'I feel a little bit more versed now that I've seen that they recommend that they do it once a month instead of, you know, continuously checking. That's made me feel a lot more calmer in that aspect.'*

Laura had developed a habit of checking every time she showered due to family members advising her to do this, however, the information provided by the animation disrupts old habits and creates an opportunity for new habits to be formed as per the habit discontinuity hypothesis (Fiorella, 2020). Other factors may also have aided in this behaviour change such as providing a stable context cue of a set mobile phone monthly reminder therefore increasing saliency (Booker and Mullan, 2013; Wood and Neal, 2016). Laura feeling calmer is a positive outcome, with self-examination not beneficial when performed in an emotionally aroused state (Soriano et al., 2019).

For many young women with NF1 there is a sense of feeling empowered to act, now that they have BCA information.

> **Lily:** '*So, if I find a lump or anything, I can go to my GP and say, 'quick, I need to get seen.'*

> **Rose:** *'[...] the video has definitely made me realise that I can go, and I can't be pushed away as I have been before.'*

> **Anne:** '*[...] I think I would be more confident in going. You'd say, 'look I've noticed this, it's new'. I mean that even if it's a case of, 'oh right well let's keep an eye on it', but at least I've made that initial contact and got that reassurance.'*

These responses demonstrate a shift in power dynamics from the traditionally authoritative-HP/passive-patient interaction (Odero et al., 2020) to one where the patient takes a pivotal role in decision making (Grover et al., 2022). Healthcare empowerment is multidimensional involving power (Kuokkanen and Leino-Kilpi, 2000), knowledge (Pekonen et al., 2020), patients' behaviours, and shared decision-making (Aujoulat and d'Hoore, 2007). There is an awareness of a positive impact on behaviours such as prompt help seeking, and a desire to be within the decision-making process of one's own health. This is also communicated among associates, particularly mothers.

Bernie (A): *'I think what it's reinforced in my mind, it's absolutely critical, as soon as possible because there is that increased risk.'*

Mavis (A): *'It's encouraging people to go to the doctor to share, and reassuring that it's not-, no one's gonna laugh at you. You're gonna go and you're gonna be checked and it's gonna be fine, it's great and if not, then the next steps will be taken.'*

While the intervention objective focused on raising awareness specifically about NF1, associates also experienced a ripple effect of developing personal breast health awareness.

Brenda (A): *I suppose to encourage women to check themselves as well regularly, which I don't do to be honest, which I should do.'*

Bernie (A): *'I've just turned another age milestone and I was wondering, 'oh, when will I start going for, you know, breast screening as well?' so it was, 'oh let's go on the NHS and have a look' and look at it in general about what age, you know, you start getting screening, and how often that happens.'*
Alice (A): *'It also made me aware that I know that I should check my breasts, I don't regularly check them. And the thing when it told you for me, like make a date like the first of every month, I thought that was very important so the first of every month, you know to do-, to check your breasts or just look at them, or just be more aware of them.'*

Despite positive communications, some women continue to experience confusion between a potential cancerous growth and benign manifestations such as a neurofibroma or a hormonal influence. However, this confusion is also often communicated among the general population of women despite BCA campaigns, leading many to present for tests for a benign outcome resultant of cysts, or breastfeeding, for example (Ramirez et al., 1999; O'Mahony et al., 2013; Khakbazan et al., 2014). However, with NF1 there is also the additional confusion of breast area neurofibromas.

Lucy: *'Obviously like, yeah, with the natural cycle your breasts can change. It's just knowing if it's because of that or something else.'*

Rose: *'I've got a lot of fibromas on my breast area, I would never say that I was comfortable in noticing the changes because, to me I don't know how I would know a change from a fibroma to potentially a cancerous lump.'*

Future publications would benefit from acknowledging that fibromas may grow around the breast area, but the message to seek medical help if unhappy with any changes persists.

Designing interventions within a patient-centred framework allows the patients' voice to aid in building knowledge and content (Stark et al., 2014). Patients who receive tailored information instead of a standard education are more knowledgeable (Tervo-Heikkinen et al., 2008). Specific NF1 concerns demonstrate that a "one size fits all" approach is not appropriate (Rutherford et al., 2018).

Theme 2: Broken knowledge and broken patient experts within a powerful disconnected system.

HPs often lack a knowledge of rare diseases making it more difficult for them to support their patients' requirements (McMullan et al., 2020). A lack of knowledge, and difficulties in accessing evidence-based information often results in difficulties with diagnosing patients and condition management (Crowe et al., 2019). This is pertinent to this research as this may also affect BCA levels among young women with NF1 and associates.

Sarah: *'And I went to my doctors, and I said, 'look, I think I've got this [NF1]'. And they're like, 'why?'. And I sort of told them, and they was a bit lost and said they didn't know what to do with me, and if I didn't have any problems, it's not a problem. So, I was like, 'well that's not right, really.'*

Even with a diagnosis, patients are often left to try and understand their condition and its implications.

Anya: '*With my diagnosis we never got recommended or diverted to any self-help or support groups, so we weren't able to obtain that knowledge immediately, so I think having access to resources and information directly from the healthcare professional, even if that's directly after diagnosis it would help that individual be aware*.'

Post-diagnosis information is recommended for rare disease patients and to increase cohesion between the various specialities for an improved multidisciplinary approach (Crowe et al., 2019). Correspondingly, having clear signposting to NF1 BCA information would aid patients, associates, and HPs. Rare disease research can be difficult to find, with much of it often located internationally within separate institutions and stored in varying formats (Crowe et al., 2019). It is not feasible to be knowledgeable of all rare disease types. HPs, specifically general practitioners, rely on online sources such as Orphanet and Google (Elliott and Zuryski, 2015; Svenstrup et al., 2015), at times in their patients' presence. While this is arguably better than dismissing a patient or making false assumptions, it can often be perceived as unprofessional or uncaring.

> **Laura:** *'But then comes the issue of them having not a 'scooby do' about what the condition is. There was one time when I was younger, and my mum took me and we walked into the room and he had the information page up on the screen, which we both thought was quite unprofessional.'*

Within these encounters with HPs that lack knowledge, NF1 patients and associates provide information about the condition (Plackowski et al., 2023), often becoming experts about their condition (McMullan et al., 2022).

> **Laura:** '*I tend to just give them a quick run-down of what it is and what normally is done. So, for example, today I'm going for headaches that I've had recently, but that combined with some other symptoms I've had like dizziness, and such, warrants an MRI. And if they sort of say, 'well, no you don't need one', I would just kind of say to them, you know, I already have the tumours, there could be one on the brain, it could be something else. It could be this. It could be that.'*

Despite being experts within the patient-professional relationship, this does not always translate as being listened to (Crowe et al., 2019), with it being found that caregivers also experience silencing or being silenced within their interactions with HPs (Currie and Szabo, 2019). Paternalistic values, and a lack of patient-centred care and shared decision making endure, with these translated as uncaring, not being listened to, or being afforded the time to discuss concerns, or be given adequate information (Ocloo et al., 2020). This often negatively affects collaboration and communication (McMullan et al., 2022), with patients and associates subsequently experiencing psychological stress, tiredness, loneliness, unemployment, discouragement, difficulty accessing appropriate health care, and lack of information (Elliott and Zuryski, 2015). These occurrences also create significant barriers for young women with NF1 to access breast cancer screening services, as the power is communicated as being held by HPs.

> **Anya:** '*In regards to NF, I always feel like I have to defend myself, explain, and justify why I am concerned or why I am requesting something, and it just becomes another battle, another-, another reason why we're exhausted all the time, you know, to have to try to fight for what we are entitled to, and when it's something as serious as breast cancer, we shouldn't have to justify why we want it or why we need it. It should be available to us, without question, without an interrogation.*'

> **Lucy:** '*It's almost like they disregard it [NF1] and they just look at your age and they're like, 'nah, it can't be it [breast cancer]'.*'

Despite the power that HPs are perceived to hold, the system in which they work is conveyed as disconnected. This lack of connection also creates a barrier to accessing essential services or to attend other HPs, which again adds to the barriers of accessing breast cancer services. Research conducted by Crowe et al. (2019) found that communication between NHS services does not typically occur successfully for patients with rare diseases. Interviewees feel 'stuck' as they try to contact other required services, demonstrating a disconnected infrastructure that increases the patient burden.

> **Rose:** '*I'd say for the last 2 years I've spoken to my GP about having a breast screening because I'm always concerned because the fibromas grow, and sometimes they can be painful, sometimes they can't be. My doctors have never ever helped me with getting that done. The majority of them have said I need to contact my NF clinic in *** but they are sometimes quite hard to get hold of, so I'm still like, I'm still stuck in the same position I was in before.*'

> **Saffie:** '*I'm still not under anyone clinically, I'm you know, no one, I'm not even sure if my GP is aware that I have it (NF1). Have they been passing information?*'

> **Jessica:** ‘*When we moved house, they just completely lost me within the system and then I’ve tried to go to different GPs to be like, ‘hey can you re-refer me?’ and they’ve not re-referred me, so I’ve not really had any support since I was about 12 which is not ideal obviously, given I’ve gone through puberty since then.’*

Improved communication between GPs and other HPs would better aid the management of BCA care for NF1 patients (McMullan et al.,2020).

A lack of trust is conveyed that the HP that they will attend will provide an acceptable level of service and will instil confidence and a sense of support. Trust is essential in any therapeutic relationship, expressed as the patient’s expectation that their best interest will be consciously considered and maintained (Hall et al., 2002). A patient centred communication necessitates an understanding that is mutual between both the patient and the HP, and regards the patients’ perspectives, values, and health needs, with a sharing of responsibility and power (Asan et al., 2021). Patients are provided space to convey their own day-to-day experiences of living with the condition for a deeper understanding, and a more sympathetic communication (Jeppesen et al., 2015). This aids in (re)building trust and create a benchmark to discern any changes within future appointments, including any breast changes that may warrant further investigation. However, there is a concern that not all HPs will adopt this approach.

> **Laura:** *‘But obviously the basic training would be, what it is, how it affects someone, and meeting with that patient, having a meeting, like an appointment with the patient, being like, ‘how does this affect you?’, ‘what’s normal for you?’, so that they know that if I go in with something that is different, they know the next step [...] And I’m sure there are some doctor’s surgeries out there that do that, but mine don’t ((laughs)).’*

This powerful yet disconnected system is under immense strain (Cooksley et al., 2023), progressively harming its patients (Jones et al., 2022). Patients often do not want to contribute to the strain by taking up more time than required.

> **Rose:** ‘*I work for the NHS, and I understand the strain that the NHS is under...and I think sometimes, it makes me a bit scared to call and say, ‘this is what I know. This is what I want done’.’*

> **Bruno (A):** *'Because the condition isn't regular known about [...] a lot of doctors aren't familiar with the idea, it can be a bit (.) scary in the sense of, 'are they going to take me seriously?' kind of thing and then they might get in their own head, and think, 'oh I don't want to waste people's time'.'*

> **Amy (A):** *'[…] or in the sort of climate that we're in now, not wanting to take up sort of healthcare professionals time.'*

Therefore, this disconnected system itself, also creates another barrier to seeking help for a breast concern or accessing services. Both staff morale and patient satisfaction is low, with little expectation of improvement in the short term (Cooksley et al., 2023). This is not an isolated experience within the UK. Ireland also experiences such grievances, with the Irish health system experiencing challenges such as staff shortages and prolonged financial austerity (Fleming et al., 2022).

Theme 3: In the middle of a chain reaction: Stronger links to action through a shared awareness.

It becomes apparent that rare disease learning, including NF1 BCA, requires a shared awareness with rare disease communication involving individuals with a rare disease, family, carers, HPs, and the voluntary sector (McMullan et al., 2020). However, there are difficulties with finding accessible and accurate information (Marquez and Ladd, 2019), and speaking with someone who understands the condition to provide appropriate information and assistance (Spring, 2014). Awareness sharing is a common action within the rare disease community, a link in a chain, whereby those that are affected by the same condition (and in this case also supporting those affected) empower one another to become advocates (Zhu et al., 2017). Without a shared awareness the chain becomes broken, with several parties required for knowledge acquisition to occur (Spring, 2014).

> **Sasha (A):** *'I think it's 'knowledge is power' as they say. It's being able to have that knowledge available to you so either through your healthcare professionals or through researching yourself. I think it's really important that people that have NF1 take some responsibility to actually research things themselves, and you know, be connected to the charities that are available because I think their help and their knowledge is invaluable.'*

Charities, particularly those that support individuals with NF1, reduce the burden of searching for accurate information and support by sharing awareness (McMullan et al., 2022).

> **Sarah:** *'I was like, 'where do I go? What do I do?'. I was e-mailing. I was getting nowhere so I went back to the Nerve Tumours people […] And then she told me about the breast screening, and what I should go looking for […] but if it wasn't for the Nerve Tumour Trust, I probably wouldn't be here now, talking to you, cos I'd still be thinking, 'yeah, we're alright'.'*

HPs that provide NF1 specific information or have demonstrated a curiosity to research the condition for the provision of appropriate levels of care, also contribute to building stronger chains for awareness of the condition, earlier screening eligibility, and associated risks. An increase in knowledge allows for this to be shared with patients, with HPs an important and trusted information source (Asan et al., 2021). Informed patients are empowered patients whereby knowledge is essential for active participation in the care and management of their condition (Higgins et al., 2017).

> **Willow:** *'Yeah, so I went to the GUM clinic to speak to the doctors or nurses, whoever it was about changing from the pill to some other form of contraception that might be slightly more reliable to somebody who forgets to take that pill every single day, and they were probably just asking general questions, medical history blah de blah and I said about NF1 and I think she probably went away and googled it because nobody's ever heard of it, and came back and said, 'oh I've just had a little look and there's an increased risk of breast cancer so I wouldn't suggest that you continued with the pill anyway because the pill obviously carries the increased risk of breast cancer'. And I was like, 'Oh! Okay! Well, it's a good thing I've come in, you know, the past how many years I've been on the pill for. No one's bothered to mention that to me'.'*

Participants demonstrate building of NF1 BCA links from watching the animation, including empowering their daughters with knowledge to reduce future barriers.

Sarah: *'I'm a little bit proud of myself that I can do that now because before I wouldn't have been able to, and I think it's more for when my daughter grows up as now as well that she doesn't have the same walls that I've had.'*

Lilly: *'I now have this for her, you know, she's only young. I want her to know what to look out for.'*

Mavis (A): '*It's helped me feel more confident in speaking to my daughter about checking and also knowing what we should be looking for.'*

For others, the motive involves sharing awareness among other women with NF1, so that they may have a better prognosis.

Teagan: *'I feel it's good because I want people to be more aware of it [...] It's a bit like other things, you think, 'oh I don't have to worry until this issue, to this age'. If people are aware they can catch things earlier and stop having-, to have any like treatments in the future, or worse, like people could pass away.'*

There is also a recognition that taking part in this research increases awareness which provides increased confidence when speaking to HPs, and that the animation can be shared to increase this cohort's knowledge to build stronger awareness links. This stems from increased knowledge that empowers patients to shift power dynamics (Hickmann et al., 2022).

Laura: *There's not enough specialists out there, so you know, some doctors be like, 'oh no, you're not eligible for this screening', then you can go, 'look this is, you know a proven fact', and show them the animation, and they can be like, 'oh okay'.'*

Creating a theoretically based animation is not enough, with it being highlighted that there is a necessity to have the information available from various sources such as GPs, schools, general BCA charities, and websites. Again, this demonstrates the importance of a shared awareness for learning. Individuals and families affected by a rare disease can greatly benefit from peer support and information provided by charities such as the Childhood Tumour Trust, however these are often equally rare in number, with some not having any access to dedicated support groups (Lasker et al., 2005), and therefore awareness opportunities. A wider availability may help with increasing a shared awareness among more individuals.

> **Jessica:** *'If you were promoting for example, breast cancer awareness in schools, to make sure it was mentioned that certain health conditions including NF1 could make you more vulnerable. Like say a breast cancer charity for example is giving a presentation, you could maybe encourage them to say, 'well if you have NF1 or other conditions, you'd be more vulnerable', and 'to make sure that you, kind of learn more, check yourself more like, get checked out if you need to'. Because I think most of the awareness we were given in school, for example, was very generalised, whereas actually having one slide on, sort of concurrent conditions could make all the difference for a lot of people.'*

> **Brenda (A):** *'I mean it would be nice if it was added into-, in your doctor's surgery when you have your leaflets about breast cancer.'*

A keenness to share the animation is expressed, demonstrating an understanding of the importance of sharing awareness to learn awareness. Sharing online can provide a quick and easy way of transmitting to many, with the Internet increasingly used as a source of both rare disease support and information (McMullan et al., 2020). However, there is often a question of credibility and reliability with online sources (Crowe et al., 2019). Increasing accessibility to a reliable source such as the animation also allows for information to be experienced several times to aid in memory consolidation (Zhan et al., 2018).

> **Alice (A):** *'I'm sure by looking at it that it will encourage lots of people and keep reminding them. And again, it's something that if you can keep watching it, not just once, if you got access to it, sort of quite regularly, it becomes something that you get in your mind. If you see it more than once, I think, so you get it into your mind more exactly what the avatar or whatever it is, is showing you, you know?'*

Increasing NF1 BCA also aids in building stronger chains among individuals that do not have NF1 to consider issues from the perspective of a young woman with NF1, and how they can better support them. This is related to empathy of considering another person's perspective (Dickert and Kass, 2009).

> **Amy (A):** *'Definitely it made me think about my cousin more. We've, you know, known about the NF1 for a long time. I think it's easy to (.) not take it for granted because that sounds weird but, it's easy to be normalised and then you think about, you know, watching something like this, you think, 'oh that's another thing that she's got to deal with' […] it made me reflect on the fact that I don't have-, having not, not having NF1.'*

> **Christina (A):** '*I don't always understand what my niece is going through and if I can support the awareness getting through or shift screening where it's more accessible, then I am pleased to help.'*

Participants communicating previous knowledge of NF1 BCA before watching the animation conveyed that this was obtained in recent years through the Childhood Tumour Trust. I provided much of this information through previous research conducted during my health psychology MSc and PhD, often during Breast Cancer Awareness Month.

> **Anya:** *'I did have the knowledge prior to watching that animation, but the animation was very helpful because typically I wouldn't have had the knowledge if it wasn't for like the charities, the Childhood Tumour Trust, who are always raising awareness anyway.'*

> **Sasha (A):** *'Through the Childhood Tumour Trust charity because I'm a part of that. It's been on their forums, on their websites.'*

> **Saffie:** *'The Childhood Tumour Trust, they've been quite good. There's lots of information with them.'*

It is evident how significant the power of research and providing accurate and accessible information can contribute to the chain of knowledge acquisition through sharing awareness.

Theme 4: Goldilocks and the three animation learning cares: Engaging design, content clarity, and inclusivity.

The animation was received positively by all participants, with no difficulties reported with accessing the online intervention. The rapid development of information technologies and near-universal internet access have changed how educational and informational resources are accessed (Knapp et al., 2022), with web-based information about health and disease prevention now widely available (Meppelink et al., 2015). Animators have also begun to explore ways in which filmmaking and animation may aid in representing social worlds of those affected by rare genetic disorders (Gorman et al., 2022). Pertaining to the animation itself, three key areas that were conveyed recurrently during interviews were engaging design, content clarity, and its inclusivity. Animations are effective in describing complex information by the application of visual and textual approaches (Occa and Morgan, 2019), and therefore diverge from videos by their application of artificial images, with videos employing real objects and persons (Feeley et al., 2023). Messages based on both auditory and visual information positively influence individuals' attitudes toward a message (Meppelink et al., 2015), with the theory of planned behaviour (Ajzen, 1991) explicitly demonstrating that attitudes toward the behaviour affect behavioural intention.

> **Lucy:** *'Having the video does help because, just having like a webpage of information, 'oh, this is like a lot to read and a lot to digest'. It's an easier form to understand the information. And when it's animated, you can like (.) depict things a lot easier, I think than just like having, you know, actual humans. If that makes sense?'*

To increase learning, animations complement either text/words or narration, therefore viewers obtain information in two reinforcing ways (Feeley et al., 2023). This is based on the cognitive theory of multimedia learning (CTML; Mayer, 2008) as discussed in Chapter Five, whereby successful learning can occur when individuals are able to mentally construct information. Attention may also be enhanced when the two channels of audio and visual are activated, rather than solely one, as asserted within dual channel theory within animations (Knapp et al., 2022). These considerations are also important, with communication of health-related information established in improving health literacy and intentions to change health-related behaviours (Calderòn et al., 2014; Meppelink et al., 2015). To reduce health disparities, health information should be designed to be understood by those with low health literacy, but also to not be rejected by people with higher levels of health literacy (Meppelink et al., 2015). The animation has been designed to be quite simplistic in that there are no extraneous details that would otherwise distract from required learning (Homer et al., 2008). Striking the balance is therefore important to ensure that the animation is informative for all, but not communicated in a condescending manner because of its simplistic approach.

> **Breast-CAM-NF1 (A):** *'It was a brilliant video - really easy to watch, really informative and not at all patronising.'*

Health literacy is related to functional literacy (Sørensen et al., 2019), with individuals with low health literacy levels often having additional reading problems or learning difficulties. Therefore, spoken information is effective for audiences with low levels as no reading is required (Mazor et al., 2010).

> **Jessica***: 'So, I think especially if someone had like learning difficulties, for example, being able to see the graphics alone would probably be quite helpful as well.'*

Those with low levels of health literacy often lack the health-related background information to comprehend what is being conveyed (Chin et al., 2011), and are therefore at increased risk of cognitive overload when being provided with health-related information (Wilson and Wolf, 2009). The active reduction of cognitive load by employing a simple and brief animation aids in reducing a sense of being overwhelmed.

> **Teagan:** *'It was really clear. It wasn't too much information, or too long. It was a good amount of time because sometimes if you have information videos that are too long, I think you can forget what they've said, or it just gets a bit overwhelming.'*

The animation length is perceived by the participants as just the right amount to be able to concentrate on what is being communicated, or merely as an acceptable length. This is comparable to the Goldilocks principle whereby details, actions and reactions are within preferred limits, rather than extremes (Balas-Tamar and Lile, 2015). This is particularly evident among infants' cognitive development, where there is a clear preference demonstrated for information that is neither too simple nor too complicated (Kidd et al., 2012). Guided by CTML principles, the viewer should not have their cognitive capacity complicated by jargon or watch something exceeding 5-6 minutes in duration (Feeley et al., 2023).

> **Jessica:** *'It wasn't too long, it wasn't too short. I think the information was very clear, the fact that it used both verbal written information, and graphics. I think it did a lot to kind of get someone's attention.'*

> **Anya:** '*I think it's a very informative animation and it's very simple, easily understood and it's straight to the fact. It's a very short brief video that is also very good so it's gonna engage with that, you know, that person watching for the whole time hopefully.'*

The animation strives to be inclusive in its demographic diversity, demonstrating that NF1 can affect anyone employing various ethnicities, professions, and responsibilities of young women with NF1. The provision of subtitles is also included to increase accessibility, with these important in improving inclusivity for individuals who are deaf or hard of hearing, and individuals whose native language is not English (Gernsbacher, 2015).

> **Amy (A):** *'It's a very accessible video in terms of the style of animation, there are subtitles from what I can remember, so I think it is quite, you know, an accessible video in a way [...], I think the diversity of the sort of characters or the people involved, I think that was a good thing to see, so I was pleased that that was involved, and that was something that was considered.'*

Interestingly, the animation is perceived as more representative of individuals with NF1, with the application of animated breasts also creating a sense that it is representative of *all* breasts.

> **Bruno (A):** *'And just going back to what I was saying before about the animation covers all demographics really, you know, age, gender, and things like that because it's very welcoming to everyone like I was saying, if you have, like you know, reconstruction of real actors and things like that, not only could it be a bit depressing, not everyone will relate to it because you might say, you know, if it's an actor or whatever, they haven't got NF1, you can tell kind of thing but when you put animation on it, it's not really about, you know, it's a bit more like that. It's not really real life but whilst also being real-life, if that makes sense?'*

> **Alice (A):** *'I don't know how you could just really use (.) sort of other people to do it because you know, it's just filming their breasts and everyone's breasts are different anyway, but it just kept it more uniform.'*

An important point was revealed by participants, in that the animation would also be suitable for children. This is not surprising, as animated graphics have also been found to improve learning in various age groups, including young children (Takacs et al., 2015). This research only interviewed young women with NF1 and associates, therefore further research is required to garner feedback from younger individuals. However, the animation potentially becomes a pertinent tool in approaching BCA education to a younger NF1 cohort, with it being found that NF1 can be associated with precocious puberty (Kocova et al., 2015). Precocious puberty is the development of secondary sexual characteristics before the age of 8 years in girls and 9 years in boys, with the condition predominantly dominant in females (Latronico et al., 2016). Precocious puberty has been reported primarily within children with NF1 diagnosed with optic pathway gliomas, with lesions that are located close to the hypothalamus interfering with the hypothalamic-pituitary-gonadal axis that results in the early onset of puberty (Brito et al., 2023). It becomes an important consideration to educate about BCA among young girls with NF1 at an earlier stage, with an accessible and acceptable intervention such as this animation.

> **Bernie (A):** *'I mean I'm obviously a lot older than the age group that it's targeting but 'cos it's targeting towards a younger audience, I think it's quite good, you know, it's not too serious, it's a bit fun and it's, you know. I showed it to my daughter, and she said, 'oh! That's really good. I like that!''*

> **Lilly:** *'It's a really clear imagery and it's easy to understand for young people as well... (.)...because I'm also a parent with a child with NF1 so it's easier to understand.'*

As this BCA intervention was well received, it could be utilised as part of a series of videos/animations to increase knowledge about NF1 and various components that are pertinent to the condition. Visual, audio, and video aids are important within education (Friesen, 2011). Kayler et al. (2019) recommend short, targeted videos for each component of a given health topic making it possible for learning to be incremental and based upon a patient's or their family's learning needs. Therefore, a series of animations could be designed and implemented for this purpose. There is also a clear argument for the collaboration between health psychology researchers, with a strong investment in behaviour change, and the animation industry to harness the power of this format within health education (Pate et al., 2020).

Theme 5: Keeping safe from taboo(bs) and scary facts by a 'cartoonish character'.

A common insight gained was that the animation provided a protective distance from what has been interpreted as both the taboos of breasts and breast cancer information. As communicated previously within the application of terror management theory (Greenberg et al., 1986), the woman's body, and hence the breasts, often provide a reminder of a 'creatureliness' and consequently the inevitability of death (Courtney and Goldenberg, 2021). Breasts are often also associated with the external representation and sexualised form of femininity in Western society (Grabe et al., 2005) and are considered a 'defended object', that stirs emotions of anxiety, fear, shame, envy, and conflict due to both sexed and gendered investments in these as cultural figures or metaphors (Gripsrud et al., 2018). These contribute to increased anxiety and shame when viewing the breasts by the woman, or a lack of awareness or desire to become aware of threats to the breast and potentially to life (Fredrickson and Roberts, 1997; Moradi and Huang, 2008). This is also experienced by those interviewed.

> **Sarah**: *'I think for me that it sinks in better because I think if you saw, like, a real woman on the screen, like feeding or showing, or whatever, because it's a bit of a taboo subject you feel a bit, 'oh', tense as you're watching it. And it's like, I don't know, do you know like, that's a woman, that's her breasts, that's-, and it shouldn't be a taboo subject, but I think it automatically puts people off a little bit. Where if you see an animation, it's not anybody, it's no one's face. It's just like watching a programme, d'know, a children's programme [...] I think it was better in animation, than an actual person stood there. Because, then it's not so taboo.'*

This provides evidence of a socialist constructionist approach to the woman's form, whereby the body is invented, shaped, and constrained by society (Shilling, 2012). Within these views, it is these perceptions that decide on how a physical body is experienced, and views subsequently sustained and normalised. This suggests a Foucauldian approach to the body whereby the body is not only given meaning by discourse but is also formed through discourse, with the body, in this case the woman's breasts, no longer presented as a steady biological object, but instead as an unstable entity due to its socially constructed changing parts by changing views (Shilling, 2012). The idea of viewing exposed breasts, even among women themselves, may be considered as embarrassing due to conflicting principles, or a ‘paradoxical ambiguity’, whereby these specific anatomical parts are perceived within various societies and therefore within the normative thinking of their people as both objects of lust such as that exhibited within pornography, but also as objects that are incessantly exposed to moral censorship (Gripsrud et al., 2018). It is these societal perceptions that influence women’s perceptions of breasts, with women considering their body and therefore breasts to be taboo (Lau et al., 2022), which may make looking at their own breasts uncomfortable, let alone another woman’s breasts.

> **Brenda (A):** *‘[...] you might feel a bit uncomfortable actually watching a real woman maybe, I don’t know.’*

However, as conveyed by participants, being in an animated format creates a shift in mindset whereby the embarrassment and therefore ‘taboo’ of viewing breasts is removed.

> **Lilly:** *‘Sometime-, for me it’s- (.), if you see an actual person, you would feel a bit embarrassed seeing that but, like that form, in an animation format, you know it’s been designed so as not to embarrass somebody.’*

> **Breast-CAM-NF1 (A):** *‘Nice and clear video, takes away the embarrassment of the subject and more importantly links it to NF1 and highlights the increased risk, but in a non-scary way.’*

Cartoons drawn in static form have shown to transcend taboos (Figoureux and Van Gorp, 2021), and political issues or motives as the focus is on the cartoon (Dougherty, 2002). Animation can do this by negating the societal constructions of sexualised and taboo objects, with the animated form of woman, and accordingly their breasts, instead operating in a safe space outside the constraints of societal and patriarchal norms that shift away from women as an erotic spectacle, to the representation of woman and the breasts as a subject (Wells, 2013). This evidently allows for learning to occur without discomfort or embarrassment.

Willow: *'I think if it was more kind of 'live people' that might make people feel uncomfortable, so, especially like younger people, I think that would make them feel, could make them feel uncomfortable.'*

Bernie (A): '*Yeah, I think some people can get very embarrassed talking about, you know, bodies and things, so I think because it's like a cartoonish character, it's not so embarrassing and so you can look at things and then it's not like, you know, if it's a younger child they'd be all giggly and things, but I think it makes it much easier to have a discussion about it, because it is in that format.'*

Breasts can also be perceived as dichotomous as both an act of goodness and as a threat, as life-giving organs for breastfeeding, but conversely as life-taking organs thorough their susceptibility to cancer (Gripsrud et al., 2016; 2018). The animation provides a safety from the upsetting issues surrounding cancer, which often carries an assumption of death (Moser et al., 2014; 2021), which is negatively perceived or more commonly considered as 'scary'.

Christina (A): '*I thought it was- (.) it was safe. It made-, it was very easy to watch and understand and it was encouraging, some simple tips, but not scary, not overly medical.'*

Sasha (A): '*But I think watching that, it was easy to watch, and it wasn't frightening.'*

Bruno (A): *'So, I think if you did it with like, you know, a reconstruction of actors or things like that, it's-, you can kind of like switch off a little bit because it's not as engaging, like you know what I mean. Or it could become a little bit too morbid and then that could scare people away from going themselves because you could scare 'em completely away from understanding the information and they could completely shut it out and switch the video off.'*

By reducing taboos and threats for individuals by employing an animated form, it subsequently allows a channel of communication to be opened, with an enhanced sense of connection being formed through the childlike features of many cartoon characters that are perceived as on a threshold on the outer, social world (Holmes, 2013), making it easier to speak with others about the topic.

Mavis (A): *'It was very easy to understand, easy to watch and I think it would be easy to discuss with either family or a professional. And it would make someone a lot less maybe fearful.'*

Despite the cartoon characters having clearly depicted anatomical body parts of breasts, it is also understood by the viewer as a constructed image and not a real human being. The animated breasts, while in cartoon form, are naturally unnatural, in that they have the attributes of the natural human breast but are unnatural in that they are not of a human, with the animated body becoming a fluid form that closely adheres to realism thorough the accurate depiction of the woman's breasts (Wells, 2013). With the tabooed objects translated into animated form, the breasts are no longer threatening, and the animated faces are friendly. There is now an ability to relate to the cartoon figures, rather than figures and faces that look too human (Holmes, 2013).

Christina (A): '*I saw it as non-threatening because it was a cartoon, and it's not a real person.'*

Bruno (A): *'It's not really real life but whilst also being real-life.'*

This is much like how animation is experienced in childhood (Holmes, 2013).

Laura: '*It's animation that makes you think of your childhood ((laughs)).'*

With clear indications provided by those interviewed that an animated format can create a protective distance so as to allow for learning to occur about anatomical parts that may be associated with taboos or embarrassment, it may be prudent to consider this as a potential format for future health education subjects that require awareness among individuals, such as those concerning prostate, testicular, and gynaecological matters.

9.4 Overall remarks of analysis

Many participants communicated that they believed that their knowledge of breast cancer warning signs and their levels of confidence for breast checking increased. Employing semi-structured interviewing allows for a deeper exploration into participants' thoughts, beliefs, and feelings about a particular topic (DeJonckheere and Vaughn, 2019), with interviews imparting a sense of increased empowerment to contact a HP and ask for what they require if there is a breast concern. While it was not possible to ascertain from the Breast-CAM-NF1, interviewing participants allowed for the communication of pertinent information, that the most significant learning of NF1 BCA appears to be the five-fold increased risk of developing breast cancer at a younger age. This highlights the usefulness of adopting a mixed methods approach to further explore data related to a research topic (DeJonckheere and Vaughn, 2019).

However, one distinct discovery that would not have been possible without the interviews, is that of a comprehensive understanding of barriers to being breast cancer aware. Poor rare disease knowledge of HPs is communicated as creating a barrier to learning BCA information, preventing access to screening, and having breast concerns taken seriously. It is recognised within rare disease literature that it is an ongoing issue with HPs not having an acceptable understanding of such conditions (McMullan et al., 2020), however, these professionals are perceived as holding the power. The healthcare system in which both the young women with NF1 and their associates are positioned is conveyed as disconnected, again contributing to BCA barriers.

It becomes apparent the importance of sharing information pertaining to NF1 and NF1 BCA to increase learning in individuals for autonomy in taking ownership of their health and the decisions that may have to be made. Increasing awareness by sharing also increases competence and relatedness as discussed within self-determination theory (Deci and Ryan, 1985), but as observed it has also aided in shifting perspectives as experienced among associates from watching the animation. These individuals were perceived to develop an increased consideration of NF1 experiences. Arguably, this would benefit HPs by exposure to the animation to increase competence, but also to aid in creating autonomy among their NF1 patients and associates by sharing the animation and the information. This understanding stems from adopting both an inductive and deductive approach, and if another researcher approached the research in a different way, these may not have been highlighted as pertinent, or at all (Knott et al., 2022).

The design of the animation was perceived positively with no changes suggested by participants, with feedback predominantly involving an ability to keep a viewer engaged, easy to understand, and an increased relatedness as the animated cartoon could be anyone from anywhere. The feedback was not entirely unexpected, with it being found that learning from animation is more successful than learning from still images (Ploetzner et al., 2020). This demonstrates the importance of initially undertaking a systematic evaluation of theory and evidence for behaviour change and intervention design by considering a range of options that are most promising (Michie et al., 2014), and the inclusion of PPI to ensure that research is relevant to user needs that is more likely to have beneficial impacts (Gray-Burrows et al., 2018). Additionally, an important outcome of the design is that it appears to have provided a protective distance allowing viewers to engage with the content that can often be perceived with fear and taboo. While scarce in its exploration within the literature, it has been previously found that cartoons drawn in static form have shown to transcend taboos (Figoureux and Van Gorp, 2021). Arguably, it may be ascertained that this may occur within animation.

It is recognised that other methods of qualitative analysis may have been employed. If it weren't for my own previous diagnosis of breast cancer at a young age, I believe that interpretative phenomenological analysis (Smith and Osborn, 2015) would have also been suitable with its double hermeneutic approach, with participant claims and the researcher's interpretation of the meaning considered. However, RTA allowed for further transparency within reflexive accounts that proved to be an important consideration with identifying my various identities within the research. The application of RTA has demonstrated that overall, a novel animation is feasible for increasing NF1 BCA in young women with NF1 and their associates, by exploring BCA components as outlined within the Breast-CAM-NF1, and an animated format.

9.5 Summary of the key points in this chapter

Table 32 provides a summary of themes.

Table 32

Summary of Themes

	Title	**Summary**
Theme 1	**Tentative action and empowered thinking with**	• Many conveyed increases in knowledge of breast cancer warning signs, and confidence for breasts checking.

	learning beyond the lump.	Tentative moves towards empowerment to contact a HP to ask (or indeed demand) to be listened to were shared. Animation encouraged many to incorporate BCA actions. Most significant learning appears to have been the five-fold increased risk of developing breast cancer.
Theme 2	**Broken knowledge and broken patient experts within a powerful disconnected system.**	Poor rare disease knowledge among HPs is communicated as a barrier to being breast cancer aware, preventing access to important screening or having breast concerns taken seriously with the professional construed as holding the power. Many interviewed shared their exasperation of continuously having to explain their condition or the need for certain tests. A healthcare system conveyed as disconnected also contributes a barrier to ensuring that NF1 patients are receiving an appropriate level of breast care.
Theme 3	**In the middle of a chain reaction: Stronger links to action through a shared awareness.**	Sharing NF1, including NF1 BCA information increases learning opportunities among more individuals, allowing them to increase ownership of their health decisions. Associates demonstrated a change of perspective about NF1, with an increased consideration of NF1 experiences. This strengthens a chain to increase NF1 awareness and take supportive action.
Theme 4	**Goldilocks and the three learning cares: Engaging design, content clarity, and deliberate inclusivity.**	Positive response to the animation design conveyed, predominantly surrounding its ability to keep a viewer engaged. All found the content easy to understand, but also relatable. A 'Goldilocks effect', is conveyed by being at the right level of design considerations.
Theme 5	**Keeping safe from taboo(bs) and scary facts by a 'cartoonish character'.**	Animation provides a protective distance to engage with information that may create a fear response such as cancer, or from embarrassment when talking about or viewing women's breasts.

9.6 The next stage of the research

Pertinent learnings have come from undertaking both quantitative and qualitative research to explore the feasibility of a novel NF1 BCA intervention. The final chapter will provide a discussion and concluding points of a preliminary evaluation of the feasibility of a novel NF1 breast cancer awareness intervention. The thesis will end by providing future research recommendations and a final reflection.

Chapter Ten

Discussion and concluding points of a preliminary evaluation of the feasibility of a novel NF1 specific breast cancer awareness intervention

10.1 Introduction

The association between NF1 and an increased risk of breast cancer at a younger age among women with NF1 has only recently been widely accepted (Madanikia et al., 2012; Da Silva et al., 2015; Evans et al., 2020). With this, there is a dearth of evidence-based interventions to aid in raising BCA within this cohort, and subsequently a lack of knowledge of the increased risk and recommendations among women with NF1, their associates, and HPs. This is despite the acknowledged risk of women with NF1 having an up to five-fold increased risk of developing breast cancer under the age of 50 years (Maani et al., 2019; Viskochil, 2021) with these cancer subtypes often presenting with aggressive grade 3 type tumours (Yap et al., 2018), and advanced staging compared to non-NF1 breast cancers (Uusitalo et al., 2017). This lack of information subsequently affects levels of health literacy, creating a negative effect for decision making pertaining to the women's health (Altin and Stock, 2016). This was a particularly relevant focus within this research, with Crawford et al. (2016) finding that adults with NF1 are less likely to partake in health monitoring and uptake due to low levels of health literacy, often related to a lack of evidenced based and accessible NF1 guidelines. Conversely, there are findings that communicate that those with NF1 and their associates often become the 'expert' in their condition, attempting to decipher what sources can be trusted particularly online, and explain their condition to HPs (Nutt and Limb, 2011; Budych et al., 2012). Recognising the importance of raising awareness to present with a breast concern earlier in the hope of being diagnosed at an earlier stage for a better prognosis, it is important that a BCA intervention specific to young women with NF1 and their associates is available to increase BCA knowledge and self-efficacy in having confidence to recognise breast changes, and to encourage prompt medical consultation for a breast concern.

This research explored the development and feasibility of a novel BCA animation for young women with NF1, and their associates by presenting an initial phase of intervention examination, development and implementation. Feasibility was explored by applying a mixed method approach with a qualitative emphasis to examine whether the utilisation of a novel NF1 BCA intervention, including the utilised research methodology, indicated potential for further progression and development. Dobkin (2009) and Gitlin (2013) outline the importance of successive phases for development and testing of novel health related behavioural interventions. This overarching objective is therefore explored by considering five objectives of a feasibility study by reference to guiding questions as set out by Orsmond and Cohn (2015), e.g., *To what extent is the intervention acceptable and appealing to participants*, and *Are criteria clear and sufficient or too inclusive or restrictive?* This final chapter provides a summary of preliminary evaluation and concludes with the provision of recommendations for future research.

10.2 Discussion of preliminary evaluation of intervention feasibility

1. Evaluation of recruitment capability and resulting sample characteristics

Young women with NF1 were found to lack awareness of the five-fold increased risk of developing breast cancer at a younger age, and a recommendation for earlier breast cancer screening from 40 years of age (Plunkett and Pilkington, 2024). This evidence demonstrates that the intervention is relevant and needed. However, recruitment difficulties, and subsequently small participant numbers within rare disease research were acknowledged from the beginning of the research (Whicher et al., 2018). Approximately 25,000 individuals in the UK have been diagnosed with NF1 (Nerve Tumours UK, n.d.). Republic of Ireland figures are not as clearly communicated, with only an overall NF total that includes all NF-subtypes reported of 2,500 individuals (NF Association Ireland, n.d.). From these figures, it is not specified how many are women with NF1, however it can be deduced that this number will be smaller, reducing the number of available participants for research. The specified samples for recruitment included young women with NF1 (18-40 years), and associates (any gender with a close relation or connection with a young woman with NF1), with individuals excluded if they had received a previous diagnosis of breast cancer or were attending regular breast screening (young women with NF1). The exclusion criteria were applied as it was considered that young women with NF1 already attending screening would skew results as they would have an awareness of risk if they were being screened before the recommended age of 40 years. Associates and young women with NF1 who had received a previous diagnosis of breast cancer were excluded for similar reasons, positing that they would have a higher knowledge compared to others within these cohorts. However, recruitment difficulties highlighted a need to consider more inclusive criteria. Despite best efforts particularly from the Childhood Tumour Trust with advertising and sharing the research with various NF/rare disease charities, and advertising via various online platforms, recruitment numbers promptly slowed after 2 months, and then stopped after four months. It is recommended that these exclusion criteria are potentially omitted in future research, with further questions asked to ascertain if a young woman with NF1 is attending regular breast screening, and if a participant experienced a previous diagnosis of breast cancer. These may aid in providing a more comprehensive understanding of NF1 BCA, of whether the intervention itself supports BCA components such as knowledge of warning signs, help-seeking behaviour, risk, breast screening knowledge, and confidence with breast checking, or if it may be due to another factor such as attending screening or having experienced breast cancer.

A larger sample from a wider cohort of young women with NF1 and associates such as recruiting from further NF charities may increase statistical power (Andrade, 2020) and may provide more varied opinions and experiences within interviews. While the research was advertised on social media platforms of the Childhood Tumour Trust and Nerve Tumours UK, from speaking with participants most were recruited through the former. This is a small charity with members experiencing a desire to act to empower one another to become advocates (Zhu et al., 2017). However, this may mould perceptions and opinions. Additionally, the characteristics of this study's participants may not be consistent with the range of expected characteristics as informed by the research literature. All young women with NF1 and associates identified themselves as English/Welsh/Scottish/Northern Irish/British despite NF1 affecting an individual regardless of gender, race, or ethnicity (Children's Tumor Foundation, n.d.). With no participants from other ethnicities, there are potential omissions within the intervention design, methodology, and/or delivery. Participation from a more diverse pool of participants is recommended for providing a more accurate representation of a population's needs (Patel, 2023).

The prevalence of learning and cognitive impairments among those with NF1 were considered within the design of the intervention. While it was apparent that some of the participants had learning difficulties by them communicating this within interviews, it is acknowledged that the intervention may not have been suitably inclusive to involve participants with greater learning difficulties. Most women with NF1 demonstrated a high level of educational attainment as shown in Chapter Seven, which is an important determinant of health literacy (Stormacq et al., 2019). However, a low completion rate with the highest drop-out rate at the PIS stage (65%) raises concerns with the length of the PIS (7-pages) which may have deterred individuals from moving forward. A lengthy document which may contribute to poorer comprehension and retention of key details compared to briefer versions (Ennis and Wykes, 2016). Individuals with lower levels of education attainment and/or more severe learning difficulties may have been unintentionally excluded. Other methods to communicate PIS information, such as a video format (Hammond and Cooper, 2011) or providing summary points alongside the main version is recommended to consider within future research. However, it is important that the participant is fully informed of all aspects contained within the PIS.

Involvement with NF clinics, and HPs is recommended to analyse NF1 BCA levels from watching the animation to gain an understanding of feasibility among this specific cohort, and to garner a better understanding of their rare disease knowledge acquisition. Low levels of rare disease knowledge amongst HPs have been documented (e.g., Kopeć and Podolec, 2015; Ramalle-Gómara et al., 2020; Sanges et al., 2020; Domaradzki and Walkowiak, 2021), demonstrating a potential need for this intervention. Further consideration of recruitment strategies utilised is recommended within PPI consultation.

2. Evaluation and refinement of data collection procedures and outcome measures

From interviews conducted, and from feedback from the Childhood Tumour Trust, it was communicated that there were no challenges experienced by participants in understanding the questions and other data collection procedures. However, from preliminary evaluation of the pre- and post-test analyses of the Breast-CAM-NF1, it was ascertained that there may have been confusion regarding the item testing knowledge of what age a woman is most likely to develop breast cancer if they have NF1. The animation communicated that it is women with NF1 under the age of 50 years that have a five-fold increased risk of breast cancer. However, the pre- and post-test questions only provided a choice of a '40-year-old woman', '60-year-old woman', '80-year-old woman', 'woman of any age', and 'don't know' as communicated within the Breast-CAM (Linsell et al., 2010). Despite the five-fold increased risk communicated as a noteworthy learning within interviews, the Breast-CAM-NF1 may benefit from further development and validation to include a direct question on risk. This emphasises the importance of recognising the limitations with employing measurements that whilst are valid, may require more careful adaptation to ensure clarity whilst maintaining validity to reduce the risk of the measure being a ‘poor contextual fit’ (Einola and Alvesson, 2021). Genetics, and wider considerations of incidence and risk factors would also benefit from being included within measurements like those included within the Breast Cancer and Heredity Knowledge Scale (Ondrusek et al., 1999) albeit tailored to an NF1 context. A deeper exploration into breast cancer health behaviours such as cues to actions, benefits and barriers of BSE, and mammogram for example, like measures that provide a health belief model framework (e.g., Mohamed et al., 2019) may also provide a wider understanding of NF1 BCA.

While the short timescale allowed participants the capacity to complete the intervention without it taking too much time, completing a post-test questionnaire immediately after watching the animation may present limitations. Improvements may have resulted from participants remembering questions or the questions aiding in raising awareness and triggering learning after the pre-test (Marsden and Torgerson, 2012), with knowledge or attitude reported initially as high, particularly as the animation was only approximately 3 minutes in length allowing for a quick transition from pre-test to post-test. Subsequent research may consider employing more time between pre- and post-test measures to measure long-term changes whilst striving to not become a time burden for participants (Orsmond and Cohn, 2015). With the effects of confounding variables on results unknown, such as the environment of participants completing the tests, future administration of questionnaires in a more controlled environment such as NF clinics may be beneficial to consider. However, it is recognised that the online method of data collection procedures did not carry any negative reports from participants, or the charities. These provide a cost-effective and convenient approach, whereby respondents can partake at a convenient time, and can take as much time as they need to respond to questions (Regmi et al., 2016). It is also noted that accessibility to online methods is high, with 92% of adults, and 99% of 16-44 years recent internet users (Office of National Statistics, 2021). The mean completion times of fully completed online questionnaires were 12 minutes: 41 seconds for young women with NF1, and 14 minutes: 9 seconds for associates demonstrating a non-arduous time requirement within both cohorts. Both a QR Code and Link/web address were offered as methods of access, however, most individuals utilised the link/web address. As the research was shared primarily by the Childhood Tumour Trust, it was reported by this charity that providing a link was easier to share via social media platforms and was therefore utilised more than the QR Code. However, if recruitment is expanded to wider populations such as within clinics, the QR Code may provide increased access by scanning by a patient if advertised on a poster within a wating room, for example.

While in-person interviews may therefore be considered if recruiting from clinics, the continuation of Microsoft Teams and/or telephone appears to demonstrate feasibility and would benefit from continuing to be employed. No negative feedback was provided either from participants or charities with utilising these. In particular, telephone interviewing has been found to provide greater anonymity, and lesser intensity as may be experienced with in-person methods (Irvine, 2011). Microsoft Teams can also offer anonymity by the act of switching off the camera. The qualitative method of interviews also demonstrated feasibility within this research, with it allowing for further exploration into NF1 BCA topics that may not be covered within pre-post-test measures.

3. Evaluation of acceptability and suitability of intervention and study procedures

The intervention within a digital animation format was well received by participants within interviews, with no accessing difficulties reported. The digital format is one that has become more widely acceptable and expected, with health and disease prevention web-based information now readily available (Meppelink et al., 2015). Participants reported finding the short animation a useful method to explain NF1 BCA, with animations aiding in explaining complex information by utilising textual and visual approaches (Occa and Morgan, 2019). The animation length of 3 minutes 10 seconds was perceived by participants as an adequate amount, with Feeley et al. (2023) recommending that a viewer should not have their cognitive capacity burdened by something that exceeds a duration of 5-6 minutes. It allows participants to not be disturbed excessively from their daily life activities, a consideration presented by Orsmond and Cohn (2015). Participants communicated that the intervention was easy to understand and engaging with just the right level of design considerations. This is important to consider when contributing to levels of health literacy, with it being understood as a person's capacity within their own individual context, to receive and comprehend information to manage and improve health (Liu et al., 2020). Considering the prevalence of learning difficulties and cognitive impairments among those with NF1, if the animation had not been designed appropriately, it may have negatively affected health literacy levels. However, those who communicated that they had learning difficulties found the animation a positive and engaging experience. While the closed captioning function was accessible to all, and often automatically played, future versions may consider adding a note communicating the availability of closed captioning to increasing inclusivity and accessibility.

Viewers also developed a sense of relatedness with the animated character 'Bea' being considered as anyone, from anywhere; yet the visibility of café-au-lait macules depicted that the protagonist has NF1. This design inclusion alongside the short animation duration may also be beneficial for HPs if included within future research for potentially increasing NF1 BCA knowledge for screening and breast cancer risk education and increasing NF1 diagnostic numbers. Participants experienced a protective distance to engage with what may otherwise create fear due to the topic of cancer, or taboo due to the viewing of a woman's breasts. Despite the animated body adhering to a realist construction through accurate depiction of a woman's breasts (Wells, 2013), these are no longer threatening or embarrassing by animation. Having the confidence to access such information is also important in developing increased levels of health literacy (Public Health England, 2015). Some participants considered that the animation may potentially be suitable for children. This is pertinent feedback for future intervention delivery, with NF1 associated with precocious puberty (Kocova et al., 2015).

No participant directly reported to the researcher, or to the Childhood Tumour Trust, or lodged a complaint detailing any adverse events from partaking in the research. Considering the potential for distress that may occur with discussing a topic related to breast cancer, contact details of both NF and breast cancer charities were provided to participants, with this recommended to continue to be undertaken.

4. **Evaluation of resources and ability to manage and implement study and intervention**
Being a PhD student, and an early career researcher; research, organisation, and administration was often a new experience, and at times challenging. However, having personally experienced a diagnosis of breast cancer, it also allowed for an ease with communicating about BCA. While the animation team delivered an acceptable and engaging animation, they too were new to creating a behaviour change intervention and were previously unfamiliar with the condition of NF1, with an NF1 information session

provided within the initial meeting. No great design delays were experienced, with regular meetings (fortnightly and at times weekly) allowing for transparency of what was expected, and for any questions to be addressed. The Childhood Tumour Trust were regularly consulted, and provided support, information and feedback throughout the research. The supervisory team, and wider university teams such as Ethics were also available for clarification of issues pertaining to methodology. Future research may benefit from continuing regular meetings, particularly where there is often a lack of awareness pertaining to rare diseases. With the RISE project advertising for an animation team in exchange for RISE points, transcription recognition, and references on request, there were no budgetary considerations. Meetings primarily took place online via Microsoft Teams, and the animation team utilised drawing and recording studios gratis within the School of Digital Arts.

However, future stages of research may benefit from a more comprehensive research team, with individuals with various expertise in research methods within rare disease, and more advanced statistical skills. Further budgetary considerations may be required if employing an external design agency or if offering payment for PPI and/or participant involvement. Within this feasibility study, PPIs and participants were not offered compensation such as cash or vouchers. While this may increase participant recruitment levels, there are ethical considerations to consider such as participants perceiving undue influence, or unjust inducement (Largent et al., 2023). However, Halpern et al. (2004) reported no occurrence of these, with participants generally personally motivated to partake in research (Largent et al., 2023). Time constraints were present with there being a need for the research to be conducted within the three years as sponsorship from the Childhood Tumour Trust was provided only for this duration. It is envisaged that with wider participant recruitment pools, recruitment numbers would be greater, even with a short time frame such as 6 months.

5. Preliminary evaluation of participant responses to intervention

While the evaluation of intervention outcomes is more appropriate within a pilot study, the feasibility study stage allows for a preliminary evaluation of participants responses to the intervention (Orsmond and Cohn, 2015). However, with small participant numbers, it is necessary to be cautious when interpreting results and acknowledge that underpowered significance tests may represent both Type II (false negative), and Type I (false positive) results. This research utilises what is recommended by Orsmond and Cohn (2015), of combining quantitative and qualitative methods to garner an assessment of promise for feasibility. To assess whether the NF1 BCA intervention showed promise of being successful, pre- and post-test measures were examined utilising an adapted version of the Breast Cancer Awareness Measurement (Linsell et al., 2010), the Breast-CAM-NF1, and reviewed qualitative interviews from young women with NF1, and associates.

The preliminary findings suggest a reduction in reasons that young women with NF1 would put off going to their doctor with a breast concern, a reported increase in confidence among young women with NF1 in noticing breast changes, and an increase in correct answers of the screening eligibility age for breast screening for young women with NF1 in the UK and Ireland. While results from the Breast-CAM-NF1 suggested an increase in confidence among young women with NF1 in noticing breast changes, a non-significant result was found in differences in knowledge levels of breast cancer warning symptoms. However, within interviews several participants conveyed an increase in knowledge of breast cancer warning signs by imparting that they previously only considered a lump as a potential symptom. As considered within the discussion of these results in Chapter Seven, response bias including acquiescence bias demonstrating a tendency to agree with all questions perceived to be the correct responses based on the experiment that they are partaking in (Watson, 1992) may have occurred. 14 out of 24 participants demonstrated no median changes, potentially 'ticking' boxes without certainty. However, these 14 participants scored the maximum scores in both pre- and post-tests, which may also imply an already high level of BCA knowledge despite the intervention. With an increase in confidence of noticing breast changes, and the communication of knowledge acquisition of wider warning signs, it may suggest a development of BCA self-efficacy whereby there is both a belief and a capacity to act out this behaviour (Bandura, 1977). Interestingly, self-efficacy to be breast cancer aware was also communicated by associates, whereby the animation created a personal awareness for their own breast health, demonstrating effectiveness of intervention style and delivery format. Despite a non-significant result for differences in breast checking frequency of young women with NF1, interviews communicated a positive shift with breast checking frequency to once a month, whether checking less if they were checking too frequently, or checking more if they were not checking at all or sporadically. However, this may also indicate social desirability bias, where an over report of more desirable attributes (Latkin et al., 2017), in this case reporting a change to the recommended monthly checking may have occurred. Further exploration into how reminders or cues are created to undertake this behaviour within interviews may provide a clearer distinction of whether this is occurring or not.

A reported significant increase in correct answers of the screening eligibility age for breast screening for young women with NF1 in the UK and Ireland aligns with what has been communicated within interviews. In previous research conducted by Plunkett and Pilkington (2024), it was ascertained that knowledge of breast cancer screening age eligibility of 40 years in the UK and Ireland was low. With this knowledge reported to have increased from watching the novel NF1 BCA animation, it may also suggest that levels of health literacy have increased. With low levels of health literacy related to inferior health outcomes (Bergström et al., 2014) including limited disease knowledge, detection behaviours (Rudd, 2013; Gibney et al., 2020), and difficulties in accessing both health services and health care providers (Marquez and Ladd, 2019), it was important that these were targeted for self-efficacy, and prompt medical consultation for a breast concern. As communicated by Crawford et al. (2016), adults with NF1 have a decreased uptake of health management and monitoring due to low levels of health literacy, often resultant from a lack of accessible and evidence-based guidelines for NF1.

As considered within Chapter Two, and in concurrence with Panieri (2012), for early detection to be effective it is important that women are not only educated on how to recognise breast cancer warning signs, but to also be empowered to take control of their own health and promptly consult a HP. Differences between pre-post data suggest that from watching the animation, young women with NF1 reported a reduction in reasons that may dissuade them from attending a doctor if they had a breast concern. This tentatively suggests that women with NF1 are more likely to attend a HP from watching the animation, potentially indicating positive health seeking behaviours. Within the Breast-CAM-NF1, it is also suggested that from watching the animation, young women with NF1 may attend their doctor more promptly. However, it was observed that there was already a high level of assertiveness to contact a doctor promptly, even before watching the animation. This was also noted among associates. Despite this, a sense of empowerment was communicated by the young women with NF1 from watching the animation to contact a HP to ask, and in some cases demand if required, for what is needed such as subsequent appointments or scans, and importantly to be listened to.

However, the interviews conveyed barriers to being breast cancer aware that are separate to knowledge and self-efficacy. Reported poor rare disease knowledge of HPs, and a disconnected healthcare system that is under pressure are also perceived as BCA barriers. As previously communicated, these barriers are recommended to be explored further particularly with HPs to better understand and to support rare disease knowledge acquisition within this cohort to improve future intervention designs and research.

10.3 Research strengths, limitations, and future recommendations

To the best of the researcher's knowledge, no specific NF1 BCA intervention had previously been designed. This research has presented a unique contribution by the delivery of such a novel animation. The application of suitable theoretical frameworks particularly within intervention design and PPI involvement aided in providing an in-depth analysis and communication of intervention design and delivery. Findings, including the observed strengths and limitations of aspects such as data collection, employed measures, and recruitment provided a level of transparency to aid in developing subsequent research. While the research has addressed the research question and provided a more comprehensive understanding into NF1 BCA, there are several particulars it cannot communicate. Most notably, despite being referred to within the research and communicated by participants, it is unable to convey the perspectives of HPs. It is recommended that subsequent research analyses levels of NF1 BCA within this cohort from watching the animation, to gain an understanding of the intervention feasibility and to garner a better understanding of their rare disease knowledge acquisition. A larger and more diverse recruitment of participants and PPI such as NF clinic involvement and expanded charity involvement is recommended in future work, as the non-significant results may have been due to a lack of statistical power and small participant numbers (Andrade, 2020). However, these non-significant results do not in any way diminish the richness of interview data that through triangulation from a mixed method approach with a qualitative emphasis, enhances outcomes from one method with that of another (Erzberger and Kelle, 2003).

Whilst an information leaflet was designed with key points taken from the animation, it was not part of the analysis. Instead, it was provided to participants alongside debrief information solely as a prompt sheet of what was covered within the intervention. Future research may consider examining whether this influences NF1 BCA levels, potentially as another arm within a pilot study or RCT to provide a comparison to the animated video. Additionally, it is recognised that after the application of BCTs, an updated version of a behaviour change technique ontology was published (Marques et al., 2023), with it posited that these ontologies provide further comprehensiveness and expression of how information is represented compared to taxonomies. It is acknowledged that differing BCTs and perhaps design outcomes may occur. The Breast-CAM-NF1 would benefit from further refinement and validation to include a direct question on risk pertaining to NF1 for an improved contextual fit. Aspects such as genetics, incidence and risk factors pertinent to NF1 may also benefit from being included.

While the animation was designed with careful consideration of individuals with learning difficulties recognising its prevalence amongst individuals with NF1 (Vogel et al., 2017) and was positively received by those that communicated within interviews that they had learning difficulties, future research may benefit from the inclusion of those with greater levels, and further cognitive impairments. From preliminary evaluation demonstrating a high drop-out rate from the research at the PIS stage, it is acknowledged that the research was not as accessible as it could have been with a lengthy PIS. Longer information sheets can result in poorer comprehension and retention of key details compared to briefer versions (Ennis and Wykes, 2016). Future research may benefit from considering the inclusion of other methods such as a video format (Hammond and Cooper, 2011) or summary points alongside the main version whilst ensuring the participant is fully informed. Inclusion of NF clinics may aid in improving diversity of learning difficulties.

A distinct gap in care that occurs after children with NF1 transition from clinical paediatric care became apparent within interviews, where often no further care related to their condition is provided in adulthood. It is evident that many young women with NF1, and associates such as mothers of daughters with NF1, were not made aware of the increased risk of developing breast cancer at a younger age during paediatric care. Fleming et al. (2022) argue that it is vital that individuals with NF1 are transitioned from paediatric to adult services, that includes easy access to consistent surveillance, and resources to pursue specialist care when required. The preliminary findings therefore have the potential to inform policy and practice changes, if considered more thoroughly in future research.

It is acknowledged that this research has demonstrated real world positive impacts. In May 2024, actions had been taken to support NF1 BCA knowledge acquisition based on the preliminary findings from this research. This included the delivery of an NF1 and breast cancer education session at The Christie Hospital, one of the largest cancer treatment centres in Europe. Findings and recommendations were shared to a diverse audience including healthcare professionals, allied healthcare professionals, and the public. The animation, and research findings have also been communicated to the All-Party Parliamentary Group of the Rare, Genetic, and undiagnosed conditions and therefore its secretariat Genetic Alliance UK. Two items were tabled regarding consideration for automatic breast screening invitations due to the increased earlier risk of breast cancer with NF1, and a broader request for information to know what steps the UK government are taking to raise clinician awareness of the relationship between NF1 and breast cancer. Discussions with local MPs are ongoing. Ideally, an automatic invitation for breast screening would be sent out to eligible individuals approaching 40 years of age which is currently lacking. Whilst oversights may occur, for example, some women may not be properly registered as having NF1, an automated invitation may aid in increasing screening uptake within this cohort despite poor knowledge of an earlier screening eligibility amongst HPs and patients.

In October 2024, Rare Revolution Magazine an online publication that highlights both rare disease patient stories and research breakthroughs collaborated with the Childhood Tumour Trust to raise NF1 BCA. Information pertaining to this research, including the animation was communicated as part of the campaign. While separate to this research, by mid-October this campaign demonstrated high interactions with 3,390,215 impressions, and 113,038 total engagements (Appendix AE). This is something to consider within subsequent analyses of BCA levels, as this exposure to the animation may provide indications of high levels in both pre- and post-test measures. However, this may be explored within interviews to ascertain how awareness was obtained. It may be beneficial to utilise platforms such as Rare Revolution Magazine to enhance future research advertisement and recruitment.

10.4 Concluding reflection

Preliminary evaluation of the development and feasibility of a novel breast cancer awareness intervention for young women with NF1 and associates has been explored, in the hope that ultimately research including an intervention may support women with NF1 to promptly and confidently present for an earlier diagnosis and a far better prognosis if faced with breast cancer. The research, while perhaps a ‘small cog in a big wheel’ is hoped to empower those within the NF1 community. My own experience of having gone through physically and emotionally challenging treatments for breast cancer has made me increasingly aware of the importance of being breast cancer aware. I am still here to be with my husband, and children, and to undertake this research not only because of treatments, but because I spotted early changes to my breast. However, BCA is not an inclusive ‘one size fits all’ phenomenon. Holistic understandings among cohorts, like within this research, is imperative to ensure that one term of ‘breast cancer awareness’ is not mistaken as one experience that is shared by all.

I am grateful to the participants. Through their honest communications they have amplified the often-unheard voices within the rare disease community, specifically NF1, to aid in increasing the number of earlier breast cancer diagnoses, ultimately for better outcomes.

10.5 Summary of key points in this chapter

- The feasibility of a novel BCA animation for young women with NF1, and their associates was explored to examine whether the intervention and the utilised research methodology indicated potential for progression.
- Recruitment capability and resulting sample characteristics would benefit from wider participant recruitment to increase numbers, and participant diversity. NF clinics and HPs are recommended to be included in future research.
- Data collection would benefit from a longer timescale between pre- and post-test questionnaires to allow for increased analysis accuracy of results. It is recommended that the Breast-CAM-NF1 is adapted to allow for a more accurate testing of NF1 BCA risk. Future measurements may also benefit from considering genetics.
- The intervention format was reported as acceptable and suitable, with the animation communicated as aiding in knowledge and creating a protective distance from contentious topics of breast cancer and breasts.

- Future studies may benefit from having further research team members, to aid in applying more specialised and advanced methodologies.
- Preliminary evaluation of participant responses tentatively suggests an increase in confidence among young women with NF1 in noticing breast changes, significant changes in knowledge of breast screening age eligibility, and a reduction in reasons that would dissuade them from attending a doctor if they had a breast concern.
- Interviews communicated poor HP rare disease knowledge as a barrier to BCA. It is recommended that future research includes HPs for exploration of rare disease knowledge acquisition, including its barriers.
- Acknowledging the long length of the PIS, future research may benefit from considering the inclusion of other methods such as a video format or summary points alongside the main version whilst ensuring the participant is fully informed.

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Appendices

Appendix A

Inclusion-Exclusion Screening Table

Orange – No from title and abstract

Green – No from applying limitations

Grey – Duplicate

Yellow – Yes

Search Engine	Suitable	Title	Authors
Web of Science	Age not suitable (50 to 70)	Assessment of the Effects of Breast Cancer Training on Women Between the Ages of 50 and 70 in Kemalpasa, Turkey	Mermer and Turk (2014)
Medline	Age not suitable (older women)	Promoting early presentation intervention sustains increased breast cancer awareness in older women for three years: A randomized controlled trial.	Kaushal et al. (2017)
CINAHL	Age not suitable under 18 years	Effect of Structured Teaching Programme regarding Breast Self-Examination Among Adolescent Girls of Selected College at Guwahati (Assam).	Jenita et al. (2017)
Web of Science	Age older women	Promoting early presentation of breast cancer in older women: sustained effect of an intervention to promote breast cancer awareness in routine clinical practice	Dodd et al. (2017)
Web of Science	Age older women	Promoting early presentation of breast cancer in women over 70 years old in general practice	Campbell et al. (2016)
APA Psychinfo	Duplicate	Breast cancer knowledge, beliefs, and screening behaviors of college women: Utilization of the health belief model.	Guilford (2012)
Web of Science	Duplicate	Effect of cancer education on the practice of breast self-examination among adult women in Nigeria	Udeze et al. (2020)
Web of Science	Duplicate	Application of Personalized Education in the Mobile Medical App for Breast Self-Examination	Blajda et al. (2022)
Web of Science	Duplicate	Result of randomized control trial to increase breast health awareness among young females in Malaysia	Akhtari-Zavare et al. (2016)
Web of Science	Duplicate	Theory-based training to promote breast cancer screening among women with breast cancer worries: randomized controlled trial	Tashan et al. (2020)
Web of Science	Duplicate	Effect of Direct Education on Breast Self Examination Awareness and Practice among Women in Bolu, Turkey	Gucuk and Uyeturk (2013)
Web of Science	Duplicate	Likelihood of Breast Screening Uptake among Reproductive-aged Women in Ethiopia: A Baseline Survey for Randomized Controlled Trial	Agide et al. (2019)
Web of Science	Duplicate	Knowledge, Attitudes, and Practices of Breast Cancer Screening Methods Among Female Patients in Primary Healthcare Centers in Najran, Saudi Arabia	Alshahrani et al. (2019)
Web of Science	Duplicate	The Health Belief Model and Prediction of Breast Self-examination Practices in Female Mexican College Students	Juarez-Garcia and Tellez (2019)
Web of Science	Duplicate	Factors associated with breast cancer screening intention in Kathmandu Valley, Nepal	Bhandari et al. (2021)
Web of Science	Duplicate	Breast Cancer Awareness of Rural Women in Malaysia: is it the Same as in the Cities?	Norlaili et al. (2013)
Web of Science	Duplicate	The effect of a smartphone application on women's performance and health beliefs about breast self-examination: a quasi-experimental study	Shakery et al. (2021)
Web of Science	Duplicate	A Community-Based Assessment of Knowledge and Practice of Breast Self-Examination and Prevalence of Breast Disease in Southwest Cameroon	Azemfac et al. (2019)

CINAHL	Duplicate	Breast Cancer Awareness and Associated Factors Amongst Women in Peshawar, Pakistan: A Cross-Sectional Study.	Ullah et al. (2021)
CINAHL	Duplicate	Result of randomized control trial to increase breast health awareness among young females in Malaysia.	Akhtari-Zavare et al. (2016)
CINAHL	Duplicate	KNOWLEDGE AND PRACTICE OF BREAST SELF-EXAMINATION AMONG RURAL WOMEN IN SOUTH-WEST NIGERIA: IMPLICATIONS FOR DEVELOPMENT OF WOMEN EMPOWERMENT PROGRAMME.	Hanson et al. (2017)
CINAHL	Duplicate	Using EPPM to Evaluate the Effectiveness of Fear Appeal Messages Across Different Media Outlets to Increase the Intention of Breast Self-Examination Among Chinese Women.	Chen and Yang (2019)
CINAHL	Duplicate	Impact of a Breast Cancer Educational Program on Female University Students' Knowledge, Attitudes, and Practices.	Alsaraireh and Darawad (2019)
CINAHL	Duplicate	Breast Cancer Awareness and Associated Factors Amongst Women in Peshawar, Pakistan: A Cross-Sectional Study.	Ullah et al. (2021)
CINAHL	Duplicate	Factors associated with delay in seeking care for breast symptoms.	Soh et al. (2022)
CINAHL	Duplicate	The Effect of Counseling on Breast Cancer Awareness in Rural Iranian Women: a Randomized Controlled Clinical Trial.	Alizadeh et al. (2019)
CINAHL	Duplicate	Self-Efficacy and Perceived Barriers as Determinants of Breast Self-Examination Among Female Nonmedical Students of the University of Ghana.	Boafo and Tetteh (2020)
CINAHL	Duplicate	The Effect of Education on the Early Diagnosis of Breast and Cervix Cancer on the Women's Attitudes and Behaviors Regarding Participating in Screening Programs.	Koçaöz et al. (2018)
CINAHL	Duplicate	Missed opportunities for breast awareness information among women attending the maternal and child health services of an urban tertiary hospital in Northern Nigeria.	Anyanwu et al. (2016)
CINAHL	Duplicate	Evaluation of Health Belief Model-Based Intervention on Breast Cancer Screening Behaviors among Health Volunteers.	Ghaffari et al. (2019)
CINAHL	Duplicate	Breast Cancer Knowledge and Screening Practice and Barriers Among Women in Madinah, Saudi Arabia.	Al-Zalabani et al. (2018)
CINAHL	Duplicate	Effect of structured training programme on the knowledge and behaviors of breast and cervical cancer screening among the female teachers in Turkey.	Temel et al. (2017)
CINAHL	Duplicate	Health Belief Model and Determinants of Breast Self-Examination Performance.	Mousavi et al. (2021)
CINAHL	Duplicate	Effects of smartphone application education combined with hands-on practice in breast self-examination on junior nursing students in South Korea.	Kang et al. (2020)
CINAHL	Duplicate	Social Determinants of Breast Cancer Screening among Married Women: A Cross-Sectional Study.	Ghanbari et al. (2020)
CINAHL	Duplicate	Breast cancer awareness among Indonesian women at moderate-to-high risk.	Mardela et al. (2017)
CINAHL	Duplicate	Socio-demographic Factors Associated with Utilization of Breast and Cervical Cancer Screening Methods in Turkey.	Urek et al. (2022)
CINAHL	Duplicate	Impact of health talks on knowledge, attitudes and perception of breast cancer screening and treatment amongst healthcare staff by a breast surgical unit in a public healthcare institution: a cross-sectional study.	Hing et al. (2021)
CINAHL	Duplicate	Evaluation of Information and Practices About Breast Cancer Screening Performed in Women Presented to a University Hospital in Istanbul.	Gemici et al. (2020)
CINAHL	Duplicate	Evaluation of a Culturally Tailored Education to Promote Breast and Cervical Cancer Screening Among Chinese-Australian Women.	Kwok and Lim (2016)
CINAHL	Duplicate	Prevalence and Risk Factors for Patient Delay Among Women With Breast Cancer in Rural India.	Gangane et al. (2016)
CINAHL	Duplicate	The effect of knowledge on uptake of breast cancer prevention modalities among women in Kyadondo County, Uganda.	Atuhairwe et al. (2018)
CINAHL	Duplicate	Using Facebook to communicate mammography messages to rural audiences.	Klippert and Schaper (2019)
CINAHL	Duplicate	Factors associated with breast cancer awareness and breast self-examination in Fiji and Kashmir India - a cross-sectional study.	Malik et al. (2020)
CINAHL	Duplicate	Psychosocial predictors of breast self-examination behavior among female students: an application of the health belief model using logistic regression.	Didarloo et al. (2017)
CINAHL	Duplicate	Breast cancer screening behavior, attitude, barriers among middle-aged Chinese women in Macao, China.	Gan et al. (2018)
CINAHL	Duplicate	Perceptions and health beliefs of Greek nursing students about breast self-examination: A descriptive study.	Lavdaniti (2015)
CINAHL	Duplicate	Promoting early presentation of breast cancer in older women: sustained effect of an intervention to promote breast cancer awareness in routine clinical practice.	Dodd et al. (2017)
CINAHL	Duplicate	Breast Camps for Awareness and Early Diagnosis of Breast Cancer in Countries With Limited Resources: A Multidisciplinary Model From Kenya.	Sayed et al. (2016)
CINAHL	Duplicate	Factors affecting mammography screening behaviour among rural Vietnamese women.	Duong et al. (2020)
CINAHL	Duplicate	Determinants of Breast Cancer screening: Application of Protection Motivation Theory.	Ghofranipour et al. (2020)
CINAHL	Duplicate	Promoting early presentation of breast cancer in women over 70 years old in general practice.	Campbell et al. (2016)

CINAHL	Duplicate	Psychometric Properties of the Breast Cancer Screening Beliefs Questionnaire Among Women of Indian Ethnicity Living in Australia.	Kwok et al. (2016)
CINAHL	Duplicate	Setting up a Breast Cancer Awareness Project in Mumbai: Methodology, Experiences and Challenges.	Gadgil et al. (2020)
CINAHL	Duplicate	"Promoting Early Presentation" intervention sustains increased breast cancer awareness in older women for three years: A randomized controlled trial.	Kaushal et al. (2017)
CINAHL	Duplicate	Breast cancer screening behaviors among Chinese women in Mainland China.	Bao et al. (2018)
CINAHL	Duplicate	Comparison of Training via Short Messages and Group Training on Level of Knowledge and Practice of Middle-Aged Women About Breast Cancer Screening Tests.	Naserian et al. (2018)
CINAHL	Duplicate	Knowledge of symptoms and risk factors of breast cancer among women: a community based study in a low socio-economic area of Mumbai, India.	Prusty et al. (2020)
CINAHL	Duplicate	Breast Cancer Prevention Knowledge, Attitudes, and Behaviors Among College Women and Mother-Daughter Communication.	Kratzke et al. (2013)
CINAHL	Duplicate	Differences Among College Women for Breast Cancer Prevention Acquired Information-Seeking, Desired Apps and Texts, and Daughter-Initiated Information to Mothers.	Kratzke et al. (2014)
CINAHL	Duplicate	Health Beliefs and Practice of Breast Self-Examination Among Young Cypriot Women.	Petro-Nustas et al. (2013)
CINAHL	Duplicate	The effect of breast cancer health education on the knowledge, attitudes, and practice: a community health center catchment area.	Ouyang and Hu (2014)
CINAHL	Duplicate	Breast cancer awareness among an inner city group of Nigerian women.	Moodley et al. (2014)
CINAHL	Duplicate	Determinants of cancer screening awareness and participation among Indonesian women.	Anwar et al. (2018)
CINAHL	Duplicate	The effect of education about breast self-examination on knowledge, attitude and practice of women in Nourabad Mamasani health clinics, 2009.	Kashfi et al. (2012)
CINAHL	Duplicate	Breast cancer knowledge and related behaviors among women in Abha City, southwestern Saudi Arabia.	Mahfouz et al. (2013)
CINAHL	Duplicate	The effectiveness of a community-based breast cancer education intervention in the New York State Capital Region.	Zeinomar and Moslehi (2013)
CINAHL	Duplicate	Effectiveness of a Brief Health Education Intervention for Breast Cancer Prevention in Greece Under Economic Crisis.	Merakou et al. (2013)
CINAHL	Duplicate	Determinants of stage at diagnosis of breast cancer in Nigerian women: sociodemographic, breast cancer awareness, health care access and clinical factors.	Jedy-Agba et al. (2017)
CINAHL	Duplicate	A review of breast cancer awareness among women in India: Cancer literate or awareness deficit?	Gupta et al. (2015)
CINAHL	Duplicate	Possible logistic and sociodemographyc factors on breast cancer screening in Turkey: lessons from a women's health project in Mersin province.	Abali et al. (2012)
CINAHL	Duplicate	Assessment of the Knowledge and Practice of Breast Self Examination among Female Cleaners in Obafemi Awolowo University Ile Ife, Nigeria.	Omoyeni et al. (2014)
CINAHL	Duplicate	Managing the illness experience of women with advanced breast cancer: hopes and fears of cancer-related insecurity.	Banning and Tanzeem (2013)
CINAHL	Duplicate	Early Cancer Detection/Screening Behaviors of Individuals Aged 40 Years and Over in Trabzon and the Influencing Factors.	Karadeniz and Cetinkaya (2019)
CINAHL	Duplicate	Influence of Sense of Coherence, Spirituality, Social Support and Health Perception on Breast Cancer Screening Motivation and Behaviors in African American Women.	Conway-Phillips and Janusek (2014)
CINAHL	Duplicate	Impact of social and clinical factors on diagnostic delay of breast cancer: A Cross-sectional Study.	Dianatinasab et al. (2016)
CINAHL	Duplicate	Transcultural adaptation of the Breast Cancer Awareness Measure.	Al-Khasawneh et al. (2016)
CINAHL	Duplicate	Impact of breast cancer patients' awareness on attendance at screening.	Shieh et al. (2012)
CINAHL	Duplicate	Validity and reliability assessment of health belief scales for mammography screening in Greek asymptomatic women.	Anagnostopoulos et al. (2013)
CINAHL	Duplicate	Women's health beliefs and breast cancer screening practices in Nigeria.	Olowokere et al. (2012)
CINAHL	Duplicate	Refining a questionnaire to assess breast cancer knowledge and barriers to screening in Kenya: Psychometric assessment of the BCAM.	Wachira et al. (2017)
CINAHL	Duplicate	Breast cancer knowledge, attitudes and screening behaviors in two groups of Iranian women: physicians and non-health care personnel.	Kadivar et al. (2012)
CINAHL	Duplicate	PUBLIC HEALTH. Preventive Health Practices among Women at Rural Villages in Malaysia.	Norsa'adah and Woorlida (2014)
CINAHL	Duplicate	Distribution of cervical and breast cancer risk factors in women and their screening behaviours.	Karadag et al. (2019)
CINAHL	Duplicate	From the set-up of a screening program of breast cancer patients to the identification of the first BRCA mutation in the DR Congo.	Mvila et al. (2014)
CINAHL	Duplicate	Factors that influence mammography use and breast cancer detection among Mexican-American and African-American women.	Garcia et al. (2012)

CINAHL	Duplicate	Beliefs and attitudes about breast cancer and screening practices among Arab women living in Qatar: a cross-sectional study.	Donnelly et al. (2013)
CINAHL	Duplicate	Breast cancer awareness among women in Eastern China: a cross-sectional study.	Liu et al. (2014)
CINAHL	Duplicate	Home visits to improve breast health knowledge and screening practices in a less privileged area in Jordan.	Taha et al. (2014)
CINAHL	Duplicate	Women with abnormal screening mammography lost to follow-up: An experience from Taiwan.	Kuo et al. (2016)
CINAHL	Duplicate	Sociodemographic determinants of nonattendance in a population-based mammography screening program in the city of Manisa, Turkey.	Dundar et al. (2012)
ASSIA	Duplicate	Affective associations and cognitive beliefs relate to individuals' decisions to perform testicular or breast self-exams	Brown-Kramer and Kiviniemi (2015)
ASSIA	Duplicate	Suc Khoe La Quan Trong Hon Sac Dep! Health is Better than Beauty! A Community-based Participatory Research Intervention to Improve Cancer Screening among Vietnamese Women	Nguyen and Belgrave (2014)
ASSIA	Duplicate	Uptake of Gynecological Cancer Screening and Performance of Breast Self-Examination Among 50-Year-Old Migrant and Non-migrant Women in Germany: Results of a Cross-Sectional Study (InEMa)	Berens et al. (2019)
ASSIA	Duplicate	Mammographic Screening Practices Among Chinese-Australian Women	Kwok et al. (2012)
ASSIA	Duplicate	Analysis of the Purpose of State Health Departments' Tweets: Information Sharing, Engagement, and Action	Thackeray et al. (2013)
ASSIA	Duplicate	Breast and Cervical Cancer Screening and Health Beliefs Among African American Women Attending Educational Programs	Ochoa-Frongia et al. (2012)
ASSIA	Duplicate	The role of psychosocial variables in breast self-examination practice: Results from focus group discussions in Surabaya, Indonesia	Dewi et al. (2022)
ASSIA	Duplicate	Cancer and breast cancer awareness interventions in an intellectual disability context: A review of the literature	Walsh et al. (2021)
ASSIA	Duplicate	Transcultural adaptation of the Breast Cancer Awareness Measure	Al-Khasawneh et al. (2016)
ASSIA	Duplicate	Mammographic Breast Density as a Risk Factor for Breast Cancer: Awareness in a Recently Screened Clinical Sample	O'Neill et al. (2014)
ASSIA	Duplicate	Palliative Care Needs in Breast Cancer Patients Entering Inpatient Hospice in Western Kenya	Tarus et al. (2022)
ASSIA	Duplicate	A Culturally Tailored Intervention for Promoting Breast Cancer Screening Among Women From Faith-Based Communities in Israel: A Randomized Controlled Study	Freund et al. (2019)
ASSIA	Duplicate	Shedding light on women's help seeking behaviour for self discovered breast symptoms	O'Mahony et al. (2013)
Web of Science	Duplicate	"Promoting Early Presentation" intervention sustains increased breast cancer awareness in older women for three years: A randomized controlled trial	Kaushal et al. (2017)
Web of Science	Duplicate	A Theory-Based Intervention to Improve Breast Cancer Awareness and Screening in Jamaica	Anakwenze et al. (2015)
Web of Science	Duplicate	Psychotherapeutic intervention on breast self-examination based on Health Belief Model	Stefanut and Vintila (2022)
Web of Science	Duplicate	Design and implementation of an Internet-Based cancer risk assessment tool: Use over 10 years	LaRiviere et al. (2022)
Web of Science	Duplicate	Barriers to breast cancer screening in Atlanta, GA: results from the Pink Panel survey at faith-based institutions	Balenger et al. (2022)
Cochrane Library	Duplicate	“Promoting Early Presentation” intervention sustains increased breast cancer awareness in older women for three years: a randomized controlled trial	Kaushal et al. (2017)
Cochrane Library	Duplicate	Evaluating a DVD promoting breast cancer awareness among black women aged 25-50 years in East London	Greenhough et al. (2016)
Cochrane Library	Duplicate	"Promoting Early Presentation" intervention sustains increased breast cancer awareness in older women for three years: a randomized controlled trial	Kaushal et al. (2017)
Cochrane Library	Duplicate	Getting youth to Check it Out!®: a new approach to teaching self-screening	Jones et al. (2015)
CINAHL	Duplicate	A Culturally Tailored Intervention for Promoting Breast Cancer Screening Among Women From Faith-Based Communities in Israel: A Randomized Controlled Study.	Freund et al. (2019)
CINAHL	Duplicate	Determining the need for a breast cancer awareness educational intervention for women with mild/moderate levels of intellectual disability: A qualitative descriptive study.	Walsh et al. (2022)
CINAHL	Duplicate	Low Awareness of Breast Cancer and Considerable Barriers to Early Presentation Among Saudi Women at a Primary Care Setting.	Al-Khamis (2018)
CINAHL	Duplicate	PUBLIC HEALTH. Preventive Health Practices among Women at Rural Villages in Malaysia.	Norsa'adah and Wnorlida (2014)
CINAHL	Duplicate	“Injustice! That Is the Cause”.	McEwan et al. (2014)
ASSIA	Duplicate	The Psychometric Properties of the Greek Version of Champion's Health Belief Model Scale	Tsangari et al. (2012)

ASSIA	Duplicate	Health Beliefs of African American Women on Breast Self-Exam	Registe and Porterfield (2012)
ASSIA	Duplicate	Promoting breast cancer awareness in older women during the seasonal flu vaccination campaign	Kaushal et al. (2019)
ASSIA	Duplicate	Promoting early presentation of breast cancer: a preliminary evaluation of a written intervention	Forster et al. (2014)
APA Psychinfo	Duplicate	The effect of counseling on breast cancer awareness in rural Iranian women: A randomized controlled clinical trial.	Sabeg et al. (2019)
APA Psychinfo	Duplicate	Comparison of training via short messages and group training on level of knowledge and practice of middle-aged women about breast cancer screening tests.	Naserian et al. (2018)
APA Psychinfo	Duplicate	Promoting early presentation of breast cancer: A preliminary evaluation of a written intervention.	Forster et al. (2014)
APA Psychinfo	Duplicate	Cultural beliefs and attitudes about breast cancer and screening practices among Arabic women in Australia.	Kwok et al. (2016)
APA Psychinfo	Duplicate	Effects of interventions based on health behavior models on breast cancer screening behaviors of migrant women in Turkey.	Tuzcu et al. (2016)
Web of Science	Duplicate	Effectiveness of educational intervention on breast cancer knowledge and breast self-examination among female university students in Bangladesh: a pre-post quasi-experimental study	Sarker et al. (2022)
Web of Science	Duplicate	Effect of Health Education on Female Teachers' Knowledge and Practices Regarding Early Breast Cancer Detection and Screening in the Jazan Area: a Quasi-Experimental Study	Alameer et al. (2019)
CINAHL	Duplicate	Effects of mobile text messaging on breast cancer and breast self-examination (BSE) knowledge, BSE self-efficacy, and BSE frequency: a randomised controlled trial.	Labrague et al. (2021)
APA Psychinfo	Duplicate	Effects of mobile text messaging on breast cancer and breast self-examination (BSE) knowledge, BSE self-efficacy, and BSE frequency: A randomised controlled trial.	Labrague et al. (2021)
APA Psychinfo	Duplicate	Communicating breast cancer screening with young women: An experimental test of didactic and narrative messages using video and infographics.	Occa and Suggs (2016)
Web of Science	No - age 35-65 years	Acceptability and compliance with a breast cancer prevention campaign in the Northwest Region, Iran	Dastgiri et al. (2022)
APA Psychinfo	No - age in 50s	The effect of breast cancer health education on the knowledge, attitudes, and practice: A community health center catchment area.	Ouyang and Hu (2014)
Web of Science	No - age includes over 50 years	The effectiveness of pharmacist-based coaching in improving breast cancer-related health behaviors: A randomized controlled trial	Ibrahim et al. (2021)
Web of Science	No - age includes over 50 years	From the set-up of a screening program of breast cancer patients to the identification of the first BRCA mutation in the DR Congo	Mvila et al. (2014)
Cochrane Library	No - age includes over 50 years	Impact of a mass media campaign on breast cancer symptoms awareness and screening uptake in Malaysia: findings from a quasi-experimental study	Protocol
Web of Science	No - age no suitable up to 65 years	Impact of health talks on knowledge, attitudes and perception of breast cancer screening and treatment amongst healthcare staff by a breast surgical unit in a public healthcare institution: a cross-sectional study	Hing et al. (2021)
Cochrane Library	No - age no suitable up to 70	The Effect of Counseling on Breast Cancer Awareness in Rural Iranian Women: a Randomized Controlled Clinical Trial	Alizadeh et al. (2019)
APA Psychinfo	No - age not suitable	Evaluation of health belief model-based intervention on breast cancer screening behaviors among health volunteers.	Ghaffari et al. (2019)
APA Psychinfo	No - age not suitable	Using Facebook to communicate mammography messages to rural audiences.	Klippert and Schaper (2019)
Web of Science	No - age not suitable	Phone-Based Breasts Self-Examination as an Intervention in Breast Cancer Control During the COVID-19 Pandemic	Subramanian and Ravi (2022)
Web of Science	No - age not suitable	Breast Self-examination Practices and the Effect of a Planned Training Program in Western Turkey	Donmez et al. (2012)
CINAHL	No - age not suitable	Breast self-examination training video with the sign language for deaf women: An interventional study.	Kocask Akgün and Ildan Calim (2022)
CINAHL	No - age not suitable	Breast cancer prevention in women treated at Primary Care Unit.	Leda de Arruda et al. (2015)
Medline	No - age not suitable	Outcome evaluation of an educational program for Japanese midwives to promote breast awareness for women	Kataoka et al. (2015)
Medline	No - age not suitable	Clinical breast examination screening by trained laywomen in Malawi integrated with other health services	Gutnik et al. (2016)
Web of Science	No - age not suitable	Clinical breast examination screening by trained laywomen in Malawi integrated with other health services	Anakwenze et al. (2015)
CINAHL	No - age not suitable	Promoting breast cancer awareness in older women during the seasonal flu vaccination campaign.	Kaushal et al. (2019)
CINAHL	No - age not suitable (16-74 yrs)	A Community-Oriented Approach to Breast Cancer in a Low-Resource Setting: Improving Awareness, Early Detection and Treatment of Breast Cancer in Tajikistan	Talib et al. (2016)

CINAHL	No - age not suitable (18 to 62 yrs)	The Effect of Instruction Point of View on Self-efficacy for Performing Breast Self-exams.	Aikman et al. (2017)
CINAHL	No - age not suitable (18-89 years)	Breast Cancer Education for the Deaf Community in American Sign Language.	Hickey et al. (2013)
Medline	No - age not suitable (18-89)	Breast cancer education for the Deaf community in American Sign Language	Hickey et al. (2013)
CINAHL	No - age not suitable (18-95 years)	Outcomes of a structured education intervention for Latinas concerning breast cancer and mammography.	Laughman et al. (2017)
Web of Science	No - age not suitable (20-60 yrs)	Effect of Education Based on Health Belief Model on the Behavior of Breast Cancer Screening in Women	Masoudiyekta et al. (2018)
Medline	No - age not suitable (20-65)	Theory-based training to promote breast cancer screening among women with breast cancer worries: randomized controlled trial	Tashan et al. (2020)
Web of Science	No - age not suitable (20-84 years)	Promoting Breast Cancer Awareness and Screening Practices for Early Detection in Low-Resource Settings	Wu and Lee (2019)
ASSIA	No - age not suitable (30 -83 yrs)	A Community-Based Intervention to Promote Breast Cancer Awareness and Screening among Asian American Women	Wu et al. (2014)
Web of Science	No - age not suitable (30-60 yrs)	Breast health awareness campaign and screening pilot in a Kenyan County: Findings and lessons	Mwenda et al. (2022)
APA Psychinfo	No - age not suitable (30-69)	Setting up a breast cancer awareness project in Mumbai: Methodology, experiences and challenges.	Gadgil et al. (2020)
APA Psychinfo	No - age not suitable (30-83 years)	Community-based intervention to promote breast cancer awareness and screening among Asian American women.	Tsu, Yin et al. (2014)
APA Psychinfo	No - age not suitable (35 and 83)	A theory-based intervention to improve breast cancer awareness and screening in Jamaica.	Anakwenze et al. (2015)
Medline	No - age not suitable (35-64)	Evaluation of effect of self-examination and physical examination on breast cancer	Hassan et al. (2015)
Medline	No - age not suitable (40-69)	The Effect of Counseling on Breast Cancer Awareness in Rural Iranian Women: a Randomized Controlled Clinical Trial	Sabeg et al. (2019)
CINAHL	No - age not suitable (41 to 86 yrs)	Adaptation of an evidence-based intervention for Appalachian women: new STEPS (Strength Through Education, Physical fitness and Support) for breast health.	Gallant et al. (2013)
CINAHL	No - age not suitable (42-82 years)	Evaluating the effectiveness of faith-based breast health education.	Brown and Cowart (2018)
APA Psychinfo	No - age not suitable (50-70)	Interventional education methods for increasing women's participation in breast cancer screening program	Seven et al. (2015)
Medline	No - age not suitable (over 50 years included)	Application of Personalized Education in the Mobile Medical App for Breast Self-Examination	Blaida et al. (2022)
Medline	No - age not suitable (over 60 years)	Promoting early presentation of breast cancer: a preliminary evaluation of a written intervention	Forster et al. (2014)
Medline	No - age not suitable >35 yrs	Evaluation of Health Belief Model-Based Intervention on Breast Cancer Screening Behaviors among Health Volunteers	Ghaffari et al. (2019)
Medline	No - age not suitable 18-59	Effects of Interventions Based on Health Behavior Models on Breast Cancer Screening Behaviors of Migrant Women in Turkey	Tuzcu et al. (2016)
Web of Science	No - age not suitable 20-79 years	Home visits to improve breast health knowledge and screening practices in a less privileged area in Jordan	Taha et al. (2014)
Medline	No - age not suitable 40-60 years	Comparison of Training via Short Messages and Group Training on Level of Knowledge and Practice of Middle-Aged Women About Breast Cancer Screening Tests	Naserian et al. (2018)

APA Psychinfo	No - age not suitable 40-60 years	A culturally tailored intervention for promoting breast cancer screening among women from faith-based communities in Israel: A randomized controlled study.	Freund et al. (2019)
Web of Science	No - age not suitable ages in 50s	Can urban Accredited Social Health Activist (ASHA) be change agent for breast cancer awareness in urban area: Experience from Ahmedabad India	Memon et al. (2019)
APA Psychinfo	No - age not suitable in 50s	The effectiveness of a community-based breast cancer education intervention in the New York State Capital Region.	Zeinomar and Moslehi (2013)
Web of Science	No - age not suitable more than 50 yrs	Effects of a Randomized Controlled Trial to Increase Repeat Mammography Screening in Iranian Women	Taymoori et al. (2015)
Web of Science	No - age not suitable more than 50 yrs	Increasing breast cancer awareness and breast examination practices among women through health education and capacity building of primary healthcare providers: a pre-post intervention study in low socioeconomic area of Mumbai, India	Prusty et al. (2021)
APA Psychinfo	No - age not suitable more than 50 yrs	Development and pilot test of pictograph-enhanced breast health-care instructions for community-residing immigrant women.	Choi (2012)
No (duplicate)	No - age not suitable not all 20-49 as specified in abstract.	The Effectiveness of Health Belief Model Initiative in Breast Cancer Screening Behaviors among Women Health Volunteers	Matlabi et al. (2021)
ASSIA	no - age not suitable older women	Evaluating the effectiveness of faith-based breast health education	Brown et al. (2018)
Medline	No - age not suitable over 50	Breast self-examination education for BRCA mutation carriers by clinical nurse specialists	Visser et al. (2015)
ASSIA	No - age not suitable over 50 yrs	Changing Mammography-Related Beliefs Among American Muslim Women: Findings from a Religiously-Tailored Mosque-Based Intervention	Padela et al. (2019)
Web of Science	No - age not suitable some under 18 yrs	Breast Camps for Awareness and Early Diagnosis of Breast Cancer in Countries With Limited Resources: A Multidisciplinary Model From Kenya	Sayed et al. (2016)
Web of Science	No - age not suitable some under 18 yrs	Evaluation of the SnapChat mobile social networking application for breast cancer awareness among Saudi students in the Dammam Region of the Kingdom of Saudi Arabia	Alanzi et al. (2018)
Web of Science	No - age not suitable some under 18 yrs	Effectiveness of Online Education in Teaching Breast Self-Examination	Tuna et al. (2014)
APA Psychinfo	No - age not suitable under 18 yrs	Sustainable and cost-effective teenage breast awareness campaigns: Insights from a Nigerian high school intervention study.	ifediora et al.
Web of Science	No - age not suitable under 18 yrs	Effects of an Educational Intervention on Breast Self-Examination, Breast Cancer Prevention-Related Knowledge, and Healthy Lifestyles in Scholars from a Low-Income Area in Bogota, Colombia	Masso-Calderon et al. (2018)
Web of Science	No - age not suitable under 18 yrs	The impact of a breast cancer educational intervention in Ghanaian high schools	Nsaful et al. (2022)
Web of Science	No - age not suitable under 18 yrs	Improving knowledge about breast cancer and breast self examination in female Nigerian adolescents using peer education: a pre-post interventional study	Sadoh et al. (2021)
Web of Science	No - age not suitable under 18 yrs	Preventative Health and Risk Behaviors Among Adolescent Girls With and Without Family Histories of Breast Cancer	Schwartz et al. (2019)
Web of Science	No - age not suitable under 18 yrs	Implementation of a School-Based Educational Programto Increase Breast Cancer Awareness and Promote Intergenerational Transmission of Knowledge in a Rural Mexican Community	Soto-Perez-de-Celis et al. (2017)
Medline	No - age not suitable under 18 yrs	Getting youth to Check it Out!®: a new approach to teaching self-screening	Jones et al. (2015)
APA Psychinfo	No - age not suitable under 18 yrs	The impact of education on knowledge attitude and practice of breast self-examination among adolescents girls at the Fiwasaye Girls Grammar School Akure, Nigeria	Ibitoye and Thupayegale-Tshwenegae (2021)
APA Psychinfo	No - age not suitable under 18 yrs	Getting youth to check it out!®: A new approach to teaching self-screening.	Jones et al. (2015)
APA Psychinfo	No - age not suitable under 18 yrs	Teaching breast health to adolescent females in high school: Comparing interactive teaching with traditional didactic methods.	Horton (2012)

Web of Science	No - age not suitable up to 59	Educational Study to Increase Breast Cancer Knowledge Level and Scanning Participation among Women Working at a University	Ozerdogan et al. (2017)
Cochrane Library	No - age not suitable up to 60	Outcome evaluation of an educational program for Japanese midwives to promote breast awareness for women	Kataoka et al. (2015)
Medline	No - age not suitable up to 60 years	The effect of a smartphone application on women's performance and health beliefs about breast self-examination: a quasi-experimental study.	Shakery et al. (2021)
Web of Science	No - age not suitable up to 75 years	Impact of breast cancer awareness month on detection of breast cancer in a private hospital	Karabay et al. (2018)
Web of Science	No - age range 20 -60 yrs	The effect of video-based multimedia training on knowledge, attitude, and performance in breast self-examination	Karimian et al. (2022)
Web of Science	No - age range 20 -60 yrs	Impact of health education intervention on breast cancer awareness among rural women of Tamil Nadu	Nisha and Murali (2020)
Web of Science	No - age range not clearly specified	Role-playing versus Conventional Strategy in Midwifery Clinical Education on Breast Self-examination: A Quasi-Experimental Study	Khatiban et al. (2017)
Web of Science	No - age range not clearly specified	The Effects of Training on Knowledge and Beliefs About Breast Cancer and Early Diagnosis Methods Among Women	Yilmaz et al. (2017)
CINAHL	No - age range not clearly specified	The effect of education about breast self-examination on knowledge, attitude and practice of women in Nourabad Mamasani health clinics, 2009.	Kashfi et al. (2012)
Medline	No - age range not clearly specified	Result of randomized control trial to increase breast health awareness among young females in Malaysia	Akhtari-Zavare et al. (2016)
CINAHL	No - age range not clearly specified	The Impact of Female Students' Breast Self-Examination training on their Mothers' Awareness.	Abasi et al. (2018)
CINAHL	No - age range not clearly specified	Effectiveness of a Brief Health Education Intervention for Breast Cancer Prevention in Greece Under Economic Crisis.	Merakou et al. (2013)
CINAHL	No - age range not clearly specified	Effects of Tailored Message Education About Breast Cancer Risk Appraisal for Obese Korean Women.	Park et al. (2013)
Web of Science	No - age range not clearly specified	The Effect of Peer Education upon Breast Self-Examination Behaviors and Self-Esteem among University Students	Ayran et al. (2017)
Medline	No - age range not clearly specified	Peer leaders and phone prompts: Implications in the Practice of Breast Care among College Students	Pagkatipunan (2018)
Web of Science	No - age range not clearly specified	Evaluation of the impact of a breast cancer awareness program in rural Ghana: A cross-sectional survey	Mena et al. (2014)
Web of Science	No - age range not provided	Psychotherapeutic intervention on breast self-examination based on Health Belief Model	Stefanut and Vintila (2022)
Web of Science	No - age range not provided	Comparison of the level of knowledge on, attitude towards, and skills of medical and nursing students between pre- and post- training of the breast self-examination in Oman	Ranganath et al. (2020)
Medline	No - Age range not provided	Impact of a breast cancer educational program on female university students' knowledge, attitudes, and practices	Alsaraireh and Darawad (2019)
Web of Science	No - Age range not provided	Evaluating the Effect of Health Education Intervention on the Health Beliefs and Behaviors of First-Degree Female Relatives of Breast Cancer Patients	Olgun and Dizer (2022)
Web of Science	No - no BCA intervention	Promoting Clinical Breast Evaluations in a Lower Middle-Income Country Setting: An Approach Toward Achieving a Sustainable Breast Health Program	Buribekova et al. (2018)
CINAHL	No - no BCA intervention	BREAST SELF-EXAMINATION: OLDER ADULT WOMEN'S EXPERIENCE IN AN FAMILY HEALTH UNIT.	da Silva (2015)
Web of Science	No - no BCA intervention	Setting up a community-based cervical screening service in a low-income country: a pilot study from north-western Tanzania	Masalu et al. (2017)
APA Psychinfo	No - no BCA intervention	The effect of education on the early diagnosis of breast and cervix cancer on the women's attitudes and behaviors regarding participating in screening programs.	Kocaöz et al. (2018)
APA Psychinfo	No - no BCA intervention	Evaluation of a culturally tailored education to promote breast and cervical cancer screening among Chinese-Australian women.	Kwok and Lim (2016)
APA Psychinfo	No - no BCA intervention	Effect of planned follow-up on married women's health beliefs and behaviors concerning breast and cervical cancer screenings.	Kolutek and Avci (2018)
APA Psychinfo	No - no BCA intervention	Setting up a community-based cervical screening service in a low-income country: A pilot study from north-western Tanzania	Masalu et al. (2017)
Web of Science	No - no BCA intervention	The Effect of Training and Monitoring at Home on the Knowledge Level and Practices of Married Women Regarding Breast and Cervical Cancer	Kolutek and Avci (2015)

Web of Science	No - no BCA intervention	Marketing communication in the area of breast and cervical cancer prevention	Cvijovic et al. (2016)
Web of Science	No - no BCA intervention	Effect of structured training programme on the knowledge and behaviors of breast and cervical cancer screening among the female teachers in Turkey	Temel et al. (2017)
CINAHL	No - no BCA intervention	Suc Khoe La Quan Trong Hon Sac Dep! Health is Better than Beauty! A Community-based Participatory Research Intervention to Improve Cancer Screening among Vietnamese Women.	Nguyen and Belgrave (2014)
CINAHL	No - no BCA intervention	Uptake of Gynecological Cancer Screening and Performance of Breast Self-Examination Among 50-Year-Old Migrant and Non-migrant Women in Germany: Results of a Cross-Sectional Study (InEMa).	Berens et al. (2019)
CINAHL	No - no BCA intervention	Breast and cervical cancer screening for risk assessment in Cambodian women.	Vorn et al. (2020)
CINAHL	No - no BCA intervention	Effect of Planned Follow-up on Married Women's Health Beliefs and Behaviors Concerning Breast and Cervical Cancer Screenings.	Kolutek et al. (2018)
CINAHL	No - no BCA intervention	Grenadian Women's Perspectives on Screening for Breast and Cervical Cancers: A Participatory Approach to Understanding Prevention.	Thomas-Purcell et al. (2016)
ASSIA	No - no BCA intervention	Mobile Phone Text Messaging Intervention for Cervical Cancer Screening: Changes in Knowledge and Behavior Pre-Post Intervention	Lee et al. (2014)
ASSIA	No - no BCA intervention	Raising Awareness About Cervical Cancer Using Twitter: Content Analysis of the 2015 #SmearForSmear Campaign	Lenoir et al. (2017)
ASSIA	No - no BCA intervention	Improving Cancer Screening for Underserved Women Through an FNP Student-Led Clinic	Weston et al. (2018)
CINAHL	No - no BCA intervention	The Effect of Telephone Counseling and Education on Breast Cancer Screening in Family Caregivers of Breast Cancer Patients.	Nasiriani et al. (2017)
Web of Science	No - no BCA intervention	"They say it's more aggressive in black women": Biosociality, breast cancer, and becoming a population "at risk"	Brown et al. (2019)
Web of Science	No - no BCA intervention	Strengthening Breast Cancer Screening Mammography Services in Pakistan Using Islamabad Capital Territory as a Pilot Public Health Intervention	Majeed et al. (2022)
Web of Science	No - no BCA intervention	Women with abnormal screening mammography lost to follow-up An experience from Taiwan	Kuo et al. (2016)
Web of Science	No - no BCA intervention	Understanding women's perspectives on breast cancer is essential for cancer control: knowledge, risk awareness, and care-seeking in Mwanza, Tanzania	Chao et al. (2020)
Web of Science	No - no BCA intervention	Do Saudi Nurses in Primary Health Care Centres have Breast Cancer Knowledge to Promote Breast Cancer Awareness?	Yousuf et al. (2012)
Web of Science	No - no BCA intervention	Barriers to breast cancer screening in Atlanta, GA: results from the Pink Panel survey at faith-based institutions	Balenger et al. (2022)
Web of Science	No - no BCA intervention	Awareness, attitudes and practices of women in relation to breast cancer in Niger	Abdou et al. (2020)
Web of Science	No - no BCA intervention	Breast cancer screening practices among Vietnamese women and factors associated with clinical breast examination uptake	Ngan et al. (2022)
Web of Science	No - no BCA intervention	Using Twitter for breast cancer prevention: an analysis of breast cancer awareness month	Thackeray et al. (2013)
Web of Science	No - no BCA intervention	Breast cancer awareness's and attitude among regular health-care users versus irregular in a sample of Kurdish women in the west of Iran	Rastad et al. (2021)
Web of Science	No - no BCA intervention	Determinants of breast cancer early detection for cues to expanded control and care: the lived experiences among women from Western Kenya	Kisiangani et al. (2018)
Web of Science	No - no BCA intervention	Factors that influence mammography use and breast cancer detection among Mexican-American and African-American women	Garcia et al. (2012)
Web of Science	No - no BCA intervention	Breast Cancer in Turkey; An Analysis of 20.000 Patients with Breast Cancer	Ozmen et al. (2019)
Web of Science	No - no BCA intervention	Screening for Breast Cancer in a Low Middle Income Country: Predictors in a Rural Area of Kerala, India	Sreedevi et al. (2014)
Web of Science	No - no BCA intervention	Situational analysis of breast health care systems: Why context matters	Duggan et al. (2020)
Web of Science	No - no BCA intervention	Impact of mammography screening programmes on breast cancer mortality in Switzerland, a country with different regional screening policies	Herrmann et al. (2018)
Web of Science	No - no BCA intervention	Reflexivity and the challenges of collecting sensitive data in India: a research note	Fletcher-Brown (2020)
Web of Science	No - no BCA intervention	Histopathological Spectrum of Breast Lesions - A Study Done in a Tertiary Care Hospital	Padmon et al. (2020)
Web of Science	No - no BCA intervention	Mammographic Breast Density as a Risk Factor for Breast Cancer: Awareness in a Recently Screened Clinical Sample	O'Neill et al. (2014)
Web of Science	No - no BCA intervention	Dissecting the journey to breast cancer diagnosis in sub-Saharan Africa: Findings from the multicountryABC-DOcohort study	Foerster et al. (2021)
Web of Science	No - no BCA intervention	Presentation, diagnosis and management of locally advanced breast cancer: Is it different in low/middle income countries?	Manzoor et al. (2019)
Web of Science	No - no BCA intervention	Evolution of accesses to information on breast cancer and screening on the Brazilian National Cancer Institute website: an exploratory study	Vasconcellos-Silva et al. (2018)
Web of Science	No - no BCA intervention	Lay perceptions of breast cancer in Western Kenya	Naanyu et al. (2015)
Web of Science	No - no BCA intervention	Barriers to Timely Diagnosis and Management of Breast Cancer: Observations from a Tertiary Referral Center in Resource Poor Setting	Shrevamsa et al. (2020)

Web of Science	No - no BCA intervention	Status and Determinants of Health Literacy among Adolescents in Guangdong, China	Ye et al. (2014)
Cochrane Library	No - no BCA intervention	Randomized trials on mammography screening and the left-to-nature design.	Autier et al. (2014)
CINAHL	No - no BCA intervention	Health Responsibility Levels and Knowledge and Practices Related to Early Detection of Women' Breast Cancer.	Gungormus et al. (2018)
ASSIA	No - no BCA intervention	Black and South Asian women's experiences of breast cancer: A qualitative study	Patel (2014)
APA Psychinfo	No - no BCA intervention	Breast self-examination and health beliefs in Grenadian women.	Delpech and Haynes-Smith (2015)
Medline	No - no BCA intervention	Breast cancer awareness, risk factors and screening practices among future health professionals in Ghana: A cross-sectional study	Osei-Afriyie et al. (2021)
Medline	No - no BCA intervention	Knowledge, awareness, and practice of breast self-examination among females in Mosul city, Iraq	Khalid AlQazaz et al. (2022)
Medline	No - no BCA intervention	Rural women's awareness about breast cancer in southeastern Iran: a cross-sectional study	Balouchi et al. (2016)
Medline	No - no BCA intervention	Breast cancer awareness of rural women in Malaysia: is it the same as in the cities?	Norlaili et al. (2013)
Medline	No - no BCA intervention	Adenolipoma of the breast	Nili et al. (2015)
Medline	No - no BCA intervention	Predictors affecting breast self-examination practive among Turkish women	Doganer et al. (2014)
Medline	No - no BCA intervention	Breast cancer and racial disparity between Caucasian and African American women part 1 (BRCA-1)	Tariq et al. (2013)
Medline	No - no BCA intervention	Determinants of participation in a breast cancer screening trial in trivandrum district, India	Grosse Frie et al. (2013)
Medline	No - no BCA intervention	Correlation Study of Knowledge and Behavior Regarding Breast Care among Female Undergraduate Students in China	Liu et al. (2014)
APA Psychinfo	No - no BCA intervention	Factors affecting mammography screening behaviour among rural Vietnamese women.	Duong et al. (2020)
APA Psychinfo	No - no BCA intervention	Breast cancer knowledge and screening practice and barriers among women in Madinah, Saudi Arabia.	Al-Zalabani et al. (2018)
APA Psychinfo	No - no BCA intervention	Are changes in breast self-exam recommendations and early misperceptions of breast cancer risk increasing women's future risks?	Polek and Hardie (2016)
APA Psychinfo	No - no BCA intervention	Access to and engagement with cervical and breast screening services for women with disabilities in Aotearoa New Zealand.	Pearson et al. (2022)
APA Psychinfo	No - no BCA intervention	Breast size dissatisfaction, but not body dissatisfaction, is associated with breast self-examination frequency and breast change detection in British women.	Swami and Furnham (2018)
APA Psychinfo	No - no BCA intervention	Self-efficacy and perceived barriers as determinants of breast self-examination among female nonmedical students of the University of Ghana	Boafo and Tetteh (2020)
APA Psychinfo	No - no BCA intervention	Uptake of gynecological cancer screening and performance of breast self-examination among 50-year-old migrant and non-migrant women in Germany: Results of a cross-sectional study (inEMa).	Berens et al. (2019)
APA Psychinfo	No - no BCA intervention	Practice of breast self-examination and knowledge of breast cancer among female university students in Korea.	Shin et al. (2012)
APA Psychinfo	No - no BCA intervention	Assessment of the role of breast cancer awareness in the use of health screening by Asian-American women	Batchu (2022)
APA Psychinfo	No - no BCA intervention	Factors associated with breast cancer screening behaviors in a sample of Jamaican women in 2013.	Balas et al. (2020)
APA Psychinfo	No - no BCA intervention	Psychometric properties of the Modified Breast Cancer Screening Beliefs Questionnaire among Mainland Chinese women.	Bao et al. (2017)
APA Psychinfo	No - no BCA intervention	A mixed methods, community-based investigation on women's cancer awareness in Haiti.	Tillyard et al. (2019)
APA Psychinfo	No - no BCA intervention	The health belief model and prediction of breast self-examination practices in female Mexican college students	Juarez-Garcia and Tellez (2019)
APA Psychinfo	No - no BCA intervention	Predictors of breast and cervical cancer screening uptake prior to the introduction of centralized nationwide screening in Poland.	Starczewska
APA Psychinfo	No - no BCA intervention	Breast cancer awareness, attitude and practices among female university students: A descriptive study from Jordan.	Alsaraireh and Darawad (2019)
APA Psychinfo	No - no BCA intervention	Factors associated with breast cancer screening intention in Kathmandu Valley, Nepal.	Bhandari et al. (2021)
APA Psychinfo	No - no BCA intervention	Breast and cervical cancer screening and health beliefs among African American women attending educational programs.	Ochoa-Frongia et al. (2012)
APA Psychinfo	No - no BCA intervention	Health beliefs of midwifery students at Istanbul University about breast cancer and breast self-examination acknowledgements.	Gençtürk and Demirezan (2017)
APA Psychinfo	No - no BCA intervention	Breast cancer screening behaviors among Chinese women in Mainland China.	Bao et al. (2018)
APA Psychinfo	No - no BCA intervention	Distribution of cervical and breast cancer risk factors in women and their screening behaviours.	Karadag et al. (2019)
APA Psychinfo	No - no BCA intervention	The effect of breast cancer fatalism on breast cancer awareness among Turkish women.	Altintas et al. (2017)

APA Psychinfo	No - no BCA intervention	Possible logistic and sociodemographic factors on breast cancer screening in Turkey: Lessons from a women’s health project in Mersin province.	Abali et al. (2012)
APA Psychinfo	No - no BCA intervention	Breast cancer screening beliefs and barriers among college-aged women.	Wilson (2016)
APA Psychinfo	No - no BCA intervention	Low awareness of breast cancer and considerable barriers to early presentation among Saudi women at a primary care setting.	Al-Khamis (2018)
APA Psychinfo	No - no BCA intervention	Knowledge, attitudes, and practices of breast cancer screening methods among female patients in primary healthcare centers in Najran, Saudi Arabia.	Alshahrani et al. (2019)
APA Psychinfo	No - no BCA intervention	Prevalence and risk factors for patient delay among women with breast cancer in rural India.	Gangane et al. (2016)
APA Psychinfo	No - no BCA intervention	The relationship between body image disturbance and health maintenance behaviors: An assessment of breast self-examination among women.	Ridolfi (2015)
APA Psychinfo	No - no BCA intervention	Psychometric properties of the Breast Cancer Screening Beliefs Questionnaire among women of Indian ethnicity living in Australia.	Kwok et al. (2016)
APA Psychinfo	No - no BCA intervention	Philippine-based Filipino women and breast cancer	Azutillo (2020)
APA Psychinfo	No - no BCA intervention	Validation of the Indonesian version of Champion’s Health Belief Model Scale for breast self-examination.	Dewi (2018)
APA Psychinfo	No - no BCA intervention	Health beliefs and practice of breast self-examination among young Cypriot women.	Petro-Nustas et al. (2013)
APA Psychinfo	No - no BCA intervention	Korean American women's preventive health care practices: Stratified samples in California, USA.	Lee et al. (2012)
APA Psychinfo	No - no BCA intervention	Health literacy, mammogram awareness and screening among tertiary hospital women patients.	Yilmazel (2018)
APA Psychinfo	No - no BCA intervention	Differences among college women for breast cancer prevention acquired information-seeking, desired apps and texts, and daughter-initiated information to mothers.	Kratzke et al. (2014)
APA Psychinfo	No - no BCA intervention	Perceptions and health beliefs of Greek nursing students about breast self-examination: A descriptive study.	Lavdaniti (2015)
APA Psychinfo	No - no BCA intervention	Breast cancer knowledge, attitude, and screening practices among Hispanic/Latino women.	Seepersaud (2020)
APA Psychinfo	No - no BCA intervention	Nursing students' breast cancer knowledge and breast self-examination technique confidence.	Gaud (2017)
APA Psychinfo	No - no BCA intervention	Impact of breast cancer patients' awareness on attendance at screening.	Shieh et al. (2012)
APA Psychinfo	No - no BCA intervention	Shedding light on women's help seeking behaviour for self discovered breast symptoms.	O'Mahony et al. (2013)
APA Psychinfo	No - no BCA intervention	Breast cancer knowledge and related behaviors among women in Abha City, southwestern Saudi Arabia.	Mahfouz et al. (2013)
APA Psychinfo	No - no BCA intervention	Evaluating female nursing students' knowledge and attitudes regarding breast self-examination.	Sapountzi-Krepia et al. (2017)
APA Psychinfo	No - no BCA intervention	Breast cancer perceptions and screening behaviours among Korean women in Australia.	Kwok et al. (2020)
APA Psychinfo	No - no BCA intervention	The use of advertising appeals in breast cancer detection messages: A web content analysis.	Dobrenova et al. (2019)
APA Psychinfo	No - no BCA intervention	Breast cancer screening among women of child-bearing age.	Munyaradzi et al. (2014)
APA Psychinfo	No - no BCA intervention	Breast cancer screening practices among Hong Kong Chinese women.	Kwok and Fong (2014)
APA Psychinfo	No - no BCA intervention	Breast cancer screening: The role of attachment.	Tuck and Consedine (2015)
APA Psychinfo	No - no BCA intervention	The Breast Size Satisfaction Survey (BSSS): Breast size dissatisfaction and its antecedents and outcomes in women from 40 nations.	Swami et al. (2020)
APA Psychinfo	No - no BCA intervention	Breast cancer prevention knowledge, attitudes, and behaviors among college women and mother–daughter communication.	Kratzke et al. (2013)
APA Psychinfo	No - no BCA intervention	Validation of the Korean version of the Breast Cancer Screening Beliefs Questionnaire.	Kwok et al. (2017)
APA Psychinfo	No - no BCA intervention	Breast cancer awareness among Indonesian women at moderate-to-high risk.	Mardela et al. (2017)
APA Psychinfo	No - no BCA intervention	Managing the illness experience of women with advanced breast cancer: Hopes and fears of cancer-related insecurity.	Banning and Tanzeem (2013)
APA Psychinfo	No - no BCA intervention	Patient Voices Network: Bringing breast cancer awareness and action into underserved communities.	Reilly et al. (2018)
APA Psychinfo	No - no BCA intervention	Breast cancer health beliefs and perceived barriers to self-examination amongst Hindu women in South Africa.	Govender et al. (2013)
APA Psychinfo	No - no BCA intervention	Preventative health practices among women at rural villages in Malaysia.	Norsa'adah and Woorlida (2014)
APA Psychinfo	No - no BCA intervention	Validity and reliability assessment of health belief scales for mammography screening in Greek asymptomatic women.	Anagnostopoulos et al. (2013)
APA Psychinfo	No - no BCA intervention	The psychometric properties of the Greek version of Champion's Health Belief Model Scale.	Tsangari and Petro-Nustas (2012)

APA Psychinfo	No - no BCA intervention	Breast cancer knowledge, attitudes and screening behaviors in two groups of Iranian women: Physicians and non-health care personnel.	Kadivar et al. (2012)
APA Psychinfo	No - no BCA intervention	Breast density awareness and knowledge, and intentions for breast cancer screening in a diverse sample of women age eligible for mammography.	Santiago-Rivas et al. (2019)
APA Psychinfo	No - no BCA intervention	Objectification as self-affirmation in the context of a death-relevant health threat.	Morris et al. (2013)
APA Psychinfo	No - no BCA intervention	The role of tentative decisions and health concepts in assessing information about mammography screening.	Bientzle et al. (2015)
APA Psychinfo	No - no BCA intervention	Breast cancer knowledge, beliefs, and screening behaviors of college women: Utilization of the health belief model.	Guilford (2012)
APA Psychinfo	No - no BCA intervention	Transcultural adaptation of the Breast Cancer Awareness Measure.	Al-Khasawneh et al. (2016)
APA Psychinfo	No - no BCA intervention	Communication and knowledge as motivators: Understanding Singaporean women's perceived risks of breast cancer and intentions to engage in preventive measures.	Lee et al. (2013)
APA Psychinfo	No - no BCA intervention	Breast cancer knowledge, attitudes and screening behaviors among Indian-Australian women.	Kwok et al. (2015)
APA Psychinfo	No - no BCA intervention	The impact of breast cancer knowledge and attitudes on screening and early detection among an immigrant Iranian population in southern California.	Kobeissi et al. (2014)
APA Psychinfo	No - no BCA intervention	Health beliefs and breast cancer screening in rural appalachia: An evaluation of the health belief model.	VanDyke et al. (2017)
APA Psychinfo	No - no BCA intervention	Breast cancer screening practices among Chinese-Australian women.	Kwok et al. (2012)
APA Psychinfo	No - no BCA intervention	Factors that influence mammography use and breast cancer detection among Mexican-American and African-American women.	Garcia et al. (2012)
APA Psychinfo	No - no BCA intervention	Living with increased risk for breast and ovarian cancer: Do religion and spirituality influence health behavior?	Dunn (2014)
APA Psychinfo	No - no BCA intervention	The preventative power of 'pink': Delineating the effects of social identification and protection motivation theory in breast cancer-related advertisements.	Devlin and Dillard (2016)
APA Psychinfo	No - no BCA intervention	A comparison of lesbian, bisexual, and heterosexual female college undergraduate students on selected reproductive health screenings and sexual behaviors.	Kerr et al. (2013)
APA Psychinfo	No - no BCA intervention	Educational differences in likelihood of attributing breast symptoms to cancer: A vignette-based study.	Marcu et al. (2016)
APA Psychinfo	No - no BCA intervention	Predictors of breast self-examination performance among Jordanian university female students.	Sharour et al. (2017)
APA Psychinfo	No - no BCA intervention	Breast cancer awareness messages: Impact on behaviors and knowledge of university students.	Justice (2018)
Web of Science	No - no BCA intervention	Breast Self-Examination Practice and Associated Factors Among Women Attending Family Planning Service in Modjo Public Health Facilities Southwest Ethiopia	Workineh et al. (2021)
Web of Science	No - no BCA intervention	Assessing the Key Attributes of Low Utilization of Mammography Screening and Breast-self Exam among African-American Women	Chowdhury et al. (2016)
Web of Science	No - no BCA intervention	Knowledge of breast cancer and breast self-examination practices and its barriers among university female students in Bangladesh: Findings from a cross-sectional study	Sarker et al. (2022)
Web of Science	No - no BCA intervention	Breast self-examination practice and predictors among female secondary school teachers in Addis Ababa, Ethiopia: using the health belief model	Tewelde et al. (2022)
Web of Science	No - no BCA intervention	Palpreast-A New Wearable Device for Breast Self-Examination	Arcarisi et al. (2019)
Web of Science	No - no BCA intervention	Knowledge and practice of breast self-examination among undergraduate students in Bahir Dar University, North-West Ethiopia, 2016: A cross-sectional study	Tewabe and Mekuria (2019)
Web of Science	No - no BCA intervention	Predictors of breast self - examination among female teachers in Ethiopia using health belief model	Birhane et al. (2015)
Web of Science	No - no BCA intervention	STAGES OF CHANGES, BREAST SELF-EXAMINATION PRACTICE AND RELATED HEALTH BELIEFS IN WOMEN- A THEORY-BASED STUDY	Ashtarian et al. (2018)
Web of Science	No - no BCA intervention	Breast self-examination and its associated factors among women who attended anti-retroviral therapy clinic in Bahir Dar city administration, North West Ethiopia	Wondie et al. (2022)
Web of Science	No - no BCA intervention	Breast self-examination practice and the associated factors among Bule Hora University students, Oromia Regional State, Ethiopia. An institution based cross sectional study	Tegegn et al. (2022)
Web of Science	No - no BCA intervention	Knowledge regarding breast self-examination among the women in Nepal: A meta-analysis	Sathian et al. (2019)
Web of Science	No - no BCA intervention	BREAST SELF-EXAMINATION AS A METHOD FOR EARLY DETECTION OF BREAST CANCER BASED ON LITERATURE REVIEW	Marszalek and Walaszek (2015)
Web of Science	No - no BCA intervention	Barriers to breast self examination practice among Malaysian female students: a cross sectional study	Akhtari-Zavare et al. (2016)
Web of Science	No - no BCA intervention	Breast self-examination practice and associated factors among female healthcare workers in West Shoa Zone, Western Ethiopia 2019: a cross-sectional study	Shallo and Boru (2019)
Web of Science	No - no BCA intervention	Evaluation of Breast Cancer Risk Levels and Its Relation with Breast Self-Examination Practices in Women	Katlu and Bicer (2017)
Web of Science	No - no BCA intervention	Knowledge, Attitudes, and Behaviors about Breast Self-Examination and Mammography among Female Primary Healthcare Workers in Diyarbakir, Turkey	Erdem and Toktas (2016)
Web of Science	No - no BCA intervention	Prevalence and determinants of breast self-examination in Karabuk, Turkey	Karahan (2019)

Web of Science	No - no BCA intervention	Knowledge, attitude, practice towards breast self-examination and associated factors among women in Gondar town, Northwest Ethiopia, 2021: a community-based study	Asmare et al. (2022)
Web of Science	No - no BCA intervention	Females Awareness and Attitudes Regarding Breast Self-Examination and Breast Cancer in Riyadh Province	Ahmed et al. (2021)
Web of Science	No - no BCA intervention	The Effect of Model Based Health Education on Performing Breast Self-Examination in Women	Ashtarian et al. (2018)
Web of Science	No - no BCA intervention	Breast self-examination in Greek midwives and midwifery students	Dinas et al. (2018)
Web of Science	No - no BCA intervention	Assessment of knowledge and practice of breast self-examination among reproductive age women in Akatsi South district of Volta region of Ghana	Dadzi and Adam (2019)
Web of Science	No - no BCA intervention	Efficacy of linking Breast Awareness Clinics in Gynecology and Obstetrics departments: A pilot project in Zubaida Bani Wing, Fazle-Omar Hospital, Chenab Nagar, Pakistan	Tahir et al. (2022)
Web of Science	No - no BCA intervention	Application of the Health Belief Model in Breast Self-Examination by Iranian Female University Students	Pirzadeh (2018)
Web of Science	No - no BCA intervention	Designing and Psychometric Evaluation of Breast Self-Examination Behavior Predicting Scale (BSEBPS)	Pourhaji and Ghofranipour (2018)
Web of Science	No - no BCA intervention	Evaluation of Breast Self-Examination (BSE) Application in First and Second Degree Relatives of Patients with Breast Cancer	Bebis et al. (2013)
Web of Science	No - no BCA intervention	Breast Cancer Awareness and Breast Self-Examination among Undergraduate Medical School Female Students: Kocaeli University-Turkey	Kararman et al. (2019)
Web of Science	No - no BCA intervention	Breast Self-Examination and Breast Cancer Awareness among Women in a Low Socioeconomic Area of Chennai, India	Kumar and Yenuganti (2021)
Web of Science	No - no BCA intervention	Breast Self Examination: Knowledge and Practice of Young Female Students towards Breast Self Examination and Breast Cancer	Shahani et al. (2020)
Web of Science	No - no BCA intervention	Knowledge, Attitude and Practice of Breast Self-examination Among Female University Students from 24 Low, Middle Income and Emerging Economy Countries	Pengpid and Peltzer (2014)
Web of Science	No - no BCA intervention	Factors Influencing the Practice of Breast Self-Examination among Female Tertiary Students in Ho, Ghana	Ameghedzi et al. (2022)
Web of Science	No - no BCA intervention	Breast size dissatisfaction, but not body dissatisfaction, is associated with breast self-examination frequency and breast change detection in British women	Swami and Furnham (2018)
Web of Science	No - no BCA intervention	Awareness of breast cancer among adolescent girls in Colombo, Sri Lanka: a school based study	Ranasinghe et al. (2013)
Web of Science	No - no BCA intervention	Knowledge and Practice of Breast Self-Examination Among Young Women in Tertiary Education in Addis Ababa, Ethiopia	Dinegde et al. (2020)
Web of Science	No - no BCA intervention	Practice of Breast Self-Examination Among Women in Malaysia	Al-Naggar et al. (2012)
Web of Science	No - no BCA intervention	Breast Self-examination: Knowledge, Attitude and Practice among Female College Students	Paulsamy et al. (2021)
Web of Science	No - no BCA intervention	The Determination of Knowledge, Applications and Health Beliefs of Third- and Fourth-Grade Nursing Students Regarding Breast Self-Exam	Kissal et al. (2017)
Web of Science	No - no BCA intervention	Health beliefs, behaviour and determining factors in breast self - examination among a group of university students	Basaran et al. (2019)
Web of Science	No - no BCA intervention	Application of the Champion Health Belief Model to determine beliefs and behaviors of Turkish women academicians regarding breast cancer screening: A cross sectional descriptive study	Kirag and Kizilkaya (2019)
Web of Science	No - no BCA intervention	Breast Cancer knowledge and perceived barriers to help seeking among pre-clinical and clinical female medical students of King Edward Medical University, Lahore: a cross-sectional study	Qasim et al. (2020)
Web of Science	No - no BCA intervention	Knowledge of Breast Cancer and Breast Self-Examination Practice among Iranian Women in Hamedan, Iran	Akhtari-Zavare et al. (2014)
Web of Science	No - no BCA intervention	Health Beliefs and Breast Self-Examination among Female University Nursing Students in Turkey	Erbil and Bolukbas (2014)
Web of Science	No - no BCA intervention	Exploration of Barriers to Breast-Self Examination among Urban Women in Shah Alam, Malaysia: A Cross Sectional Study	Al-Dubai et al. (2012)
Web of Science	No - no BCA intervention	The Relationship Between Health Belief and Breast Self-examination Among Iranian University Students	Asghari et al. (2016)
Web of Science	No - no BCA intervention	Knowledge, Attitude, and Practice Regarding Breast Cancer Early Detection Among Women in a Mountainous Area in Northern Vietnam	Toan et al. (2019)
Web of Science	No - no BCA intervention	Knowledge, awareness, and practice of breast self-examination among females in Mosul city, Iraq	Al-Qazaz et al. (2020)
Web of Science	No - no BCA intervention	KNOWLEDGE AND PRACTICE OF BREAST SELF-EXAMINATION AMONG RURAL WOMEN IN SOUTH-WEST NIGERIA: IMPLICATIONS FOR DEVELOPMENT OF WOMEN EMPOWERMENT PROGRAMME	Hanson et al. (2017)
Web of Science	No - no BCA intervention	Adaptation and Validation of the Health Belief Model Scale for Breast Self-Examination in Mexican Women	Juarez-Garcia et al (2020)
Web of Science	No - no BCA intervention	Breast Self-Examination Practice and Associated Factors Among Secondary School Female Teachers in Gammo Gofa Zone, Southern, Ethiopia	Mekuria et al. (2020)
Web of Science	No - no BCA intervention	Knowledge, attitude, and practice of breast self-examination amongst female IT professionals in Silicon Valley of India	Kalliguddi et al. (2019)

Web of Science	No - no BCA intervention	Factors associated with breast cancer awareness and breast self-examination in Fiji and Kashmir India - a cross-sectional study	Malik et al. (2020)
Web of Science	No - no BCA intervention	Breast Self-Examination: Knowledge, Practice, and Beliefs Among Females in Jordan	Ahmad et al. (2022)
Web of Science	No - no BCA intervention	Knowledge, attitudes, and beliefs about breast cancer and barriers to breast self-examination among sikkimese women	Yambem and Rahman (2019)
Web of Science	No - no BCA intervention	An Application of the Protection Motivation Theory to Predict Breast Self-Examination Behavior among Female Healthcare Workers	Bashirian et al. (2019)
Web of Science	No - no BCA intervention	Refining a questionnaire to assess breast cancer knowledge and barriers to screening in Kenya: Psychometric assessment of the BCAM	Wachira et al. (2017)
Web of Science	No - no BCA intervention	Barriers to Breast Self-examination among Iranian Women	Taleghani et al. (2019)
Web of Science	No - no BCA intervention	Breast self-examination beliefs and practices, ethnicity, and health literacy: Implications for health education to reduce disparities	Armin et al. (2014)
Web of Science	No - no BCA intervention	Breast Self-Examination: Knowledge and Practice Among Female Textile Workers in Vietnam	Tuyen et al. (2019)
Web of Science	No - no BCA intervention	Breast Self-Examination: the Case for a Second Look	Dietze et al. (2020)
Web of Science	No - no BCA intervention	The effect of knowledge on uptake of breast cancer prevention modalities among women in Kyadondo County, Uganda	Atuhairwe et al. (2018)
Web of Science	No - no BCA intervention	A Survey on Breast Cancer Awareness Among Medical, Paramedical, and General Population in North India Using Self-Designed Questionnaire: a Prospective Study	Ramakant et al. (2018)
Web of Science	No - no BCA intervention	Breast self-examination as a route to early detection in a lower-middle-income country: assessing psychosocial determinants among women in Surabaya, Indonesia	Dewi et al. (2022)
Web of Science	No - no BCA intervention	The role of psychosocial variables in breast self-examination practice: Results from focus group discussions in Surabaya, Indonesia	Dewi et al. (2022)
Web of Science	No - no BCA intervention	Breast Self Examination Practice and Breast Cancer Risk Perception among Female University Students in Ajman	Al-Sharbatti et al. (2013)
Web of Science	No - no BCA intervention	Exploring factors associated with breast cancer screening among women aged 15-49 years in Lesotho	Thabane et al. (2021)
Web of Science	No - no BCA intervention	Breast Cancer Awareness and Associated Factors Amongst Women in Peshawar, Pakistan: A Cross-Sectional Study	Ullah et al. (2021)
Web of Science	No - no BCA intervention	Breast self-examination among nurses in Poland and their reparation in this regard	Woynarowska-Soldan et al. (2019)
Web of Science	No - no BCA intervention	Awareness of breast cancer and breast self-examination among female undergraduate students in a higher teachers training college in Cameroon	Sama et al. (2017)
Web of Science	No - no BCA intervention	Determinants of breast self-examination practice among women in Surabaya, Indonesia: an application of the health belief model	Dewi et al. (2019)
Web of Science	No - no BCA intervention	Breast Cancer Awareness among Turkish Nursing Students	Celik et al. (2014)
Web of Science	No - no BCA intervention	A case report of small bowel obstruction from previously undiagnosed lobular breast carcinoma: First in Australian literature	Cristaudo and Zhu (2017)
Web of Science	No - no BCA intervention	Knowledge and attitude of adult females regarding breast cancer and its early detection in Alqunfudhah district: A cross sectional community based study	Alkalash et al. (2022)
Web of Science	No - no BCA intervention	Knowledge of Breast Cancer and the Practice of Breast Self-Examination in Saudi Women: An Online Survey	Allohibi et al. (2021)
Web of Science	No - no BCA intervention	Assessment of Knowledge, Attitudes, and Behaviors of Turkish Women on Breast and Cervical Cancer in Karabuk Province, Turkey	Sevinc et al. (2020)
Web of Science	No - no BCA intervention	Breast Cancer Downstaging Practices and Breast Health Messaging Preferences Among a Community Sample of Urban and Rural Ugandan Women	Scheel et al. (2017)
Web of Science	No - no BCA intervention	Using the health belief model to predict breast self examination among Saudi women	Abolfotouh et al. (2015)
Web of Science	No - no BCA intervention	Breast self-examination awareness and practices in young women in developing countries: A survey of female students in Karachi, Pakistan	Ahmed et al (2018)
Web of Science	No - no BCA intervention	Husbands' Knowledge of Breast Cancer and Their Wives' Attitudes and Practices Related to Breast Cancer Screening in Saudi Arabia: Cross-sectional Online Survey	Sabgul et al. (2021)
Web of Science	No - no BCA intervention	Women's Awareness and Attitude Toward Breast Self-Examination in Dezful City, Iran, 2013	Marzouni et al. (2015)
Web of Science	No - no BCA intervention	Psychosocial predictors of breast self-examination behavior among female students: an application of the health belief model using logistic regression	Didarloo et al. (2017)
Web of Science	No - no BCA intervention	A path analytic model of health beliefs on the behavioral adoption of breast self-examination	Moey et al. (2021)
Web of Science	No - no BCA intervention	Examination of factors affecting women's barrier perception to participate in breast cancer screenings in a region affiliated with a family health center in Turkey	Ersin and Polat (2016)
Web of Science	No - no BCA intervention	Knowledge, Attitudes and Behaviour of Women Working in Government Hospitals Regarding Breast Self Examination	Yurdakos et al. (2013)
Web of Science	No - no BCA intervention	The Effects of Educational Level on Breast Cancer Awareness: A Cross-Sectional Study in Turkey	Gurdal et al. (2012)
Web of Science	No - no BCA intervention	Awareness of Breast Cancer Warning Signs and Screening Methods among Female Residents of Pokhara Valley, Nepal	Sathian et al. (2014)
Web of Science	No - no BCA intervention	Progress in diagnosis of breast cancer: Advances in radiology technology	Linder and Schiska (2015)

Web of Science	No - no BCA intervention	Factors that Influence Awareness of Breast Cancer Screening among Arab Women in Qatar: Results from a Cross Sectional Survey	Donnelly et al. (2014)
Web of Science	No - no BCA intervention	Knowledge, attitudes, and practices related to breast cancer screening among female health care professionals: a cross sectional study	Heena et al. (2019)
Web of Science	No - no BCA intervention	Knowledge and practice of breast self-examination among sample of women in Shatra/Dhi-Qar/Iraq	Ewaid et al. (2018)
Web of Science	No - no BCA intervention	Impact of social and clinical factors on diagnostic delay of breast cancer: A Cross-sectional Study	Dianatinasab et al. (2016)
Web of Science	No - no BCA intervention	BREAST CANCER AWARENESS, ATTITUDE, PERCEPTION AND SCREENING PRACTICES AMONG FEMALE UNDERGRADUATE STUDENTS	Suhail (2021)
Web of Science	No - no BCA intervention	Breast Cancer Awareness among Women in an Urban Setup in Western India	Singh et al. (2018)
Web of Science	No - no BCA intervention	Awareness of Breast Cancer Screening among the Medical and General Population of the North Region of Cameroon	Simo et al. (2021)
Web of Science	No - no BCA intervention	Breast self-examination and associated factors among women in Wolaita Sodo, Ethiopia: a community-based cross-sectional study	Lera et al. (2020)
Web of Science	No - no BCA intervention	The Relationship between Risk Levels of Breast Cancer and Use of Early Diagnosis and Screening Services in Healthcare Workers in Turkey	Acikgoz et al. (2020)
Web of Science	No - no BCA intervention	Determinants of cancer screening awareness and participation among Indonesian women	Anwar et al. (2018)
Web of Science	No - no BCA intervention	Examination of Breast Cancer Screening Knowledge, Attitudes, and Beliefs among Syrian Refugee Women in a Western Canadian Province	Racine et al. (2022)
Web of Science	No - no BCA intervention	Determining the Awareness of and Compliance with Breast Cancer Screening among Turkish Residential Women	Yilmaz et al. (2013)
Web of Science	No - no BCA intervention	Perception of Breast Health amongst Malaysian Female Adolescents	Che et al. (2014)
Web of Science	No - no BCA intervention	Informational Needs of Postmastectomy Patients	Yesilyurt and Findik (2016)
Web of Science	No - no BCA intervention	Practice of Breast Cancer Early Diagnosis Methods among Women Living in Samsun, and Factors Associated with This Practice	Aker et al. (2015)
Web of Science	No - no BCA intervention	Primary and secondary prevention of breast cancer	Kolak et al. (2017)
Web of Science	No - no BCA intervention	Evaluation on the Practice and Behaviour of Women Applied for Gynecology Outpatient Clinics About Screening Methods for Early Diagnosis of Breast Cancer	Hocaoglu et al. (2017)
Web of Science	No - no BCA intervention	An Integrated Machine Learning Scheme for Predicting Mammographic Anomalies in High-Risk Individuals Using Questionnaire-Based Predictors	Sun et al. (2022)
Web of Science	No - no BCA intervention	Breast, Cervix and Colorectal Cancer Knowledge among Nurses in Turkey	Andsoy and Gul (2014)
Web of Science	No - no BCA intervention	Determinants of Breast Cancer screening: Application of Protection Motivation Theory	Ghofranipour et al. (2020)
Web of Science	No - no BCA intervention	Breast cancer awareness among Afghan refugee women in Turkey	Kizilkaya et al. (2022)
Web of Science	No - no BCA intervention	Beliefs and Behaviors of Breast Cancer Screening in Women Referring to Health Care Centers in Northwest Iran According to the Champion Health Belief Model Scale	Fouladi et al. (2013)
Web of Science	No - no BCA intervention	Breast Cancer Knowledge, Attitudes and Practices amongst Women in Qatar	Hamed et al. (2022)
Web of Science	No - no BCA intervention	The Association of Health Literacy with Breast Cancer Knowledge, Perception and Screening Behavior	Rakhshkhorshid et al. (2018)
Web of Science	No - no BCA intervention	Determination of Information and Support Needs of First Degree Relatives of Women with Breast Cancer	Andic and Karayurt (2012)
Web of Science	No - no BCA intervention	Young Women's Perceptions Regarding Communication with Healthcare Providers About Breast Cancer, Risk, and Prevention	Lunsford et al. (2018)
Web of Science	No - no BCA intervention	Breast Cancer Awareness among Saudi Females in Jeddah	Radi (2013)
Web of Science	No - no BCA intervention	Breast Cancer Knowledge, Behaviors, and Preferences in Malawi: Implications for Early Detection Interventions From a Discrete Choice Experiment	Kohler et al. (2017)
Web of Science	No - no BCA intervention	Screening in the Era of Economic Crisis: Misperceptions and Misuse from a Longitudinal Study on Greek Women Undergoing Benign Vacuum-assisted Breast Biopsy	Domeyer et al. (2013)
Web of Science	No - no BCA intervention	Early Cancer Detection/Screening Behaviors of Individuals Aged 40 Years and Over in Trabzon and the Influencing Factors	Karadeniz and Cetinkaya (2019)
Web of Science	No - no BCA intervention	Perceptions of Iranian women regarding breast cancer screening behaviour	Noori and Schouten (2018)
Web of Science	No - no BCA intervention	Cancer prevention awareness among young adult Polish females on the basis of the assessment of knowledge and health behaviours	Wiraszka et al. (2016)
Web of Science	No - no BCA intervention	Determination of Knowledge and Behavior of Women Working at a Hospital on Breast Cancer Early Detection Methods, and Investigation of Efficiency of Planned Education	Acikgoz et al. (2015)
Web of Science	No - no BCA intervention	The transtheoretical model, health belief model, and breast cancer screening among Iranian women with a family history of breast cancer	Farajzadegan et al. (2016)
Web of Science	No - no BCA intervention	Community-based study on the knowledge, awareness, and practices of females towards breast cancer in Buraimi, Oman	Chattu et al. (2018)

Web of Science	No - no BCA intervention	Health Beliefs and Breast Cancer Screening Behavior among a Group of Female Health Professionals in Turkey	Yilmaz and Durmus (2016)
Web of Science	No - no BCA intervention	Attitudes of South Asian Women to Breast Health and Breast Cancer Screening: Findings from a Community Based Sample in the United States	Poonawalla et al. (2014)
Web of Science	No - no BCA intervention	Knowledge of medical school students on breast cancer and cervical cancer, and their prevention	Liszcz and Badowska-Kozakiewicz (2015)
Web of Science	No - no BCA intervention	Risk perception and screening behavior of Filipino women at risk for breast cancer: implications for cancer genetic counseling	Lagarde et al. (2019)
Web of Science	No - no BCA intervention	A survey of breast cancer knowledge and attitude in Iranian women	Nafissi et al. (2012)
Web of Science	No - no BCA intervention	Assessing Risk and Knowledge of Women on Breast Cancer and Providing Lifestyle Advice for the Management of Breast Cancer Risk	Ghouse et al. (2021)
Web of Science	No - no BCA intervention	Factors associated with time to first healthcare visit, diagnosis and treatment, and their impact on survival among breast cancer patients in Mali	Frie et al. (2018)
Web of Science	No - no BCA intervention	An Analysis of the Association Between Cancer-Related Information Seeking and Adherence to Breast Cancer Surveillance Procedures	Tan et al. (2013)
Web of Science	No - no BCA intervention	Modifiable patient-related barriers and their association with breast cancer detection practices among Ugandan women without a diagnosis of breast cancer	Sharp et al. (2019)
Web of Science	No - no BCA intervention	Awareness About Breast Cancer Among Adult Women in Jordan	Al-Najar et al. (2021)
Web of Science	No - no BCA intervention	Analysis of Knowledge About Male Breast Cancer Among Higher Education Male Students	Faria et al. (2021)
Web of Science	No - no BCA intervention	TRUST AND MISTRUST IN SHAPING ADAPTATION AND DE-IMPLEMENTATION IN THE CONTEXT OF CHANGING SCREENING GUIDELINES	Shelton et al. (2021)
Web of Science	No - no BCA intervention	Integration of breast cancer prevention and early detection into cancer palliative care model	Bonsu and Ncama (2019)
Web of Science	No - no BCA intervention	Assessment of knowledge, attitudes, and behaviors regarding breast and cervical cancer among women in western Turkey	Korkut (2019)
Web of Science	No - no BCA intervention	Determinants of Participation in a Breast Cancer Screening Trial in Trivandrum District, India	Frie et al. (2013)
Web of Science	No - no BCA intervention	Breast cancer screening behavior, attitude, barriers among middle-aged Chinese women in Macao, China	Gan et al. (2018)
Web of Science	No - no BCA intervention	Social Determinants of Breast Cancer Screening among Married Women: A Cross-Sectional Study	Ghanbari et al. (2020)
Web of Science	No - no BCA intervention	Male Partners' Knowledge, Attitudes, and Perception of Women's Breast Cancer in Abha, Southwestern Saudi Arabia	Al-Musa et al. (2019)
Web of Science	No - no BCA intervention	Evaluation of Information and Practices About Breast Cancer Screening Performed in Women Presented to a University Hospital in Istanbul	Gemici et al. (2020)
Web of Science	No - no BCA intervention	Improving early detection of breast cancer in sub-Saharan Africa: why mammography may not be the way forward	Black and Richmond (2019)
Web of Science	No - no BCA intervention	Knowledge and practices on breast cancer detection and associated challenges among women aged 35 years and above in Tanzania: a case in Morogoro Rural District	Ng'ida et al. (2019)
Web of Science	No - no BCA intervention	Pattern of Presentation of Patients With Breast Cancer in Iraq in 2018: A Cross-Sectional Study	Mutar et al. (2019)
Web of Science	No - no BCA intervention	Quality of Breast Cancer Early Detection Services Conducted by Well Woman Clinics in the District of Gampaha, Sri Lanka	Vithana et al. (2013)
Web of Science	No - no BCA intervention	Breast cancer screening practices amongst female tertiary health worker in Nnewi	Madubogwu et al. (2017)
Web of Science	No - no BCA intervention	Design and implementation of an Internet-Based cancer risk assessment tool: Use over 10 years	LaRiviere et al. (2022)
Web of Science	No - no BCA intervention	Screening Results of Non-communicable Diseases in Adults and Elderly People Living in the Rural Area: A Cross-sectional Descriptive Study	Tuzcu and Muslu (2020)
Web of Science	No - no BCA intervention	Risk Factors Associated with Breast Cancer among Women in Addis Ababa, Ethiopia: Unmatched Case-Control Study	Tolessa et al. (2021)
Web of Science	No - no BCA intervention	Socio-demographic Factors Associated with Utilization of Breast and Cervical Cancer Screening Methods in Turkey	Urek et al. (2022)
Web of Science	No - no BCA intervention	Hong Kong female's breast cancer awareness measure: Cross-sectional survey	Yeung et al. (2019)
Web of Science	No - no BCA intervention	Determinants of late detection and advanced-stage diagnosis of breast cancer in Nigeria	Agodirin et al. (2021)
Web of Science	No - no BCA intervention	An Example from the Rural Areas of Turkey: Women Breast Cancer Risk Levels and Application and Knowledge Regarding Early Diagnosis-Scan of Breast Cancer	Turk et al. (2017)
Web of Science	No - no BCA intervention	The Use of Fitness Influencers' Websites by Young Adult Women: A Cross-Sectional Study	Duplaga (2020)
Web of Science	No - no BCA intervention	Evaluation of the Pink Luminous Breast LED-Based Technology Device as a Screening Tool for the Early Detection of Breast Abnormalities	Ocasio-Villa et al. (2022)
Web of Science	No - no BCA intervention	Knowledge, attitudes and practices concerning breast cancer, cervical cancer and screening among healthcare professionals and students in Mogadishu, Somalia: a cross-sectional study	Walz et al. (2022)
Web of Science	No - no BCA intervention	Knowledge of nursing students about breast cancer prevention	Cichomska et al. (2020)

Web of Science	No - no BCA intervention	Appraisal of Breast Cancer Symptoms by Iranian Women: Entangled Cognitive, Emotional and Socio-Cultural Responses	Khakbazan et al. (2014)
Web of Science	No - no BCA intervention	Assessment Awareness of Public About Breast Cancer and its Screening Measurements in Asir Region, KSA	Alshahrani et al. (2019)
Web of Science	No - no BCA intervention	Factor structure and internal reliability of breast cancer screening Champion's Health Belief Model Scale in Yemeni women in Malaysia: a cross-sectional study	Norman et al. (2021)
Web of Science	No - no BCA intervention	Factors associated with advanced-stage diagnosis of breast cancer in north-west Ethiopia: a cross-sectional study	Tesfaw et al. (2021)
Web of Science	No - no BCA intervention	Trends of Breast Cancer and its Management in the Last Twenty Years in Aden and Adjacent Governorates, Yemen	Harbra and Basaleem (2012)
Web of Science	No - no BCA intervention	Barriers on Breast Cancer Early Detection Methods	Aksoy et al. (2015)
Web of Science	No - no BCA intervention	Factors associated with delay in seeking care for breast symptoms	Soh et al. (2022)
Web of Science	No - no BCA intervention	Apps for individuals diagnosed with breast cancer: a preliminary assessment of the content and quality of commercially available apps in Spanish	Martin-Payo et al. (2021)
Web of Science	No - no BCA intervention	Assessing the level of breast cancer awareness among recently diagnosed patients in Ain Shams University Hospital	El-Shinawi et al. (2013)
Web of Science	No - no BCA intervention	Meta Analysis of Studies about Breast Self Examination between 2000-2009 in Turkey	Ergin et al. (2012)
Web of Science	No - no BCA intervention	Health Belief Model and Determinants of Breast Self-Examination Performance	Mousavi et al. (2021)
Web of Science	No - no BCA intervention	Beliefs and Behavior of Malaysia Undergraduate Female Students in a Public University Toward Breast Self-examination Practice	Akhtari-Zavare et al. (2013)
Web of Science	No - no BCA intervention	Determining the need for a breast cancer awareness educational intervention for women with mild/moderate levels of intellectual disability: A qualitative descriptive study	Walsh et al. (2022)
Web of Science	No - no BCA intervention	Understanding Breast Cancer Screening Practices in Taiwan: a Country with Universal Health Care	Wu et al. (2012)
Web of Science	No - no BCA intervention	Literacy and Breast Cancer Prevention: a Population-Based Study from Iran	Harirchi et al. (2012)
Web of Science	No - no BCA intervention	Knowledge and Attitude towards Breast Cancer among Medical Undergraduate Students	Iqbal et al. (2021)
Web of Science	No - no BCA intervention	Perception, attitude and experience of women living in Jeddah with or without Breast lump towards BSE & mammography: Pre- Post study	Gouse et al. (2022)
Web of Science	No - no BCA intervention	Sociodemographic Determinants of Nonattendance in a Population-Based Mammography Screening Program in the City of Manisa, Turkey	Dundar et al. (2012)
Web of Science	No - no BCA intervention	Breast Cancer Knowledge and Screening Behaviour among Women with a Positive Family History: A Cross Sectional Study	Subramanian et al. (2013)
Web of Science	No - no BCA intervention	Training female adolescent students with intellectual disabilities about genital hygiene skills using peer training	Kirbas et al. (2022)
Web of Science	No - no BCA intervention	Health marketing in an emerging market: The critical role of signaling theory in breast cancer awareness	Heidari and Feizi (2018)
Web of Science	No - no BCA intervention	Age-group differences in risk perceptions of non-communicable diseases among adults in Diepsloot township, Johannesburg, South Africa: A cross-sectional study based on the Health Belief Model	Kaba et al. (2017)
Web of Science	No - no BCA intervention	Beliefs and attitudes about breast cancer and screening practices among Arab women living in Qatar: a cross-sectional study	Donnelly et al. (2013)
Web of Science	No - no BCA intervention	Possible pro-carcinogenic association of endotoxin on lung cancer among Shanghai women textile workers	Checkoway et al. (2014)
Web of Science	No - no BCA intervention	Checking Behavior, Fear of Recurrence, and Daily Triggers in Breast Cancer Survivors	Soriano et al. (2019)
Web of Science	No - no BCA intervention	Perceived Behavioral Control in Mammography: A Qualitative Study of Iranian Women's Experiences	Khazir et al. (2019)
Web of Science	No - no BCA intervention	Influences on anticipated time to ovarian cancer symptom presentation in women at increased risk compared to population risk of ovarian cancer	Smits et al. (2017)
Web of Science	No - no BCA intervention	Comparison of Barriers Against Mammography Screening in Socioeconomically Very Low and Very High Populations	Ozmen et al. (2016)
Web of Science	No - no BCA intervention	Determinants of stage at diagnosis of breast cancer in Nigerian women: sociodemographic, breast cancer awareness, health care access and clinical factors	Jedy-Agba et al. (2017)
Web of Science	No - no BCA intervention	Predictors of Mammography Screening among Iranian Women Attending Outpatient Clinics in Tehran, Iran	Ahmadian et al. (2012)
Web of Science	No - no BCA intervention	Models of health behaviour predict intention to use long-acting reversible contraception	Roderique-Davies et al. (2016)
Web of Science	No - no BCA intervention	Missed opportunities for breast awareness information among women attending the maternal and child health services of an urban tertiary hospital in Northern Nigeria	Anyanwu et al. (2016)
Web of Science	No - no BCA intervention	Psychological predictors of intention and avoidance of attending organized mammography screening in Norway: applying the Extended Parallel Process Model	Ivanova and Kvalem (2021)
Web of Science	No - no BCA intervention	Factors associated with insufficient awareness of breast cancer among women in Northern and Eastern China: a case-control study	Liu et al. (2014)
Web of Science	No - no BCA intervention	Breast cancer awareness among women in Eastern China: a cross-sectional study	Liu et al. (2014)

Web of Science	No - no BCA intervention	Breast Cancer Awareness and Barriers to Early Presentation in the Gaza-Strip: A Cross-Sectional Study	Elshami et al. (2018)
Web of Science	No - no BCA intervention	Unintended consequences of an 'all-clear' diagnosis for potential cancer symptoms: a nested qualitative interview study with primary care patients	Renzi et al. (2016)
Web of Science	No - no BCA intervention	Women's cultural perceptions and attitudes towards breast cancer: Northern Ghana	Asobayire and Barley (2015)
Web of Science	No - no BCA intervention	Prevalence and sociodemographic correlates of routine breast cancer screening practices among migrant-Australian women	Lam et al. (2018)
Web of Science	No - no BCA intervention	Willingness to Receive Periodic Health Examination Based on the Health Belief Model Among the Elderly in Rural China: A Cross-Sectional Study	Zhang et al. (2021)
Web of Science	No - no BCA intervention	Breast Awareness, Self-Reported Abnormalities, and Breast Cancer in Rural Ethiopia: A Survey of 7,573 Women and Predictions of the National Burden	Ayele et al. (2021)
Web of Science	No - no BCA intervention	Female medical students' awareness, attitudes, and knowledge about early detection of breast cancer in Syrian Private University, Syria	Omar et al. (2020)
Web of Science	No - no BCA intervention	A Population-Based Cross-Sectional Study Comparing Breast Cancer Stage at Diagnosis between Immigrant and Canadian-Born Women in Ontario	Iqbal et al. (2017)
Web of Science	No - no BCA intervention	Factors associated with time interval between the onset of symptoms and first medical visit in women with breast cancer	Barros et al. (2020)
Web of Science	No - no BCA intervention	Evaluation of Knowledge, Attitudes and Behaviors on the Breast Care of Patients and Health Care Personnels Who Apply to Family Medicine Policlinic	Pehlivanoglu et al. (2018)
Web of Science	No - no BCA intervention	Determinants of breast cancer in Saudi women from Makkah region: a case-control study (breast cancer risk factors among Saudi women)	Alsolami et al. (2019)
Web of Science	No - no BCA intervention	Impact of educational level and travel burden on breast cancer stage at diagnosis in the state of Sao Paulo, Brazil	de Almeida et al. (2022)
Web of Science	No - no BCA intervention	Breast Cancer Screening Awareness, Knowledge, and Practice among Arab Women in the United Arab Emirates: A Cross-Sectional Survey	Elobaid et al. (2014)
Web of Science	No - no BCA intervention	Fear of Mastectomy Associated with Delayed Breast Cancer Presentation Among Ghanaian Women	Martei et al. (2018)
Web of Science	No - no BCA intervention	Barriers to early diagnosis of symptomatic breast cancer: a qualitative study of Black African, Black Caribbean and White British women living in the UK	Jones et al. (2015)
Web of Science	No - no BCA intervention	Epidemiology, Pathological Characteristics and Estrogen and Progesterone Receptor Status of Operated Cases of Female Breast Cancer: A Retrospective Review of 266 Cases from Kerala	Vettunarambil et al. (2015)
Web of Science	No - no BCA intervention	Breast Cancer Beliefs as Potential Targets for Breast Cancer Awareness Efforts to Decrease Late-Stage Presentation in Uganda	Scheel et al. (2017)
Web of Science	No - no BCA intervention	Women's Breast Cancer Knowledge and Health Communication in the United Arab Emirates	Abu Awwad et al. (2020)
Web of Science	No - no BCA intervention	Socio-demographic factors and reasons associated with delay in breast cancer presentation: A study in Nigerian women	Ibrahim and Oludara (2012)
Web of Science	No - no BCA intervention	Perception of Breast Cancer Screening among Iranian Women without Experience of Mammography: A Qualitative Study	Khazee-Pool et al. (2014)
Web of Science	No - no BCA intervention	Experiences of Women Who Refuse Recall for Further Investigation of Abnormal Screening Mammography: A Qualitative Study	Sung et al. (2022)
Web of Science	No - no BCA intervention	Awareness of Breast Cancer Risk among Female University Students from 24 Low, Middle Income and Emerging Economy Countries	Peltzer and Pengpid (2014)
Web of Science	No - no BCA intervention	A review of breast cancer awareness among women in India: Cancer literate or awareness deficit?	Gupta et al. (2015)
Web of Science	No - no BCA intervention	Knowledge of symptoms and risk factors of breast cancer among women: a community based study in a low socio-economic area of Mumbai, India	Prusty et al. (2020)
Web of Science	No - no BCA intervention	Knowledge of breast cancer among medical students in Syrian Private University, Syria: a cross-sectional study	Ismail et al. (2021)
Web of Science	No - no BCA intervention	Age- and treatment-related associations with health behavior change among breast cancer survivors	Anderson et al. (2017)
Web of Science	No - no BCA intervention	Breast cancer awareness in the sub-Saharan African ABC-DO cohort: African Breast Cancer-Disparities in Outcomes study	McKenzie et al. (2018)
Web of Science	No - no BCA intervention	Factors Associated With Delayed Diagnosis of Breast Cancer in Northeast Thailand	Poum et al. (2014)
Web of Science	No - no BCA intervention	Epidemiological, clinical and diagnostic profile of breast cancer patients treated at Potchefstroom regional hospital, South Africa, 2012-2018: an open-cohort study	Kakudji et al. (2020)
Web of Science	No - no BCA intervention	Awareness and Prevalence of Mammography Screening and its Predictors - A Cross Sectional Study in a Primary Care Clinic in Malaysia	Yusof et al. (2014)
Web of Science	No - no BCA intervention	Effect of Comprehensive Breast Care on Breast Cancer Outcomes: A Community Hospital Based Study from Mumbai, India	Gadgil et al. (2012)
Cochrane Library	No - no BCA intervention	Translation and Validation of the Breast Cancer Awareness Measurement Tool in Malaysia (B-CAM-M)	Htay et al. (2020)
CINAHL	No - no BCA intervention	Awareness about breast cancer and outcome of teaching on breast self examination in female degree college students.	Vasishta et al. (2018)
CINAHL	No - no BCA intervention	Relationship between demographic factors, health education, breast cancer-related knowledge, attitudes, and breast self-examination behavior among Chinese female college student: A structural equation analysis.	Zhang et al. (2021)

CINAHL	No - no BCA intervention	A Study to Assess the Knowledge Regarding Breast Self-Examination among the Nursing Students of RP. Inderaprastha Institute of Medical Sciences with the view to Provide Education Through Video.	Rachna (2021)
CINAHL	No - no BCA intervention	Greek Women's Knowledge and Perceptions Related to Breast Cancer Prevention.	Bakalis et al. (2022)
CINAHL	No - no BCA intervention	Breast Cancer Awareness and Breast Self-Examination among Undergraduate Medical School Female Students: Kocaeli University-Turkey.	Karaman et al. (2019)
CINAHL	No - no BCA intervention	Breast Cancer Knowledge, Beliefs, and Screening Behaviors of College Women: Application of the Health Belief Model.	Guilford et al. (2017)
CINAHL	No - no BCA intervention	Factors influencing breast cancer screening practices among women of reproductive age in South Kayonza District, Rwanda.	Igiraneza et al. (2021)
CINAHL	No - no BCA intervention	Structural equation modeling to detect predictors of breast self-examination behavior: Implications for intervention planning.	Ju et al. (2021)
CINAHL	No - no BCA intervention	The relationship between the fear of breast cancer, risk factors, and early diagnosis behaviors of women by age groups.	Taylan et al. (2021)
CINAHL	No - no BCA intervention	Practice of Breast Self-Examination and Associated Factors among Female Nurses of Hawassa University Comprehensive Specialized Hospital, South Ethiopia in 2018.	Jemebere (2019)
CINAHL	No - no BCA intervention	Exploring breast cancer and screening awareness among Irish women with intellectual disabilities.	Reidy et al. (2018)
CINAHL	No - no BCA intervention	Breast cancer screening knowledge among Hungarian women: a cross-sectional study.	Reményi Kissné et al. (2021)
CINAHL	No - no BCA intervention	A qualitative study to determine Kuwaiti Women's knowledge of breast cancer and barriers deterring attendance at mammography screening.	Marzouq Muhanna and Floyd (2019)
CINAHL	No - no BCA intervention	PRENATAL CLINICAL DEMONSTRATION FOR THE MANAGEMENT OF THE BREAST ENGORGEMENT PREVENTION: QUASI-EXPERIMENTAL STUDY.	Oliveira et al. (2021)
CINAHL	No - no BCA intervention	Ten Year Profile of a Best Practice Program Aimed at Rural Women.	Lane and Martin (2015)
CINAHL	No - no BCA intervention	Determination of Breast Self-Examination Knowledge and Breast Self-Examination Practices among Women and Effects of Education on their Knowledge.	özdemir et al. (2014)
CINAHL	No - no BCA intervention	THE RELATIONSHIP BETWEEN SELF-EFFICACY AND PERFORMANCE OF BREAST SELF-EXAMINATION AMONG NURSES: A SURVEY IN SOUTHEAST OF IRAN.	Eghbali et al. (2019)
CINAHL	No - no BCA intervention	Palliative Care Needs in Breast Cancer Patients Entering Inpatient Hospice in Western Kenya.	Tarus et al. (2022)
CINAHL	No - no BCA intervention	Intention to Receive Breast Cancer Screening and Related Factors of Influence Among Vietnamese Women in Transnational Marriages.	Fang-Hsin (2018)
CINAHL	No - no BCA intervention	Determination of Women's Health Beliefs, Breast Cancer Fears, and Fatalism Associated with Behaviors Regarding the Early Diagnosis of Breast Cancer.	Kissal et al. (2018)
CINAHL	No - no BCA intervention	Breast self-examination practices in Nigerian women attending a tertiary outpatient clinic.	Ogunbode et al. (2015)
CINAHL	No - no BCA intervention	Breast Cancer-Related Knowledge Levels and Health Literacy in Working Women.	Ektir et al. (2017)
CINAHL	No - no BCA intervention	Awareness, use and main source of information on preventive health examinations: a survey of childbearing women in Uyo, Nigeria.	Udofia et al. (2012)
CINAHL	No - no BCA intervention	Self-Esteem and Breast Self-Examination of Women Prisoners.	Harputlu and Temel (2014)
CINAHL	No - no BCA intervention	Encouraging Arab women to beat the cancer epidemic: An investigation into positive attributes that encourage Arab women to practice prevention methods for cancer.	Subaibani and Obeng (2015)
CINAHL	No - no BCA intervention	Breast cancer awareness among an inner city group of Nigerian women.	Moorley et al. (2014)
CINAHL	No - no BCA intervention	Breast screening knowledge and barriers among under/never screened women.	Nadalin et al. (2016)
CINAHL	No - no BCA intervention	Promoting Breast Health among Urban African-American Women: Evidence Supporting the Need for a Purposeful Pursuit of the Promise.	Millon Underwood et al. (2013)
CINAHL	No - no BCA intervention	Knowledge, Attitude, Practice, and Associated Factors of Breast Cancer Self-Examination among Urban Health Extension Workers in Addis Ababa, Central Ethiopia.	Zeru et al. (2019)
CINAHL	No - no BCA intervention	Breast Health Beliefs, Behaviors, and Barriers Among Latina Permanent Resident and Migratory Farm Workers.	Schlehofer and Brown-Reid (2015)
CINAHL	No - no BCA intervention	Assessment of the Knowledge and Practice of Breast Self Examination among Female Cleaners in Obafemi Awolowo University Ile Ife, Nigeria.	Omoyeni et al. (2014)
CINAHL	No - no BCA intervention	Sociocultural determinants of breast and cervical cancer screening adherence: an examination of variation among immigrant Latinas by country of origin.	Shelton et al. (2012)
CINAHL	No - no BCA intervention	Barriers and Facilitators to Breast Cancer Screening Among Migrant Women Within Turkey.	Tuzcu and Bahar (2015)
CINAHL	No - no BCA intervention	Breast Cancer Screening Practices among Women in Akure South Local Government Area of Ondo State, Nigeria.	Obalase et al. (2017)
CINAHL	No - no BCA intervention	Knowledge, attitudes, and practices related to breast cancer screening among female health care professionals: a cross sectional study.	Heena et al. (2019)
CINAHL	No - no BCA intervention	Health Beliefs of African American Women on Breast Self-Exam.	Registe and Porterfield (2012)

CINAHL	No - no BCA intervention	The Psychometric Properties of the Greek Version of Champion's Health Belief Model Scale.	Tsangari et al. (2012)
CINAHL	No - no BCA intervention	Breast cancer health promotion in Qatar: a survey of community pharmacists' interests and needs.	El Hajj et al. (2013)
CINAHL	No - no BCA intervention	Public and professional educational needs for downstaging breast cancer in Egypt... [corrected]	Uddin et al. (2012)
CINAHL	No - no BCA intervention	Influence of Sense of Coherence, Spirituality, Social Support and Health Perception on Breast Cancer Screening Motivation and Behaviors in African American Women.	Conway-Phillips and Janusek (2014)
CINAHL	No - no BCA intervention	Health beliefs associated with breast cancer screening among Arab women in the Northeastern United States.	Petro-Nustas et al. (2012)
CINAHL	No - no BCA intervention	Affective associations and cognitive beliefs relate to individuals' decisions to perform testicular or breast self-exams.	Brown-Kramer and Kiviniemi (2015)
CINAHL	No - no BCA intervention	Knowledge and recommendations regarding breast cancer early screening in an upper middle income country: Primary and secondary health care professionals.	Ortega-Olvera et al. (2016)
CINAHL	No - no BCA intervention	Estimated risks and optimistic self-perception of breast cancer risk in Korean women.	Chung and Lee (2013)
CINAHL	No - no BCA intervention	The role of clinical breast examination in cancer screening for women at average risk: A mini review.	Brennan (2016)
CINAHL	No - no BCA intervention	Knowledge, attitude and practice regarding breast cancer and breast self-examination among a sample of the educated population in Iraq.	Alwan et al. (2012)
CINAHL	No - no BCA intervention	The role of tentative decisions and health concepts in assessing information about mammography screening.	Bientzle et al. (2015)
CINAHL	No - no BCA intervention	Predictors of regular mammography use among American Indian women in Oklahoma: a cross-sectional study.	Tolma et al. (2014)
CINAHL	No - no BCA intervention	Physicians' attitudes and behaviour toward screening mammography in women 40 to 49 years of age.	Smith et al. (2012)
CINAHL	No - no BCA intervention	P0178 Awareness of women about breast self-examination and risk factors for breast cancer in Benghazi, Libya.	Ziuo et al. (2014)
CINAHL	No - no BCA intervention	Breast cancer risk perceptions of Turkish women attending primary care: a cross-sectional study.	Kartal et al. (2014)
CINAHL	No - no BCA intervention	Breast cancer in older patients: national cancer registry data.	Sinha et al. (2013)
CINAHL	No - no BCA intervention	Breast screening and health issues among rural females in Malaysia: How much do they know and practice?	Dahlui et al. (2013)
ASSIA	No - no BCA intervention	AANP has a "fight" plan for Breast Cancer	Cooke (2015)
ASSIA	No - no BCA intervention	A Comprehensive Health Profile of Guyanese Immigrants Aged 18–64 in Schenectady, New York	Hosler and Krammer (2018)
ASSIA	No - no BCA intervention	Breast Self-examination Among AKHA Women (Hill Tribe Group) in Chiang Rai, Thailand	Suwannaporn and Chuemchit (2022)
ASSIA	No - no BCA intervention	Husbands' Knowledge of Breast Cancer and Their Wives' Attitudes and Practices Related to Breast Cancer Screening in Saudi Arabia: Cross-sectional Online Survey	Sabugul et al. (2021)
ASSIA	No - no BCA intervention	The Effectiveness of Media Inclusiveness on the Breast Cancer Care Awareness Campaign: Evidence from North Cyprus	Onyenegecha et al. (2021)
ASSIA	No - no BCA intervention	Supporting women with learning disabilities during breast cancer diagnosis in Ireland:	Nelson and Carey (2014)
ASSIA	No - no BCA intervention	African American Women's Perspectives on Breast Cancer: Implications for Communicating Risk of Basal-like Breast Cancer	Allicock et al. (2013)
ASSIA	No - no BCA intervention	American BRCA Outcomes and Utilization of Testing (ABOUT) Study: A Pragmatic Research Model that Incorporates Personalized Medicine/Patient-Centered Outcomes in a Real World Setting	Armstrong et al. (2015)
ASSIA	No - no BCA intervention	Creating a Safe and Caring Health Care Context for Women Who Have Sex With Women	Flemmer et al. (2012)
ASSIA	No - no BCA intervention	Religious Beliefs and Cancer Screening Behaviors among Catholic Latinos: Implications for Faith-based Interventions	Allen et al. (2014)
ASSIA	No - no BCA intervention	Breast Cancer and Mammography Screening: Knowledge, Beliefs and Predictors for Asian Immigrant Women Attending a Specialized Clinic in British Columbia, Canada	Hippman et al. (2016)
ASSIA	No - no BCA intervention	Korean American Women and Mammogram Uptake	Lee et al. (2016)
ASSIA	No - no BCA intervention	Relationship Between State-Level Google Online Search Volume and Cancer Incidence in the United States: Retrospective Study	Phillips et al. (2018)
ASSIA	No - no BCA intervention	Psychosocial consequences among women with false-positive results after mammography screening in Norway	Solbjør et al. (2018)
ASSIA	No - no BCA intervention	Health and Prevention among East African Women in the U.S.	Murray et al. (2013)
ASSIA	No - no BCA intervention	Cultural Beliefs and Clinical Breast Examination in Hmong American Women: The Crucial Role of Modesty	Lee et al. (2015)
ASSIA	No - no BCA intervention	Transcultural Adaptation and Validation of Champion's Health Belief Model Scales for Prostate Cancer Screening	Abuadas et al. (2016)
ASSIA	No - no BCA intervention	Muslim Syrian refugee women's exploration of breast cancer preventative care in a Western Canadian prairie city	Racine et al. (2021)

ASSIA	No - no BCA intervention	Exploring Factors Contributing to Low Uptake of the NHS Breast Cancer Screening Programme among Black African Women in the UK	Olufikayo Bamidele et al. (2017)
ASSIA	No - no BCA intervention	Sources of Uncertainty About Daughters' Breast Cancer Risk that Emerge During Genetic Counseling Consultations	Bylund et al. (2012)
ASSIA	No - no BCA intervention	Knowledge and Beliefs about the Practice of Breast Self-examination among Macau Female Nurses	Weng and Sellick (2014)
ASSIA	No - no BCA intervention	CoppaFeel!: on a mission to educate young people about breast cancer	Dopierala (2015)
ASSIA	No - no BCA intervention	Knowledge and awareness of breast cancer and breast self-examination among college-going female students in Delhi-NCR: a cross sectional study	Ankan et al. (2022)
ASSIA	No - no BCA intervention	Breast Cancer Screening Paved with Good Intentions: Application of the Information–Motivation–Behavioral Skills Model to Racial/Ethnic Minority Women	Talley et al. (2017)
ASSIA	No - no BCA intervention	Using Mixed Methods with Multiple Stakeholders to Inform Development of a Breast Cancer Screening Decision Aid for Women with Limited Health Literacy	Cunn et al. (2021)
ASSIA	No - no BCA intervention	Exploring the lived experience of breast cancer diagnosis and treatment amongst Gujarati speaking Indian women	Patel-Kerai et al. (2015)
ASSIA	No - no BCA intervention	Frequencies of Private Mentions and Sharing of Mammography and Breast Cancer Terms on Facebook: A Pilot Study	Huesch et al. (2017)
ASSIA	No - no BCA intervention	Online Information-Seeking About Potential Breast Cancer Symptoms: Capturing Online Behavior With an Internet Browsing Tracking Tool	Marcu et al. (2019)
ASSIA	No - no BCA intervention	"If It Is Written by Allah, There Is Nothing That Can Stop It": Saudi women's breast cancer narratives	Sinky et al. (2015)
ASSIA	No - no BCA intervention	Information Needs of Breast Cancer Patients: Theory-Generating Meta-Synthesis	Lu et al. (2020)
ASSIA	No - no BCA intervention	The "Angelina Effect" and Audience Response to Celebrity vs. Medical Expert Health Messages: an Examination of Source Credibility, Message Elaboration, and Behavioral Intentions	Emmers-Sommer and Terán (2020)
ASSIA	No - no BCA intervention	Breast Cancer Screening	Wilbanks (2017)
ASSIA	No - no BCA intervention	Rethink Cancer: cancer education in schools	Kirichek et al. (2015)
ASSIA	No - no BCA intervention	Health Care Reform: Next Steps?	Olmstead (2012)
ASSIA	No - no BCA intervention	Barriers and Facilitators to Breast and Cervical Cancer Screening Among Immigrants in the United States	Adunlin et al. (2019)
ASSIA	No - no BCA intervention	Why use Markov simulation models for estimating the effect of cancer screening policies when randomised controlled trials provide better evidence?	Braillon and Bewley (2012)
ASSIA	No - no BCA intervention	Why do women not return family history forms when referred to breast cancer genetics services? A mixed-method study	Hanning et al. (2015)
ASSIA	No - no BCA intervention	How black West African migrants perceive cancer	Thomson et al. (2013)
ASSIA	No - no BCA intervention	Determinants of screening methods utilization among Iraq/Sulaimani women	Shakor et al. (2020)
ASSIA	No - no BCA intervention	Association Between Recency of Immigration and Mammography Uptake: Results from a Canadian National Survey	Adu et al. (2017)
ASSIA	No - no BCA intervention	Knowledge, attitudes and practice of breast cancer screening among female personnel of W alailak U niversity	Kotepui et al. (2015)
ASSIA	No - no BCA intervention	Patterns of Treatment and Survival among American Indian and Alaska Native Women with Breast Cancer, 2000–2015	Longacre et al. (2020)
ASSIA	No - no BCA intervention	Breast Cancer Genetics Knowledge and Testing Intentions among Nigerian Professional Women	Ngene et al. (2018)
ASSIA	No - no BCA intervention	Factors Associated with Late-Stage Breast Cancer Diagnosis in an Urban Safety-net Hospital	Ahmadiyeh et al. (2020)
ASSIA	No - no BCA intervention	Breast Cancer Risk Assessment: Calculating Lifetime Risk Using the Tyrer-Cuzick Model	Himes et al. (2016)
ASSIA	No - no BCA intervention	Comparison of the Screening Practices of Unaffected Noncarriers under 40 and between 40 and 49 in BRCA1/2 Families	Duprez et al. (2013)
ASSIA	No - no BCA intervention	Experiences of Women Who Underwent Predictive BRCA 1/2 Mutation Testing Before the Age of 30	Brunstrom et al. (2016)
ASSIA	No - no BCA intervention	Seeking Balance: Decision Support Needs of Women Without Cancer and a Deleterious BRCA1 or BRCA2 Mutation	Underhill et al. (2014)
ASSIA	No - no BCA intervention	Breast cancer awareness among Indonesian women at moderate-to-high risk	Mardela et al. (2017)
ASSIA	No - no BCA intervention	Symptom Burden in Breast Cancer Patients Seeking Hospice Care in Rural Kenya	Tarus et al. (2021)
ASSIA	No - no BCA intervention	KAP ASSESSMENT REGARDING BREAST CANCER: AWARENESS AMONG PAKISTANI FEMALES	Saeed et al. (2017)
Medline	No - no BCA intervention	Likelihood of Breast Screening Uptake among Reproductive-aged Women in Ethiopia: A Baseline Survey for Randomized Controlled Trial	Agide et al. (2019)
Web of Science	No - no BCA intervention	Breast Cancer Risk and Early Diagnosis Applications in Turkish Women Aged 50 and Over	Ceber et al. (2013)

ASSIA	No - no BCA intervention	Conversations and Misconceptions About Chemotherapy in Arabic Tweets: Content Analysis	Alghamdi et al. (2020)
ASSIA	No - no BCA intervention	Advice on personal safety for women with learning disabilities	Murphy et al. (2014)
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ASSIA	No - no BCA intervention	Internet Search Patterns of Human Immunodeficiency Virus and the Digital Divide in the Russian Federation: Infoveillance Study	Zheluk et al. (2013)
ASSIA	No - no BCA intervention	Pilot Evaluation of a Health Promotion Program for African Immigrant and Refugee Women: The UJAMBO Program	Piwowarczyk et al. (2013)
ASSIA	No - no BCA intervention	Talking about cancer with confidence: evaluation of cancer awareness training for community-based health workers	Grimmett et al. (2014)
ASSIA	No - no BCA intervention	Promoting Testicular Self-Examination and Awareness Amongst Young Men With Intellectual Disabilities: A Parallel Intervention Randomized Study	Wilson et al. (2018)
ASSIA	No - no BCA intervention	HAPPY TO SUPPORT: EMOTION AS A MEDIATOR IN BRAND BUILDING THROUGH PHILANTHROPIC CORPORATE SPONSORSHIP	Lee et al. (2015)
ASSIA	No - no BCA intervention	Association between Family Communication and Health Literacy among Underserved Racial/Ethnic Women	Zambrana et al. (2015)
ASSIA	No - no BCA intervention	The Public Perception of the #GeneEditedBabies Event Across Multiple Social Media Platforms: Observational Study	Ni et al. (2022)
ASSIA	No - no BCA intervention	Underutilization of Genetics Services for Autism: The Importance of Parental Awareness and Provider Recommendation	Vande et al. (2012)
ASSIA	No - no BCA intervention	Women's sun protection cognitions in response to UV photography: the role of age, cognition, and affect	Walsh et al. (2014)
ASSIA	No - no BCA intervention	Disgust propensity has a causal link to the stigmatization of people with cancer	Azlan et al. (2020)
ASSIA	No - no BCA intervention	Presented Abstracts from the Thirty Fifth Annual Education Conference of the National Society of Genetic Counselors (Seattle, WA, September 2016)	N/A
Web of Science	No - no BCA intervention	Assessment of the Effect of the Go Red for Women Campaign on Search Engine Queries for Cardiovascular Disease in Women	Suero-Abreu et al. (2020)
APA Psychinfo	No - no BCA intervention	The design, implementation and evaluation of an e-health video for women under age forty not eligible for mammograms: Predictors of a high rating of the video.	Vernale-Fusco (2017)
Medline	No - no BCA intervention	Evaluating a DVD promoting breast cancer awareness among black women aged 25-50 years in East London	Greenhough et al. (2016)
Medline	No - no BCA intervention	Effect of direct education on breast self examination awareness and practice among women in Bolu, Turkey	Gucuk and Uyeturk (2013)
APA Psychinfo	No - no BCA intervention	Effect of cancer education on the practice of breast self-examination among adult women in Nigeria	Udeze et al. (2020)
APA Psychinfo	No - no BCA intervention	Effects of smartphone application education combined with hands-on practice in breast self-examination on junior nursing students in South Korea.	Kang et al. (2020)
Web of Science	No - no BCA intervention	Evaluation of an Intervention Program for Promoting Breast Self-Examination Behavior in Employed Women in Iran	Bashirian et al. (2021)
Web of Science	No - no BCA intervention	A Different Approach to Breast Self-Examination Training: Family Training	Ayran et al. (2022)
CINAHL	No - no BCA intervention	Text message reminders to increase breast self-awareness practices in young women.	Fernandez Bertulfo (2015)
APA Psychinfo	No - no BCA intervention	Using EPPM to evaluate the effectiveness of fear appeal messages across different media outlets to increase the intention of breast self-examination among Chinese women.	Chen and Yang (2019)
Web of Science	No - qualitative	Health education for early detection of breast cancer in blind women	de Franca et al. (2015)
CINAHL	No - qualitative	Health education for early detection of breast cancer in blind women.	Xavier de França et al. (2015)

Web of Science	No - no BCA intervention	Fear, family and the placing of emotion: Black women's responses to a breast cancer awareness intervention	Brown et al. (2017)
Cochrane Library	No - no BCA intervention	A window-of-opportunity study of pelareorep in early breast cancer (AWARE-1)	Manso et al. (2019)
CINAHL	No - no BCA intervention	Conducting a Feasibility Study in Women’s Health Screening Among Women in a Pacific Northwest American Indian Tribe.	Stickland and Hillaire (2016)
CINAHL	No - no BCA intervention	Women's health beliefs and breast cancer screening practices in Nigeria.	Olowokere et al. (2012)
CINAHL	No - no BCA intervention	Removing the blindfolds: knowledge of blind women about breast cancer.	Pereira et al. (2015)
CINAHL	No - no BCA intervention	Level of awareness of mammography among women attending outpatient clinics in a teaching hospital in Ibadan, South-West Nigeria.	Obajimi et al. (2013)
ASSIA	No - no BCA intervention	Literacy of Breast Cancer and Screening Guideline in an Immigrant Group: Importance of Health Accessibility	Soonok et al. (2020)
ASSIA	No - no BCA intervention	Breast Cancer Perceptions and Screening Behaviours Among Korean Women in Australia	Cannas et al. (2020)
ASSIA	No - no BCA intervention	Awareness of cancer risk factors and protective factors among Australian adults	Lizama et al. (2020)
Cochrane Library	No - no BCA intervention	Alcohol and Breast Cancer: results From the Women's Wellness After Cancer Program Randomized Controlled Trial	Balaam et al. (2022)
Cochrane Library	No - no BCA intervention	Uptake and performance of clinical breast exam screening program by trained laywomen in Malawi	Gutnik et al. (2016)
Cochrane Library	No - no BCA intervention	Effectiveness of a theory-based educational intervention on breast self-exam behavior in women who referred to health care centers	Kermanchi et al. (2018)
CINAHL	No - no BCA intervention	The Effect of Motivational Interviewing-Based Training Compared with Conventional Training on the Frequency of Breast Cancer Screening Tests in Female Teachers: A Quasi-Experimental Study.	Zolfaghari et al. (2018)
CINAHL	No - no BCA intervention	Laughing in the Face of Fear (of Disease Detection): Using Humor to Promote Cancer Self-Examination Behavior.	Nabi (2016)
ASSIA	No - no BCA intervention	The Effect of Patient Narratives on Information Search in a Web-Based Breast Cancer Decision Aid: An Eye-Tracking Study	Shaffer et al. (2013)
ASSIA	No - no BCA intervention	Factors Associated with Reported Colorectal Cancer Screening Among Lao-American Immigrants in Minnesota	Rogers et al. (2020)
ASSIA	No - no BCA intervention	Older Korean American Men's Prostate Cancer Screening Behavior: The Prime Role of Culture	Lee et al. (2013)
ASSIA	No - no BCA intervention	Tackle Prostate Cancer: A Doctoral Student's Response	Lacourt (2014)
ASSIA	No - no BCA intervention	An affective booster moderates the effect of gain- and loss-framed messages on behavioral intentions for colorectal cancer screening	Ferrer et al. (2012)
ASSIA	No - no BCA intervention	Affective components of perceived risk mediate the relation between cognitively-based perceived risk and colonoscopy screening	Klasko-Foster et al. (2020)
ASSIA	No - no BCA intervention	The role of perceived sleep norms in subjective sleep appraisals and sleep-related illness behavior	Mulla et al. (2017)
ASSIA	No - no BCA intervention	Psychosocial factors associated with treatment outcomes in women with obesity and major depressive disorder who received behavioral activation for depression	Kern et al. (2019)
ASSIA	No - no BCA intervention	When sex doesn't sell to men: mortality salience, disgust and the appeal of products and advertisements featuring sexualized women	Lee et al. (2017)
ASSIA	No - no BCA intervention	The effect of disgust-related side-effects on symptoms of depression and anxiety in people treated for cancer: a moderated mediation model	Powell et al. (2016)
ASSIA	No - no BCA intervention	The Impact of Neurofibromatosis Type 1 on the Health and Wellbeing of Australian Adults	Crawford et al. (2015)
ASSIA	No - no BCA intervention	Advancing our understanding of religion and spirituality in the context of behavioral medicine	Park et al. (2017)
ASSIA	No - no BCA intervention	Using Internet Search Engines to Obtain Medical Information: A Comparative Study	Wang (2012)
ASSIA	No - no BCA intervention	**Eating Disorder Awareness Campaigns: Thematic and Quantitative Analysis Using Twitter**	Iranzu et al. (2020)
ASSIA	No - no BCA intervention	Examining Twitter Discourse on Electronic Cigarette and Tobacco Consumption During National Cancer Prevention Month in 2018: Topic Modeling and Geospatial Analysis	Lu and Lee (2021)
ASSIA	No - no BCA intervention	The Development of a Smart Health Awareness Message Framework Based on the Use of Social Media: Quantitative Study	Elaf et al. (2020)
ASSIA	No - no BCA intervention	Short Message Service (SMS) Applications for Disease Prevention in Developing Countries	Déglise et al. (2012)
ASSIA	No - no BCA intervention	Mental Health Information Seeking Online: A Google Trends Analysis of ADHD	Zhao et al. (2022)
ASSIA	No - no BCA intervention	A Direct Observation Study of Health Education Classes for Uninsured Primary Care Patients	Weaver at al. (2017)
ASSIA	No - no BCA intervention	Adolescents' Perceptions of Family Violence Risks	Chapin et al. (2014)
ASSIA	No - no BCA intervention	An Observational Study of Social and Emotional Support in Smoking Cessation Twitter Accounts: Content Analysis of Tweets	Rocheleau et al. (2015)

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CINAHL	No - qualitative	Health education for early detection of breast cancer in blind women.	Xavier de França et al. (2015)

Cochrane Library	Protocol	The Effect of Motivational Interviewing on Breast Cancer Screening Behaviors of Rural Women: a Randomized Controlled Clinical Trial	Protocol
Cochrane Library	Protocol	Community education and navigation to improve breast cancer screening uptake in Malaysia	Protocol
Cochrane Library	Protocol	Improving Access to Breast Cancer Screening and Treatment in Nigeria: the Triple Mobile Assessment and Patient Navigation Model	Protocol
Cochrane Library	Protocol	Development of Health Education program about breast awareness using Health Belief Model for nursing students	Protocol
Cochrane Library	Protocol	Nurse Navigation Program Based On Health Belief Model In Breast Cancer Screening (NaHeB-CaS)	Protocol
Cochrane Library	Protocol	Self-care education programs effect on breast self-examination behaviors	Protocol
Cochrane Library	Protocol	Designing an educational CD about Breast Self Exam and assesing its effect	Protocol
Cochrane Library	Protocol	Improving awareness of breast cancer screening and breast self-exam	Protocol
Web of Science	Qualitative	Understanding breast health awareness in an Arabic culture: qualitative study protocol	Madkhali et al. (2016)
Web of Science	Qualitative	Optimising patient-initiated follow-up care - A qualitative analysis of women with breast cancer in the UK	Moore et al. (2022)
Web of Science	Qualitative	Oncologist Perspectives on Breast Cancer Screening in India-Results from a Qualitative Study in Andhra Pradesh	Mohan et al. (2021)
Web of Science	Qualitative	Barriers and facilitators to mammography among women with intellectual disabilities: a qualitative approach	Arana-Chicas et al. (2020)
Web of Science	Review	Interventions for raising breast cancer awareness in women	Kennedy (2018)
ASSIA	Review	Defining breast cancer awareness and identifying barriers to breast cancer awareness for women with an intellectual disability: A review of the literature	Walsh et al. (2022)
ASSIA	Review	Easy read and accessible information for people with intellectual disabilities: Is it worth it? A meta-narrative literature review	Chinn et al. (2017)
ASSIA	Review - literature	Breast Cancer Screening Interventions for Arabic Women: A Literature Review	Donnelly et al. (2015)
CINAHL	Systematic review	Interventions Promoting Breast Cancer Screening Among Turkish Women With Global Implications: A Systematic Review.	Secginli et al. (2017)
ASSIA	Systematic review	Social Media and mHealth Technology for Cancer Screening: Systematic Review and Meta-analysis	Ruco et al. (2021)
ASSIA	Systematic review	Videos to influence: a systematic review of effectiveness of video-based education in modifying health behaviors	Tuong et al. (2014)
ASSIA	Systematic review	A Rapid Systematic Review of Outcomes Studies in Genetic Counseling	Madlensky et al. (2017)
ASSIA	Systematic review	Beyond the Black Box: A Systematic Review of Breast, Prostate, Colorectal, and Cervical Screening Among Native and Immigrant African-Descent Caribbean Populations	Consedine et al. (2015)
ASSIA	Systematic review	mHealth Interventions to Improve Cancer Screening and Early Detection: Scoping Review of Reviews	Schliemann et al. (2022)
ASSIA	Systematic review	Characterization of the Hispanic or Latino Population in Health Research: A Systematic Review	Aragones et al. (2014)
ASSIA	Systematic review	The Effect of Technology-Based Interventions on Pain, Depression, and Quality of Life in Patients With Cancer: A Systematic Review of Randomized Controlled Trials	Agboola et al. (2015)
ASSIA	Systematic review	Evaluating the Effectiveness of Internet-Based Communication for Public Health: Systematic Review	Ceretti et al. (2022)
ASSIA	Systematic review	Health and Wellness Technology Use by Historically Underserved Health Consumers: Systematic Review	Montague et al. (2012)
ASSIA	Systematic review	Social Media–Based Interventions for Health Behavior Change in Low- and Middle-Income Countries: Systematic Review	Seiler et al. (2022)
ASSIA	Systematic review	Interventions for raising breast cancer awareness in women	Kennedy (2018)
ASSIA	Systematic review	The impact of breast cancer awareness interventions on breast screening uptake among women in the United Kingdom: A systematic review	Anastasi and Lusher (2019)
Medline	Yes	Effects of mobile text messaging on breast cancer and breast self-examination (BSE) knowledge, BSE self-efficacy, and BSE frequency: a randomised controlled trial	Labrague et al. (2021)
Medline	Yes	Effectiveness of educational intervention on breast cancer knowledge and breast self-examination among female university students in Bangladesh: a pre-post quasi-experimental study	Sarker et al. (2022)
APA Psychinfo	Yes	Effect of health education on female teachers' knowledge and practices regarding early breast cancer detection and screening in the Jazan area: A quasi-experimental study	Alameer et al. (2019)
Medline	Yes (18-30 years)	Communicating Breast Cancer Screening With Young Women: An Experimental Test of Didactic and Narrative Messages Using Video and Infographics	Occa and Suggs (2016)
APA Psychinfo	Yes (20 and 40 years)	Effects of breast health education conducted by trained breast cancer survivors.	Yi and Park (2012)

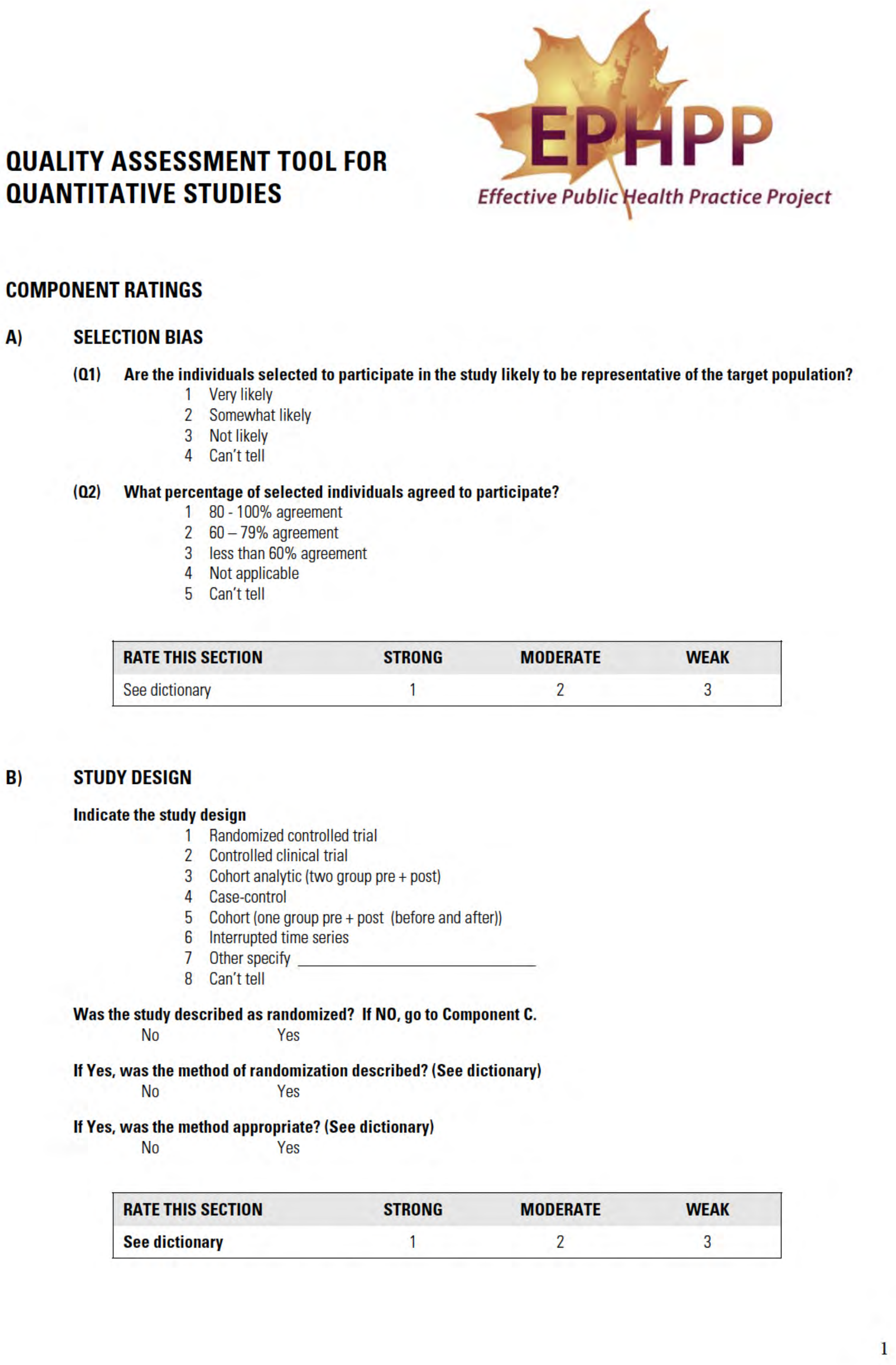
Appendix B

University Template used for Creating Data Extraction Tables for Systematic Review

	Health Coaching for Type 1 Diabetes Adherence: A Mini Systematic Review											
Reference	Sample size	Gender	Mean age	Study design	Intervention Description	Control Intervention Description	Training / experience of intervention facilitator	Measure of adherence used	Time point studied	Analysis conducted	Findings	
Bloggs et al., 2010	Intervention Group: 107 Control Group: 108	106 men, 109 women	58 (SD = 6.7)	Randomised Controlled Trial	8 weeks of 1 hour Health Coaching sessions + Leaflet on Managing Diabetes	Leaflet on Managing Diabetes	Health Coach' not described	MARS	6 weeks after end of intervention	Independent samples t test at follow-up	Mean (SD) of Intervention Group at follow-up = 6.3 (0.7), control group = 5.2 (0.8). Significant difference between groups *t* (206)=1.46 , p<.001.	

Appendix C

The Effective Public Health Practice Project Quality Assessment Tool for Quantitative Studies (2004)



QUALITY ASSESSMENT TOOL FOR QUANTITATIVE STUDIES

EPHPP
Effective Public Health Practice Project

COMPONENT RATINGS

A) **SELECTION BIAS**

(Q1) **Are the individuals selected to participate in the study likely to be representative of the target population?**

1 Very likely
2 Somewhat likely
3 Not likely
4 Can't tell

(Q2) **What percentage of selected individuals agreed to participate?**

1 80 - 100% agreement
2 60 – 79% agreement
3 less than 60% agreement
4 Not applicable
5 Can't tell

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

B) **STUDY DESIGN**

Indicate the study design

1 Randomized controlled trial
2 Controlled clinical trial
3 Cohort analytic (two group pre + post)
4 Case-control
5 Cohort (one group pre + post (before and after))
6 Interrupted time series
7 Other specify ____________________________
8 Can't tell

Was the study described as randomized? If NO, go to Component C.

No Yes

If Yes, was the method of randomization described? (See dictionary)

No Yes

If Yes, was the method appropriate? (See dictionary)

No Yes

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

C) CONFOUNDERS

(Q1) Were there important differences between groups prior to the intervention?

1 Yes
2 No
3 Can't tell

The following are examples of confounders:

1 Race
2 Sex
3 Marital status/family
4 Age
5 SES (income or class)
6 Education
7 Health status
8 Pre-intervention score on outcome measure

(Q2) If yes, indicate the percentage of relevant confounders that were controlled (either in the design (e.g. stratification, matching) or analysis)?

1 80 – 100% (most)
2 60 – 79% (some)
3 Less than 60% (few or none)
4 Can't Tell

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

D) BLINDING

(Q1) Was (were) the outcome assessor(s) aware of the intervention or exposure status of participants?

1 Yes
2 No
3 Can't tell

(Q2) Were the study participants aware of the research question?

1 Yes
2 No
3 Can't tell

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

E) DATA COLLECTION METHODS

(Q1) Were data collection tools shown to be valid?

1 Yes
2 No
3 Can't tell

(Q2) Were data collection tools shown to be reliable?

1 Yes
2 No
3 Can't tell

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

F) WITHDRAWALS AND DROP-OUTS

(Q1) Were withdrawals and drop-outs reported in terms of numbers and/or reasons per group?

1 Yes
2 No
3 Can't tell
4 Not Applicable (i.e. one time surveys or interviews)

(Q2) Indicate the percentage of participants completing the study. (If the percentage differs by groups, record the lowest).

1 80 -100%
2 60 - 79%
3 less than 60%
4 Can't tell
5 Not Applicable (i.e. Retrospective case-control)

RATE THIS SECTION	**STRONG**	**MODERATE**	**WEAK**	
See dictionary	1	2	3	Not Applicable

G) INTERVENTION INTEGRITY

(Q1) What percentage of participants received the allocated intervention or exposure of interest?

1 80 -100%
2 60 - 79%
3 less than 60%
4 Can't tell

(Q2) Was the consistency of the intervention measured?

1 Yes
2 No
3 Can't tell

(Q3) Is it likely that subjects received an unintended intervention (contamination or co-intervention) that may influence the results?

4 Yes
5 No
6 Can't tell

H) ANALYSES

(Q1) Indicate the unit of allocation (circle one)

community organization/institution practice/office individual

(Q2) Indicate the unit of analysis (circle one)

community organization/institution practice/office individual

(Q3) Are the statistical methods appropriate for the study design?

1 Yes
2 No
3 Can't tell

(Q4) Is the analysis performed by intervention allocation status (i.e. intention to treat) rather than the actual intervention received?

1 Yes
2 No
3 Can't tell

GLOBAL RATING

COMPONENT RATINGS

Please transcribe the information from the gray boxes on pages 1-4 onto this page. See dictionary on how to rate this section.

A	**SELECTION BIAS**	**STRONG**	**MODERATE**	**WEAK**	
		1	2	3	
B	**STUDY DESIGN**	**STRONG**	**MODERATE**	**WEAK**	
		1	2	3	
C	**CONFOUNDERS**	**STRONG**	**MODERATE**	**WEAK**	
		1	2	3	
D	**BLINDING**	**STRONG**	**MODERATE**	**WEAK**	
		1	2	3	
E	**DATA COLLECTION METHOD**	**STRONG**	**MODERATE**	**WEAK**	
		1	2	3	
F	**WITHDRAWALS AND DROPOUTS**	**STRONG**	**MODERATE**	**WEAK**	
		1	2	3	Not Applicable

GLOBAL RATING FOR THIS PAPER (circle one):

1	STRONG	(no WEAK ratings)
2	MODERATE	(one WEAK rating)
3	WEAK	(two or more WEAK ratings)

With both reviewers discussing the ratings:

Is there a discrepancy between the two reviewers with respect to the component (A-F) ratings?

No Yes

If yes, indicate the reason for the discrepancy

1 Oversight
2 Differences in interpretation of criteria
3 Differences in interpretation of study

Final decision of both reviewers (circle one):

1 STRONG
2 MODERATE
3 WEAK

Appendix D

Advertisement for Padlet (Associates)

Are you a friend, partner, relative, or carer of someone with NF1?

Help contribute to the design of a breast cancer awareness intervention for young women with NF1.

Add your thoughts to the first of a series of Padlets that is a tool to share your ideas and opinions.

My name is Caitríona Plunkett, and I am a PhD Researcher with Manchester Metropolitan University. As part of PhD research sponsored by the Childhood Tumour Trust, we are designing and piloting a breast cancer awareness intervention for young women with neurofibromatosis type 1 (NF1).

Women with NF1 have an increased risk of developing breast cancer at a younger age. The breast cancer awareness intervention aims to increase breast cancer awareness in young women with NF1 by educating on breast cancer risk, and signs and symptoms of breast cancer to encourage early help-seeking behaviour for a better prognosis. This educational tool is also proposed to help health professionals increase their knowledge about the condition and the associated increased breast cancer risk.

Following on from the earlier advertised Breast Cancer Awareness and NF1 PPI call out that required the input of only women with NF1, we are now looking for a wider involvement.

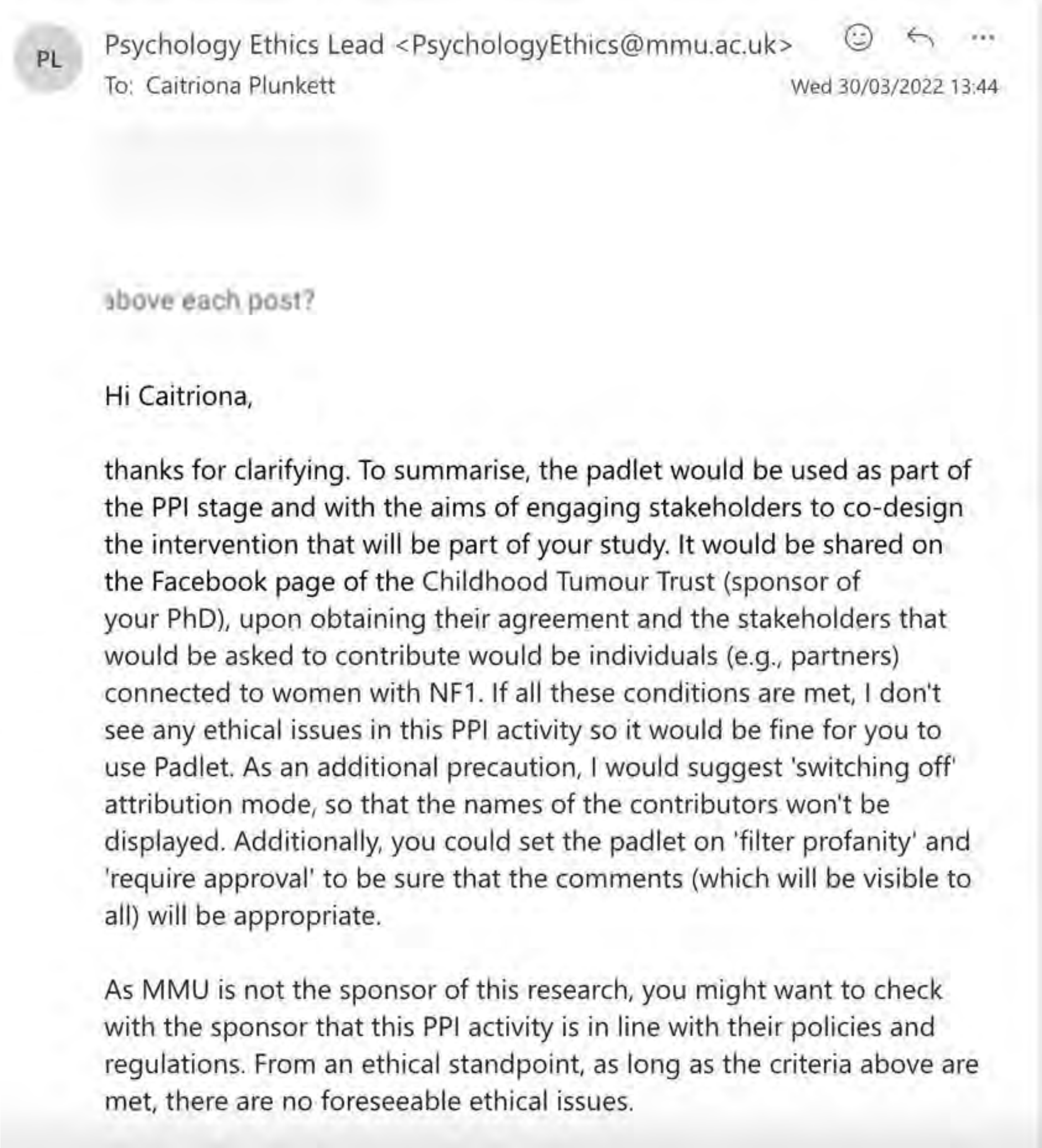
****If you are a woman with NF1 aged 18-40 years, and you would still like to be involved with the intervention design process that is ongoing within this specific group, please contact me directly on the details provided below for further information. Please do not enter details on these Padlets.****

Thank you all again for your support.

if you have further questions please contact:
Principal Investigator: caitriona.plunkett2@stu.mmu.ac.uk
Principal Supervisor: M.Pilkington@mmu.ac.uk

Appendix E

Padlet Precautions Advised by Ethics Lead



Psychology Ethics Lead <PsychologyEthics@mmu.ac.uk>
To: Caitriona Plunkett
Wed 30/03/2022 13:44

[redacted]

above each post?

Hi Caitriona,

thanks for clarifying. To summarise, the padlet would be used as part of the PPI stage and with the aims of engaging stakeholders to co-design the intervention that will be part of your study. It would be shared on the Facebook page of the Childhood Tumour Trust (sponsor of your PhD), upon obtaining their agreement and the stakeholders that would be asked to contribute would be individuals (e.g., partners) connected to women with NF1. If all these conditions are met, I don't see any ethical issues in this PPI activity so it would be fine for you to use Padlet. As an additional precaution, I would suggest 'switching off' attribution mode, so that the names of the contributors won't be displayed. Additionally, you could set the padlet on 'filter profanity' and 'require approval' to be sure that the comments (which will be visible to all) will be appropriate.

As MMU is not the sponsor of this research, you might want to check with the sponsor that this PPI activity is in line with their policies and regulations. From an ethical standpoint, as long as the criteria above are met, there are no foreseeable ethical issues.

Appendix F

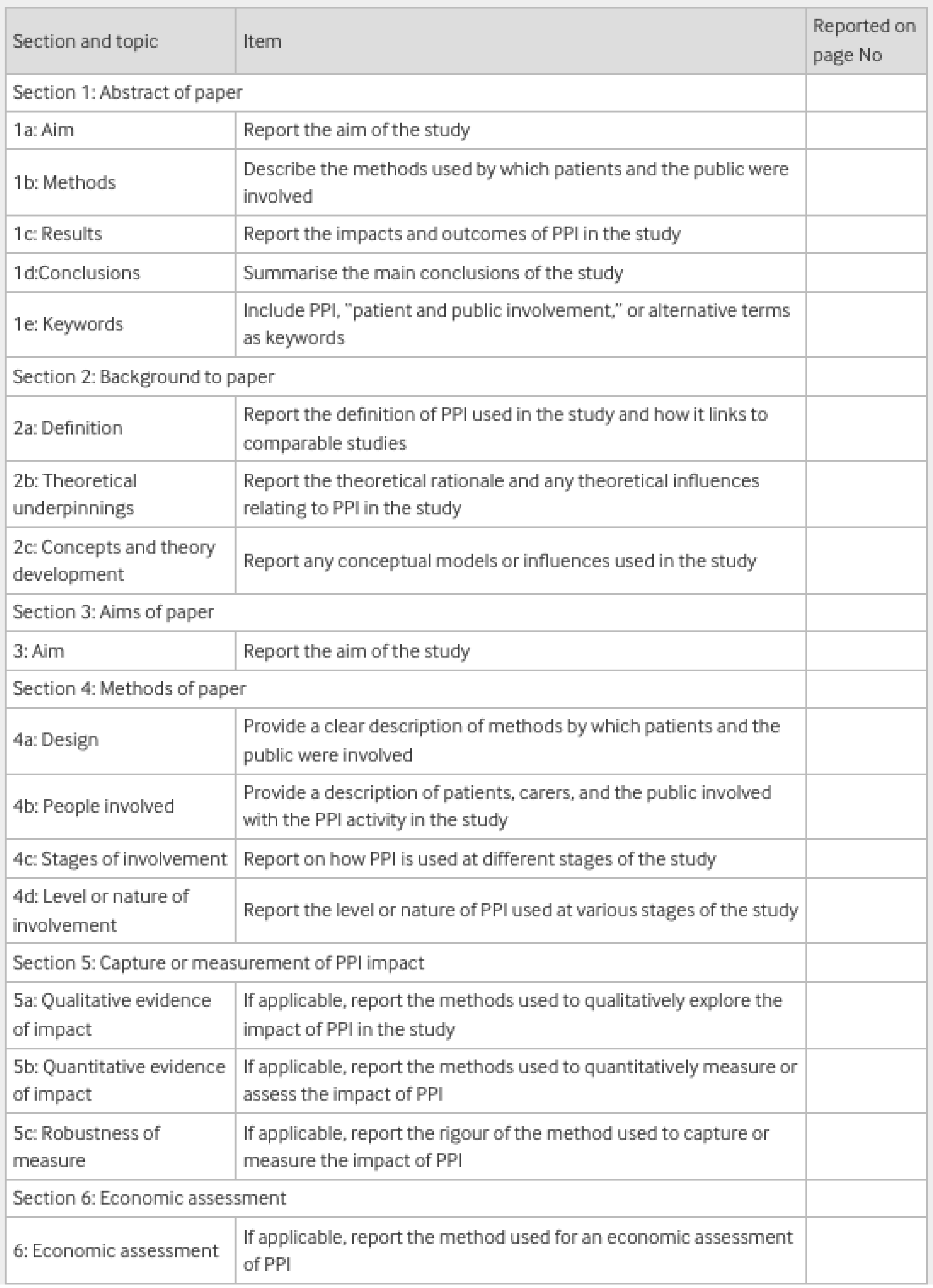
BCT Taxonomy (v1)

BCT Taxonomy (v1): 93 hierarchically-clustered techniques

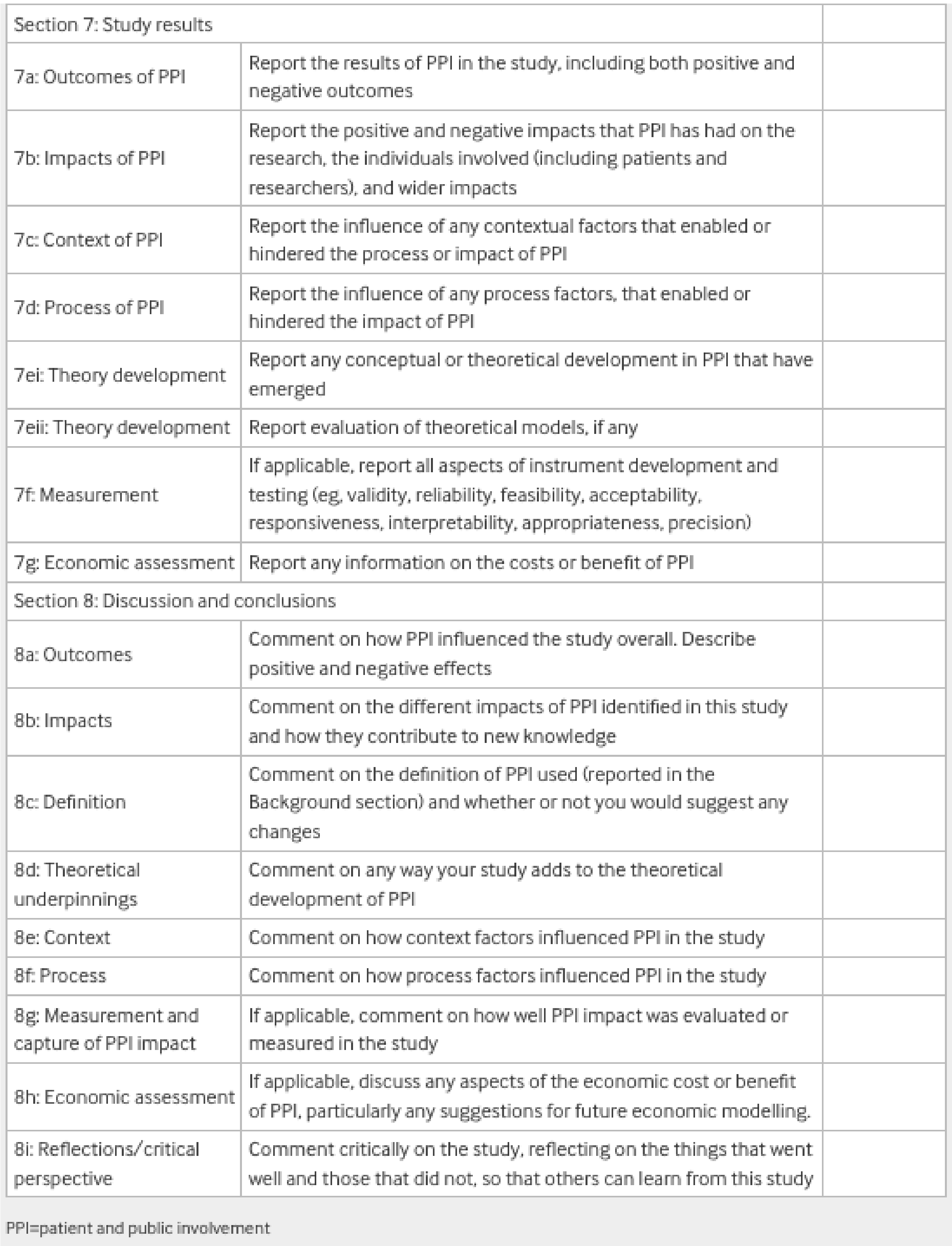
Page	Grouping and BCTs
1	**1. Goals and planning** 1.1. Goal setting (behavior) 1.2. Problem solving 1.3. Goal setting (outcome) 1.4. Action planning 1.5. Review behavior goal(s) 1.6. Discrepancy between current behavior and goal 1.7. Review outcome goal(s) 1.8. Behavioral contract 1.9. Commitment
3	**2. Feedback and monitoring** 2.1. Monitoring of behavior by others without feedback 2.2. Feedback on behaviour 2.3. Self-monitoring of behaviour 2.4. Self-monitoring of outcome(s) of behaviour 2.5. Monitoring of outcome(s) of behavior without feedback 2.6. Biofeedback 2.7. Feedback on outcome(s) of behavior
5	**3. Social support** 3.1. Social support (unspecified) 3.2. Social support (practical) 3.3. Social support (emotional)
6	**4. Shaping knowledge** 4.1. Instruction on how to perform the behavior 4.2. Information about Antecedents 4.3. Re-attribution 4.4. Behavioral experiments
7	**5. Natural consequences** 5.1. Information about health consequences 5.2. Salience of consequences 5.3. Information about social and environmental consequences 5.4. Monitoring of emotional consequences 5.5. Anticipated regret 5.6. Information about emotional consequences
8	**6. Comparison of behaviour** 6.1. Demonstration of the behavior 6.2. Social comparison 6.3. Information about others' approval
9	**7. Associations** 7.1. Prompts/cues 7.2. Cue signalling reward 7.3. Reduce prompts/cues 7.4. Remove access to the reward 7.5. Remove aversive stimulus 7.6. Satiation 7.7. Exposure 7.8. Associative learning
10	**8. Repetition and substitution** 8.1. Behavioral practice/rehearsal 8.2. Behavior substitution 8.3. Habit formation 8.4. Habit reversal 8.5. Overcorrection 8.6. Generalisation of target behavior 8.7. Graded tasks
11	**9. Comparison of outcomes** 9.1. Credible source 9.2. Pros and cons 9.3. Comparative imagining of future outcomes
12	**10. Reward and threat** 10.1. Material incentive (behavior) 10.2. Material reward (behavior) 10.3. Non-specific reward 10.4. Social reward 10.5. Social incentive 10.6. Non-specific incentive 10.7. Self-incentive 10.8. Incentive (outcome) 10.9. Self-reward 10.10. Reward (outcome) 10.11. Future punishment
15	**11. Regulation** 11.1. Pharmacological support 11.2. Reduce negative emotions 11.3. Conserving mental resources 11.4. Paradoxical instructions
16	**12. Antecedents** 12.1. Restructuring the physical environment 12.2. Restructuring the social environment 12.3. Avoidance/reducing exposure to cues for the behavior 12.4. Distraction 12.5. Adding objects to the environment 12.6. Body changes
17	**13. Identity** 13.1. Identification of self as role model 13.2. Framing/reframing 13.3. Incompatible beliefs 13.4 Valued self-identify 13.5. Identity associated with changed behavior
18	**14. Scheduled consequences** 14.1. Behavior cost 14.2. Punishment 14.3. Remove reward 14.4. Reward approximation 14.5. Rewarding completion 14.6. Situation-specific reward 14.7. Reward incompatible behavior 14.8. Reward alternative behavior 14.9. Reduce reward frequency 14.10. Remove punishment
19	**15. Self-belief** 15.1. Verbal persuasion about capability 15.2. Mental rehearsal of successful performance 15.3. Focus on past success 15.4. Self-talk
19	**16. Covert learning** 16.1. Imaginary punishment 16.2. Imaginary reward 16.3. Vicarious consequences

Appendix G

GRIPP2 Checklist



Section and topic	Item	Reported on page No
Section 1: Abstract of paper		
1a: Aim	Report the aim of the study	
1b: Methods	Describe the methods used by which patients and the public were involved	
1c: Results	Report the impacts and outcomes of PPI in the study	
1d:Conclusions	Summarise the main conclusions of the study	
1e: Keywords	Include PPI, "patient and public involvement," or alternative terms as keywords	
Section 2: Background to paper		
2a: Definition	Report the definition of PPI used in the study and how it links to comparable studies	
2b: Theoretical underpinnings	Report the theoretical rationale and any theoretical influences relating to PPI in the study	
2c: Concepts and theory development	Report any conceptual models or influences used in the study	
Section 3: Aims of paper		
3: Aim	Report the aim of the study	
Section 4: Methods of paper		
4a: Design	Provide a clear description of methods by which patients and the public were involved	
4b: People involved	Provide a description of patients, carers, and the public involved with the PPI activity in the study	
4c: Stages of involvement	Report on how PPI is used at different stages of the study	
4d: Level or nature of involvement	Report the level or nature of PPI used at various stages of the study	
Section 5: Capture or measurement of PPI impact		
5a: Qualitative evidence of impact	If applicable, report the methods used to qualitatively explore the impact of PPI in the study	
5b: Quantitative evidence of impact	If applicable, report the methods used to quantitatively measure or assess the impact of PPI	
5c: Robustness of measure	If applicable, report the rigour of the method used to capture or measure the impact of PPI	
Section 6: Economic assessment		
6: Economic assessment	If applicable, report the method used for an economic assessment of PPI	

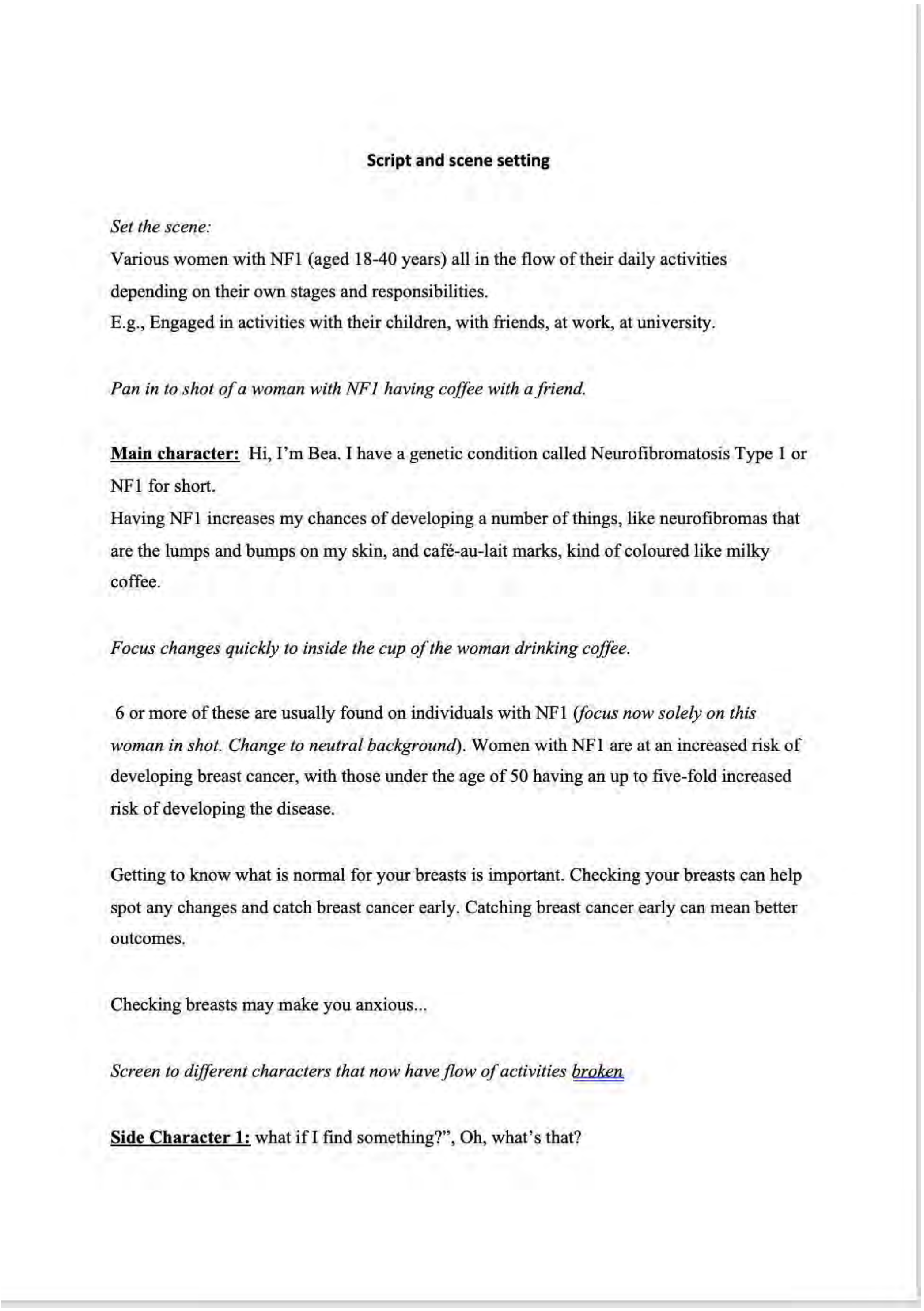


Section 7: Study results		
7a: Outcomes of PPI	Report the results of PPI in the study, including both positive and negative outcomes	
7b: Impacts of PPI	Report the positive and negative impacts that PPI has had on the research, the individuals involved (including patients and researchers), and wider impacts	
7c: Context of PPI	Report the influence of any contextual factors that enabled or hindered the process or impact of PPI	
7d: Process of PPI	Report the influence of any process factors, that enabled or hindered the impact of PPI	
7ei: Theory development	Report any conceptual or theoretical development in PPI that have emerged	
7eii: Theory development	Report evaluation of theoretical models, if any	
7f: Measurement	If applicable, report all aspects of instrument development and testing (eg, validity, reliability, feasibility, acceptability, responsiveness, interpretability, appropriateness, precision)	
7g: Economic assessment	Report any information on the costs or benefit of PPI	
Section 8: Discussion and conclusions		
8a: Outcomes	Comment on how PPI influenced the study overall. Describe positive and negative effects	
8b: Impacts	Comment on the different impacts of PPI identified in this study and how they contribute to new knowledge	
8c: Definition	Comment on the definition of PPI used (reported in the Background section) and whether or not you would suggest any changes	
8d: Theoretical underpinnings	Comment on any way your study adds to the theoretical development of PPI	
8e: Context	Comment on how context factors influenced PPI in the study	
8f: Process	Comment on how process factors influenced PPI in the study	
8g: Measurement and capture of PPI impact	If applicable, comment on how well PPI impact was evaluated or measured in the study	
8h: Economic assessment	If applicable, discuss any aspects of the economic cost or benefit of PPI, particularly any suggestions for future economic modelling.	
8i: Reflections/critical perspective	Comment critically on the study, reflecting on the things that went well and those that did not, so that others can learn from this study	

PPI=patient and public involvement

Appendix H

Animation Script



Script and scene setting

Set the scene:
Various women with NF1 (aged 18-40 years) all in the flow of their daily activities depending on their own stages and responsibilities.
E.g., Engaged in activities with their children, with friends, at work, at university.

Pan in to shot of a woman with NF1 having coffee with a friend.

Main character: Hi, I'm Bea. I have a genetic condition called Neurofibromatosis Type 1 or NF1 for short.
Having NF1 increases my chances of developing a number of things, like neurofibromas that are the lumps and bumps on my skin, and café-au-lait marks, kind of coloured like milky coffee.

Focus changes quickly to inside the cup of the woman drinking coffee.

6 or more of these are usually found on individuals with NF1 (*focus now solely on this woman in shot. Change to neutral background*). Women with NF1 are at an increased risk of developing breast cancer, with those under the age of 50 having an up to five-fold increased risk of developing the disease.

Getting to know what is normal for your breasts is important. Checking your breasts can help spot any changes and catch breast cancer early. Catching breast cancer early can mean better outcomes.

Checking breasts may make you anxious...

Screen to different characters that now have flow of activities broken

Side Character 1: what if I find something?", Oh, what's that?

Main character: or it may just be boring…

Side Character 2: (boredom sigh)

Main character: or maybe you feel a bit embarrassed

Side Character 3: well, *this* is weird! I don't really want to talk about it or check my breasts.

Main character: But it's easy and it's quick!

Scene changes to woman in her bathroom (Bea's voice is heard over the instructions but we don't see Bea directly talking to create a protective distance).

Main character: Choose a time and place that is best for you to check your breasts.

(Focus on woman that is relaxed. She will check her breasts demonstrating breast cancer awareness (what to be aware of), rather than on the mechanisms of self-breast examination).

Learn the facts and get to know what's normal for *you.*
N - F – 1

N - *New changes*
Does your breast or nipple look different in any way such as a change in size or shape? Is your nipple pulled or flattened, is there discharge, like a liquid coming from it?

F – *Feels different*?
Is there a new lump or thickening of the skin in the breast, or a swelling in the armpit or around your collarbone?

1 - *One* time a month.
Pick a time that's going to work for you. Why not set a reminder! Checking once a month will help you learn what's normal for *you and* spot any changes.

If *you* notice any changes that you are not happy with, get them checked out with a healthcare professional! Let them know that you have NF1 and that you are at increased risk of developing breast cancer at a younger age.

Don't forget that if you are a woman with NF1, it is recommended that you attend earlier annual breast screening from when you are 40 years old.
(*Scene of woman turning 40 (party balloons and streamers? looking at calendar and seeing breast screening appointment booked in*).

NF1?
Look. Feel. Learn...Done!

(Zoom in to woman with friend drinking coffee, firstly looking directly at screen smiling and relaxed, and then turning to friend. Zoom out further to individuals back in the flow of their daily lives)

Appendix I

Breast-CAM Items (Linsell et al., 2010)

Together we will beat cancer

CANCER RESEARCH UK

Breast Module
of the
Cancer Awareness Measure
(Breast-CAM)

Toolkit

The Breast-CAM was developed by Cancer Research UK, King's College London and University College London in 2009 and validated with the support of Breast Cancer Care and Breakthrough Breast Cancer.

Breast Cancer Awareness Measure (Breast CAM) Toolkit
Updated 09.02.11

Participant ID number or sticker

Appendix B: Self-complete version of the Breast Module of the Cancer Awareness Measure

We are asking these questions to find out more about breast cancer awareness. This questionnaire should take around 15 minutes to complete. It is not a test. We are interested in your thoughts and beliefs so please answer the questions as honestly as you can. All your answers will be treated as strictly confidential.

	Yes	No
1. Have you ever had breast cancer?	☐	☐

2. Do you know any of the warning signs of breast cancer?

Yes ☐ No ☐

If yes, please circle the signs you know below.

Change in position of your nipple

Pulling in of your nipple

Pain in one of your breasts or armpit

Puckering or dimpling of your breast skin

Discharge or bleeding from your nipple

A lump or thickening in your breast

Nipple rash

Redness of your breast skin

A lump or thickening under your armpit

Changes in the shape of your breast or nipple

Changes in the size of your breast or nipple

The next four questions are about finding changes in your breasts.

3. How often do you check your breasts?

Please tick one box only.

Rarely or never ☐
At least once every 6 months ☐
At least once a month ☐
At least once a week ☐
Don't know ☐

4. Are you confident you would notice a change in your breasts?

Please tick one box only.

Not at all confident ☐
Slightly confident ☐
Fairly confident ☐
Very confident ☐
Don't know ☐

5. Have you ever been to see a doctor about a change you have noticed in one of your breasts?

Please tick one box only.

Yes ☐
No ☐
Never noticed a change in one of my breasts ☐
Don't know ☐

6. If you found a change in your breast, how soon would you contact your doctor?

Write how soon you would contact your doctor here ☐ Don't know ☐

7. Sometimes people put off going to see the doctor, even when they have a symptom that they think might be serious. Could you say if any of these might put you off going to the doctor?

	Yes often	Yes sometimes	No	Don't know
Too embarrassed to go and see the doctor	☐	☐	☐	☐
Too scared to go and see the doctor	☐	☐	☐	☐
Worried about wasting the doctor's time	☐	☐	☐	☐
I find my doctor difficult to talk to	☐	☐	☐	☐
Difficult to make an appointment with the doctor	☐	☐	☐	☐
Too busy to make time to go to the doctor	☐	☐	☐	☐
Too many other things to worry about	☐	☐	☐	☐
Difficult to arrange transport to the doctor's surgery	☐	☐	☐	☐
Worrying about what the doctor might find may stop me from going to the doctor	☐	☐	☐	☐
Not feeling confident talking about my symptom with the doctor	☐	☐	☐	☐

Please write here anything else that you can think of that might put you off going to the doctor

8. In the next year, who is most likely to get breast cancer?

Please tick one box only.

A 30 year old woman ☐
A 50 year old woman ☐
A 70 year old woman ☐
A woman of any age ☐
Don't know ☐

9. How many women will develop breast cancer in their lifetime?

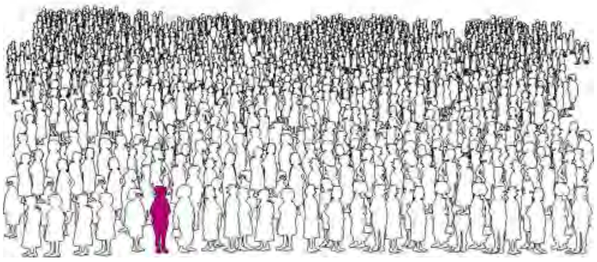
Please tick one box only.

1 in 3 women ☐
1 in 9 women ☐
1 in 100 women ☐
1 in 1000 women ☐

1 in 3

1 in 9

1 in 100



1 in 1000

The next set of questions is about breast screening.

	Write age here	Don’t know
10. At what age are women *first* invited to the NHS Breast Screening Programme?	☐☐	☐
11. At what age do women receive their *last* invitation to the NHS Breast Screening Programme?	☐☐	☐

	Yes	No	Don’t know
12. Have you ever been invited for breast screening on the NHS Breast Screening Programme?	☐	☐	☐
13. Have you ever had breast screening on the NHS Breast Screening Programme?	☐	☐	☐

14. How much do you agree that each of these can increase the chance of getting breast cancer?

	Strongly disagree	Disagree	Not sure	Agree	Strongly agree
Having a past history of breast cancer	☐	☐	☐	☐	☐
Using HRT (Hormone Replacement Therapy)	☐	☐	☐	☐	☐
Drinking more than 1 unit of alcohol a day	☐	☐	☐	☐	☐
Being overweight (BMI over 25)	☐	☐	☐	☐	☐
Having a close relative with breast cancer	☐	☐	☐	☐	☐
Having children later on in life or not at all	☐	☐	☐	☐	☐
Starting your periods at an early age	☐	☐	☐	☐	☐
Having a late menopause	☐	☐	☐	☐	☐
Doing less than 30 mins of moderate physical activity 5 times a week	☐	☐	☐	☐	☐

Please answer the following questions about yourself

Please tell us, what is your age? years

Please would you write your postcode here Don’t know ☐

Are you registered with a GP? Yes ☐ No ☐ Don’t know ☐

What is the main language spoken at home?

- ☐ English
- ☐ Urdu
- ☐ Punjabi
- ☐ Gujarati
- ☐ Sylheti
- ☐ Bengali
- ☐ French
- ☐ Other (please write name of language)

Were you born in the UK? Yes ☐ No ☐ Don’t know ☐

Which of these best describes your living arrangements?

- ☐ Own outright or have a mortgage
- ☐ Rent from Council or Housing Association
- ☐ Don’t know
- ☐ Rent from private landlord
- ☐ Other (please describe) ..

Who do you live with?

- ☐ Husband/partner
- ☐ Live alone
- ☐ Other (please describe) ..

Does anyone living in your home have a car or van available for use? Yes ☐ No ☐ Don’t know ☐

What age were you when you left full time education?

- ☐ Currently in full time education
- ☐ No full time education

Which of the following best describes your ethnic group?

White	Mixed/multiple ethnic groups	Asian/Asian British	Black/African/ Caribbean/ Black British	Other
☐ English/Welsh/ Scottish/ Northern Irish/ British	☐ White and Black Caribbean	☐ Indian	☐ African	☐ Arab
☐ Irish	☐ White and Black African	☐ Pakistani	☐ Caribbean	☐ Any other ethnic group
☐ Gypsy or Irish Traveller	☐ White and Asian	☐ Bangladeshi	☐ Any other Black/African/ Caribbean background	(please describe) ...
☐ Any other white background	☐ Any other mixed background	☐ Chinese		
		☐ Any other Asian background		

Would you please tell us, where does your household get most of its income from?

☐ Wages or salary
☐ Pension
☐ Don’t know
☐ Benefits (including unemployment or sickness benefit)
☐ Other (please describe)

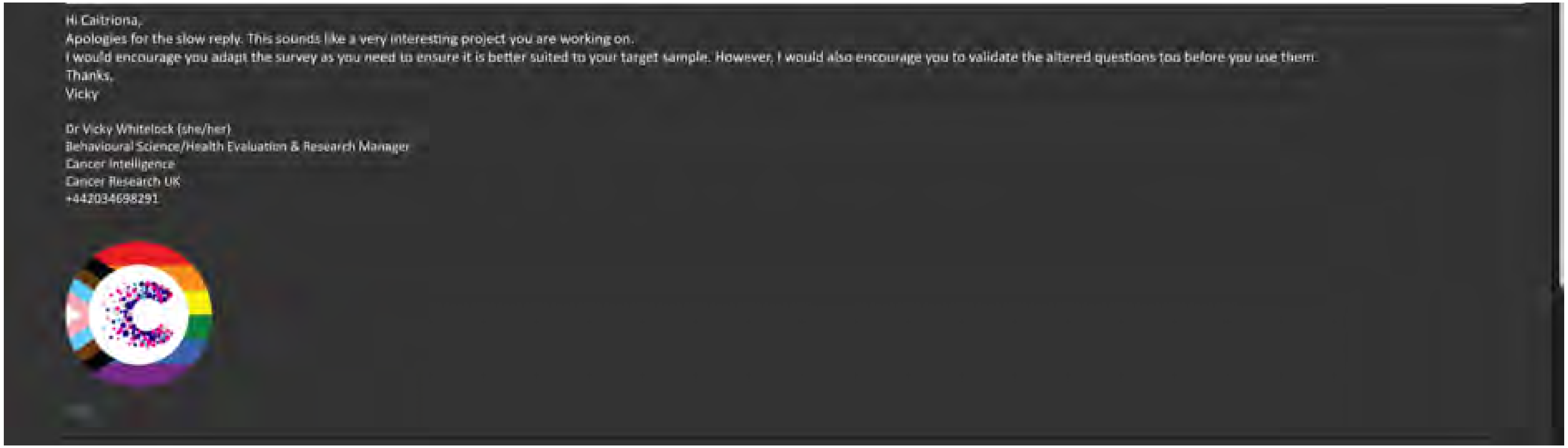
What is your sexual orientation?

☐ Heterosexual/straight
☐ Bisexual
☐ Don’t know
☐ Gay/lesbian
☐ Prefer not to say
☐ Other (please describe)

The Breast Cancer Awareness Measure was developed by Cancer Research UK, King’s College London and University College London in 2009. It was validated with the support of Breast Cancer Care and Breakthrough Breast Cancer.

Appendix J

Permission from Cancer Research UK for Amendment of Breast-CAM

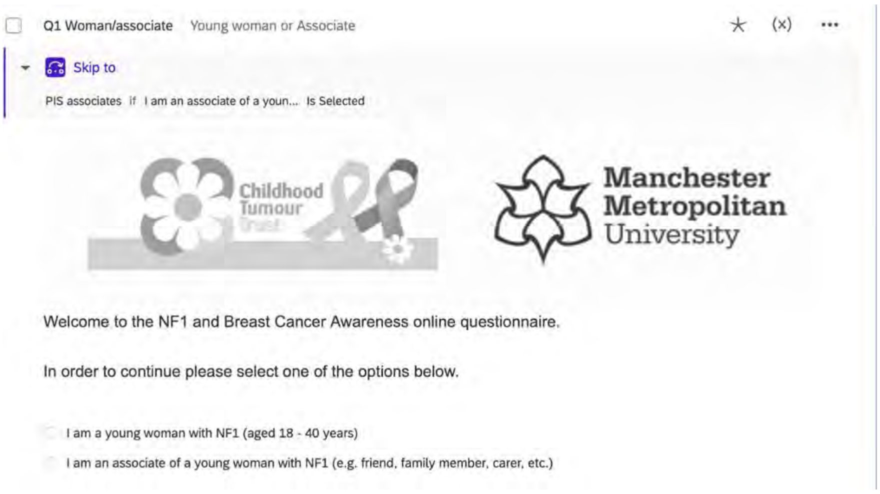


Hi Caitriona,
Apologies for the slow reply. This sounds like a very interesting project you are working on.
I would encourage you adapt the survey as you need to ensure it is better suited to your target sample. However, I would also encourage you to validate the altered questions too before you use them.
Thanks,
Vicky

Dr Vicky Whitelock (she/her)
Behavioural Science/Health Evaluation & Research Manager
Cancer Intelligence
Cancer Research UK
+442034698291

Appendix K

Breast-CAM-NF1 Items


☐ Q1 Woman/associate Young woman or Associate

PIS associates If I am an associate of a youn... Is Selected

Welcome to the NF1 and Breast Cancer Awareness online questionnaire.

In order to continue please select one of the options below.

○ I am a young woman with NF1 (aged 18 - 40 years)
○ I am an associate of a young woman with NF1 (e.g. friend, family member, carer, etc.)


Q2 PIS young women

If Young woman or Associate I am a young woman with NF1 (aged 18 - 40 years) Is Selected

Participant Information Sheet

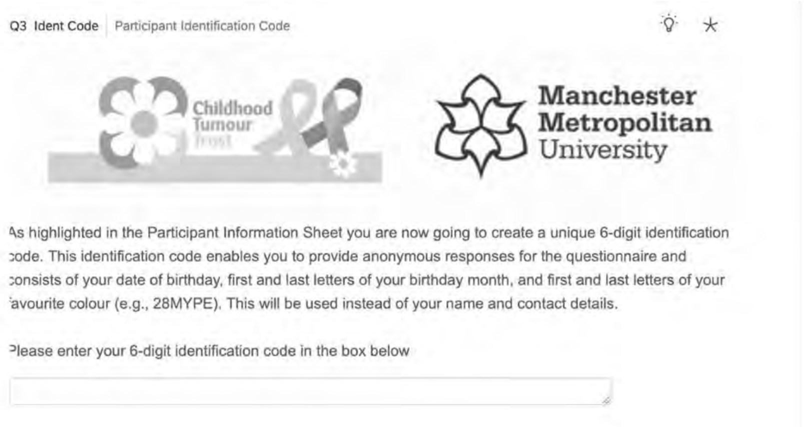
Exploring the feasibility of a breast cancer awareness intervention for young women with Neurofibromatosis Type 1 (NF1) and their associates.


Q2A PIS associates

If Young woman or Associate I am an associate of a young woman with NF1 (e.g. friend, family member, carer, etc.) Is Selected

Participant Information Sheet

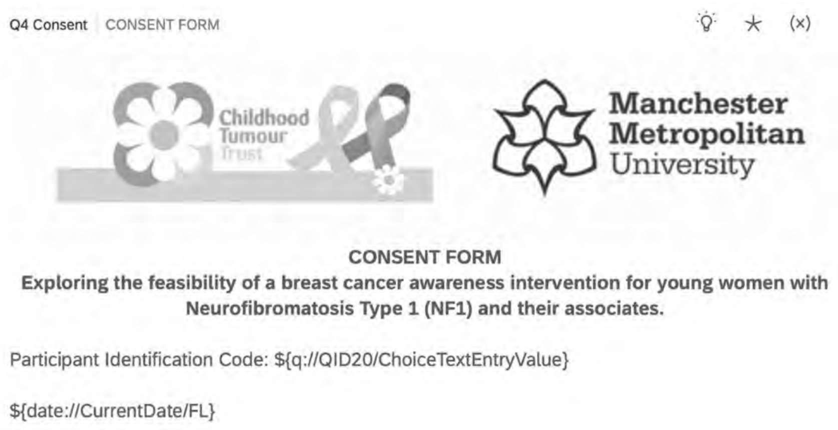
Exploring the feasibility of a breast cancer awareness intervention for young women with Neurofibromatosis Type 1 (NF1) and their associates.



Q3 Ident Code | Participant Identification Code

As highlighted in the Participant Information Sheet you are now going to create a unique 6-digit identification code. This identification code enables you to provide anonymous responses for the questionnaire and consists of your date of birthday, first and last letters of your birthday month, and first and last letters of your favourite colour (e.g., 28MYPE). This will be used instead of your name and contact details.

Please enter your 6-digit identification code in the box below



Q4 Consent | CONSENT FORM

CONSENT FORM

Exploring the feasibility of a breast cancer awareness intervention for young women with Neurofibromatosis Type 1 (NF1) and their associates.

Participant Identification Code: ${q://QID20/ChoiceTextEntryValue}

${date://CurrentDate/FL}

☐ Q5 Attend for BC | Attending treatment for breast cancer

Please confirm that you are <u>**NOT**</u> already attending regular breast cancer screening, undergoing treatment for, currently diagnosed with, or have been previously diagnosed with breast cancer.

○ I confirm

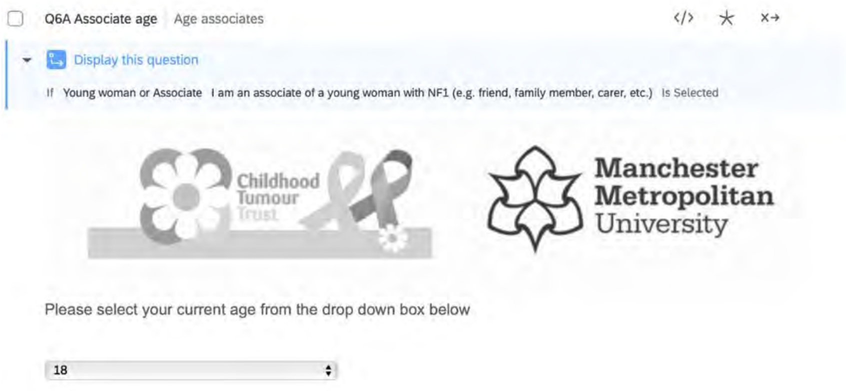
○ I DO NOT confirm

☐ Q6 Woman Age | Age young women

If Young woman or Associate I am a young woman with NF1 (aged 18 - 40 years) Is Selected

Please select your current age from the drop down box below

18



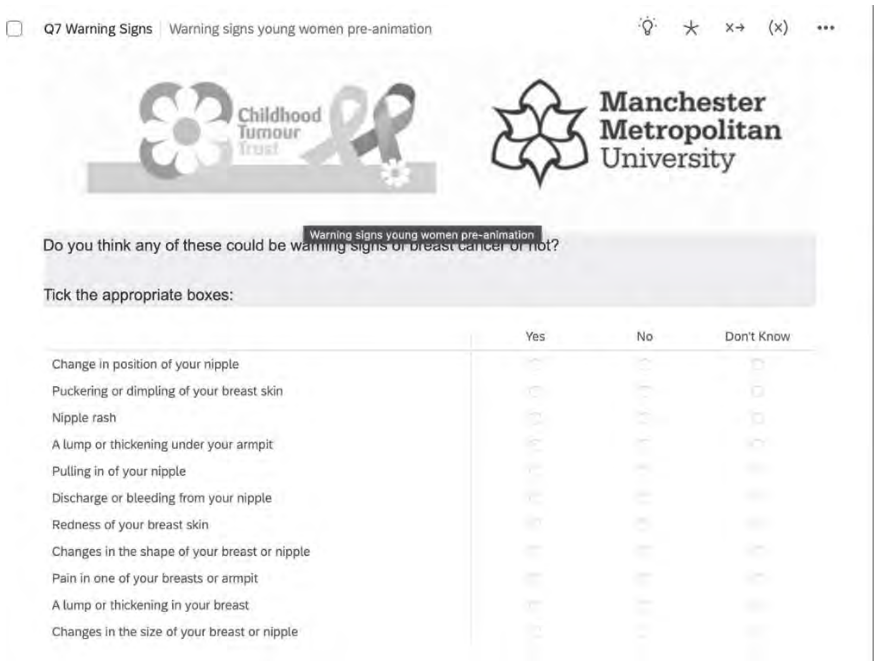
☐ Q6A Associate age | Age associates

Display this question

If Young woman or Associate I am an associate of a young woman with NF1 (e.g. friend, family member, carer, etc.) Is Selected

Please select your current age from the drop down box below

18

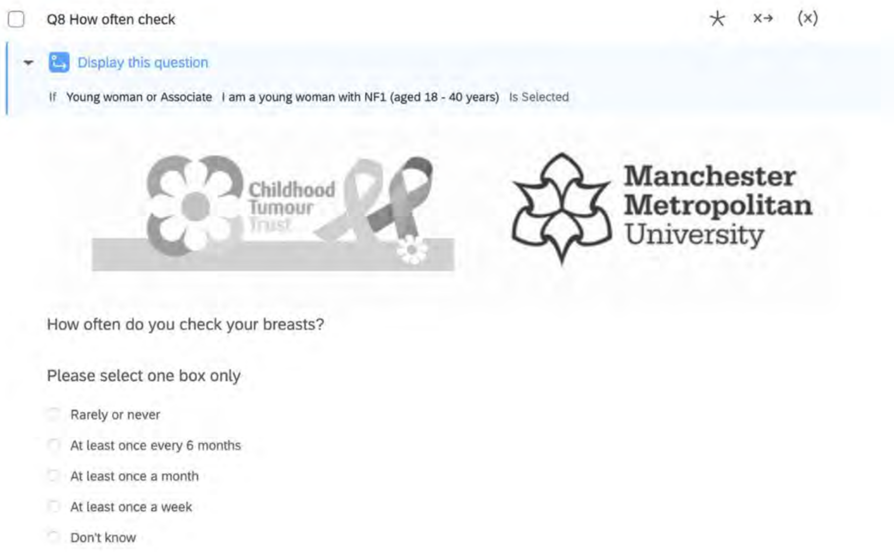


☐ Q7 Warning Signs | Warning signs young women pre-animation

Do you think any of these could be warning signs of breast cancer or not?

Tick the appropriate boxes:

	Yes	No	Don't Know
Change in position of your nipple	○	○	○
Puckering or dimpling of your breast skin	○	○	○
Nipple rash	○	○	○
A lump or thickening under your armpit	○	○	○
Pulling in of your nipple	○	○	○
Discharge or bleeding from your nipple	○	○	○
Redness of your breast skin	○	○	○
Changes in the shape of your breast or nipple	○	○	○
Pain in one of your breasts or armpit	○	○	○
A lump or thickening in your breast	○	○	○
Changes in the size of your breast or nipple	○	○	○



☐ Q8 How often check

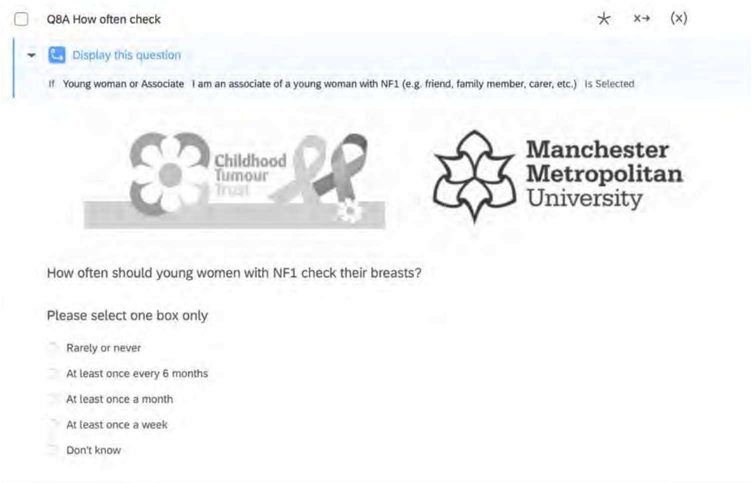
Display this question

If Young woman or Associate I am a young woman with NF1 (aged 18 - 40 years) Is Selected

How often do you check your breasts?

Please select one box only

○ Rarely or never
○ At least once every 6 months
○ At least once a month
○ At least once a week
○ Don't know



☐ Q8A How often check

Display this question

If Young woman or Associate I am an associate of a young woman with NF1 (e.g. friend, family member, carer, etc.) Is Selected

How often should young women with NF1 check their breasts?

Please select one box only

○ Rarely or never
○ At least once every 6 months
○ At least once a month
○ At least once a week
○ Don't know

☐ Q9 Confident change

Display this question

If Young woman or Associate I am a young woman with NF1 (aged 18 - 40 years) Is Selected

Are you confident you would notice a change in your breasts?

Please select one box only

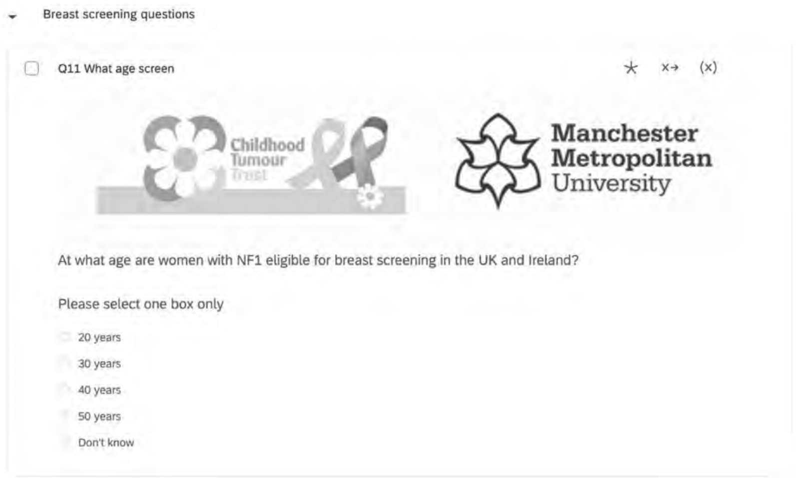
○ Not at all confident
○ Slightly confident
○ Fairly confident
○ Very confident
○ Don't know

☐ Q10 Next yr develop

In the next year who is most likely to develop breast cancer if they have NF1 (in comparison to general population risk)?

Please select one box only

○ A 40-year-old woman
○ A 60-year-old woman
○ A 80-year-old woman
○ A woman of any age
○ Don't know



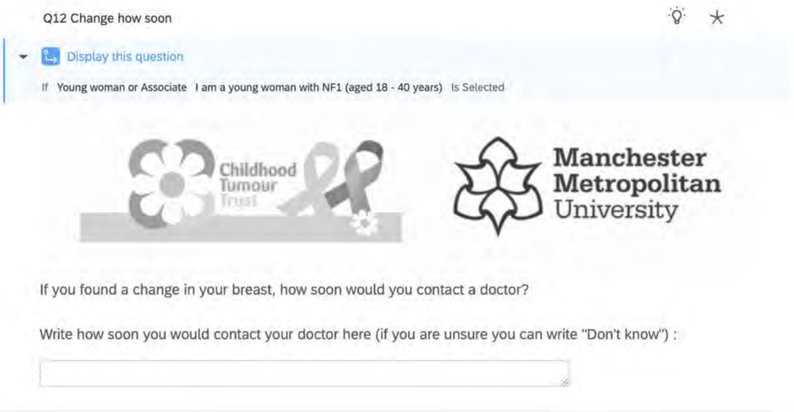
Breast screening questions

☐ Q11 What age screen

At what age are women with NF1 eligible for breast screening in the UK and Ireland?

Please select one box only

- ○ 20 years
- ○ 30 years
- ○ 40 years
- ○ 50 years
- ○ Don't know



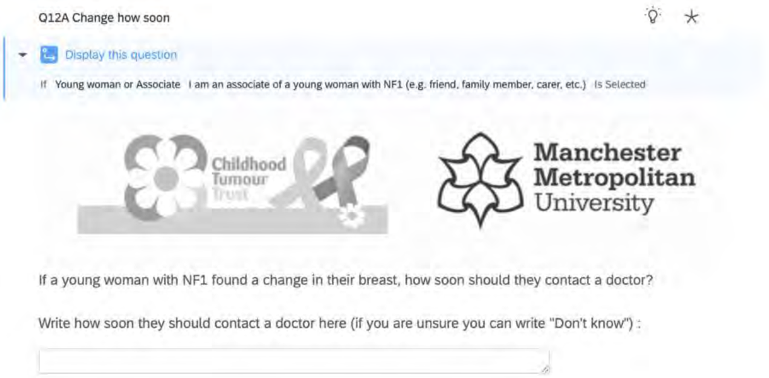
Q12 Change how soon

Display this question

If Young woman or Associate I am a young woman with NF1 (aged 18 - 40 years) Is Selected

If you found a change in your breast, how soon would you contact a doctor?

Write how soon you would contact your doctor here (if you are unsure you can write "Don't know") :



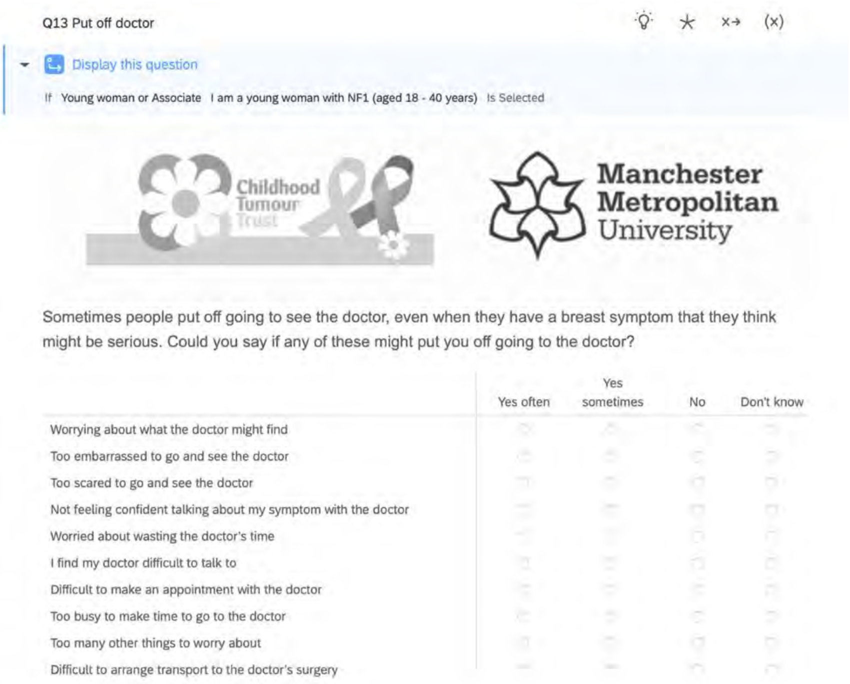
Q12A Change how soon

Display this question

If Young woman or Associate I am an associate of a young woman with NF1 (e.g. friend, family member, carer, etc.) Is Selected

If a young woman with NF1 found a change in their breast, how soon should they contact a doctor?

Write how soon they should contact a doctor here (if you are unsure you can write "Don't know") :



Q13 Put off doctor

Display this question

If Young woman or Associate I am a young woman with NF1 (aged 18 - 40 years) Is Selected

Sometimes people put off going to see the doctor, even when they have a breast symptom that they think might be serious. Could you say if any of these might put you off going to the doctor?

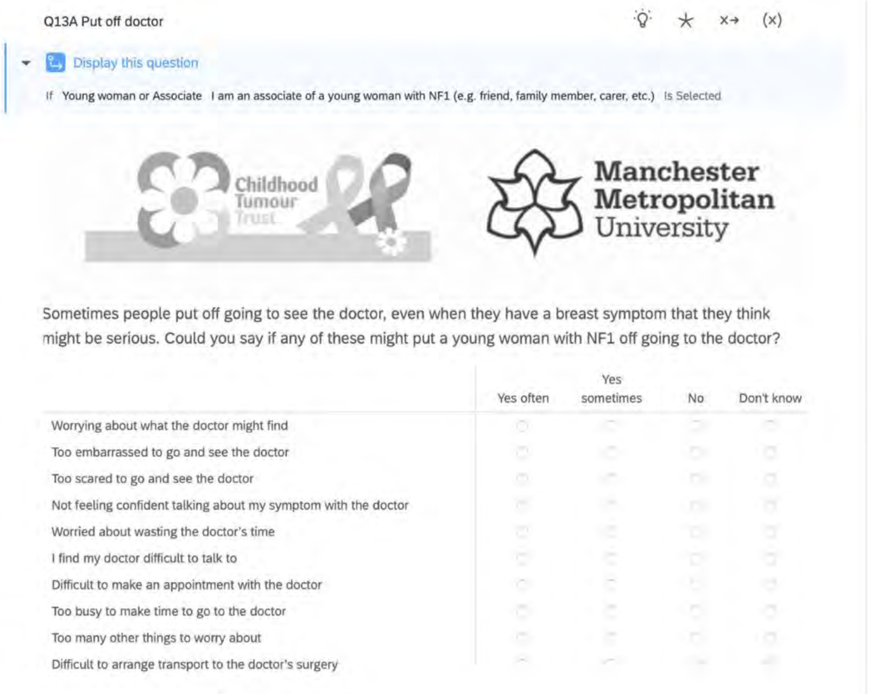
	Yes often	Yes sometimes	No	Don't know
Worrying about what the doctor might find	○	○	○	○
Too embarrassed to go and see the doctor	○	○	○	○
Too scared to go and see the doctor	○	○	○	○
Not feeling confident talking about my symptom with the doctor	○	○	○	○
Worried about wasting the doctor's time	○	○	○	○
I find my doctor difficult to talk to	○	○	○	○
Difficult to make an appointment with the doctor	○	○	○	○
Too busy to make time to go to the doctor	○	○	○	○
Too many other things to worry about	○	○	○	○
Difficult to arrange transport to the doctor's surgery	○	○	○	○

Q13-1 put off other

Display this question

If Young woman or Associate I am a young woman with NF1 (aged 18 - 40 years) Is Selected

Is there anything else that you can think of that might put you off going to the doctor?



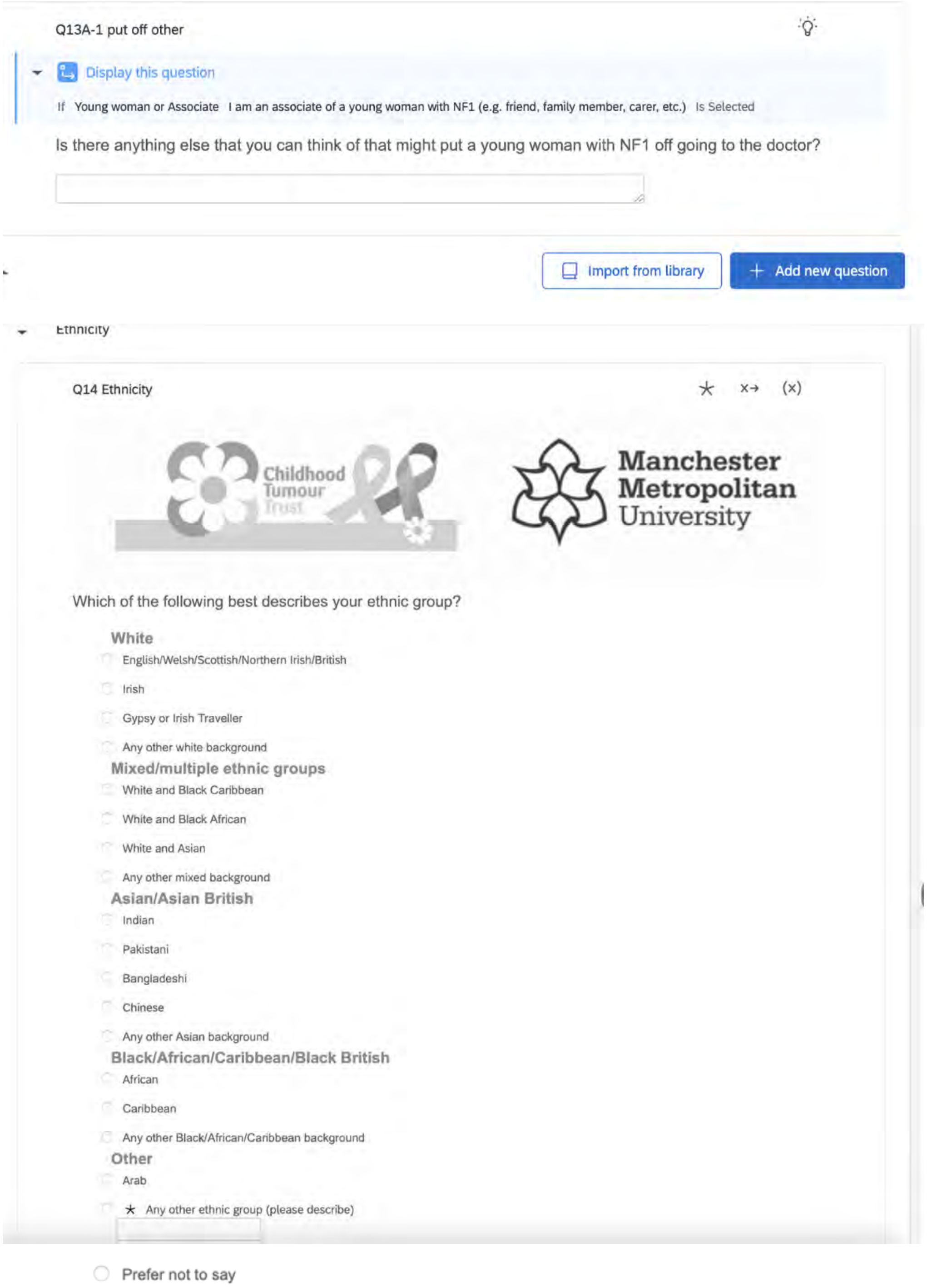
Q13A Put off doctor

Display this question

If Young woman or Associate I am an associate of a young woman with NF1 (e.g. friend, family member, carer, etc.) Is Selected

Sometimes people put off going to see the doctor, even when they have a breast symptom that they think might be serious. Could you say if any of these might put a young woman with NF1 off going to the doctor?

	Yes often	Yes sometimes	No	Don't know
Worrying about what the doctor might find	○	○	○	○
Too embarrassed to go and see the doctor	○	○	○	○
Too scared to go and see the doctor	○	○	○	○
Not feeling confident talking about my symptom with the doctor	○	○	○	○
Worried about wasting the doctor's time	○	○	○	○
I find my doctor difficult to talk to	○	○	○	○
Difficult to make an appointment with the doctor	○	○	○	○
Too busy to make time to go to the doctor	○	○	○	○
Too many other things to worry about	○	○	○	○
Difficult to arrange transport to the doctor's surgery	○	○	○	○



Q13A-1 put off other

If Young woman or Associate I am an associate of a young woman with NF1 (e.g. friend, family member, carer, etc.) Is Selected

Is there anything else that you can think of that might put a young woman with NF1 off going to the doctor?

Q14 Ethnicity

Which of the following best describes your ethnic group?

White
- ○ English/Welsh/Scottish/Northern Irish/British
- ○ Irish
- ○ Gypsy or Irish Traveller
- ○ Any other white background

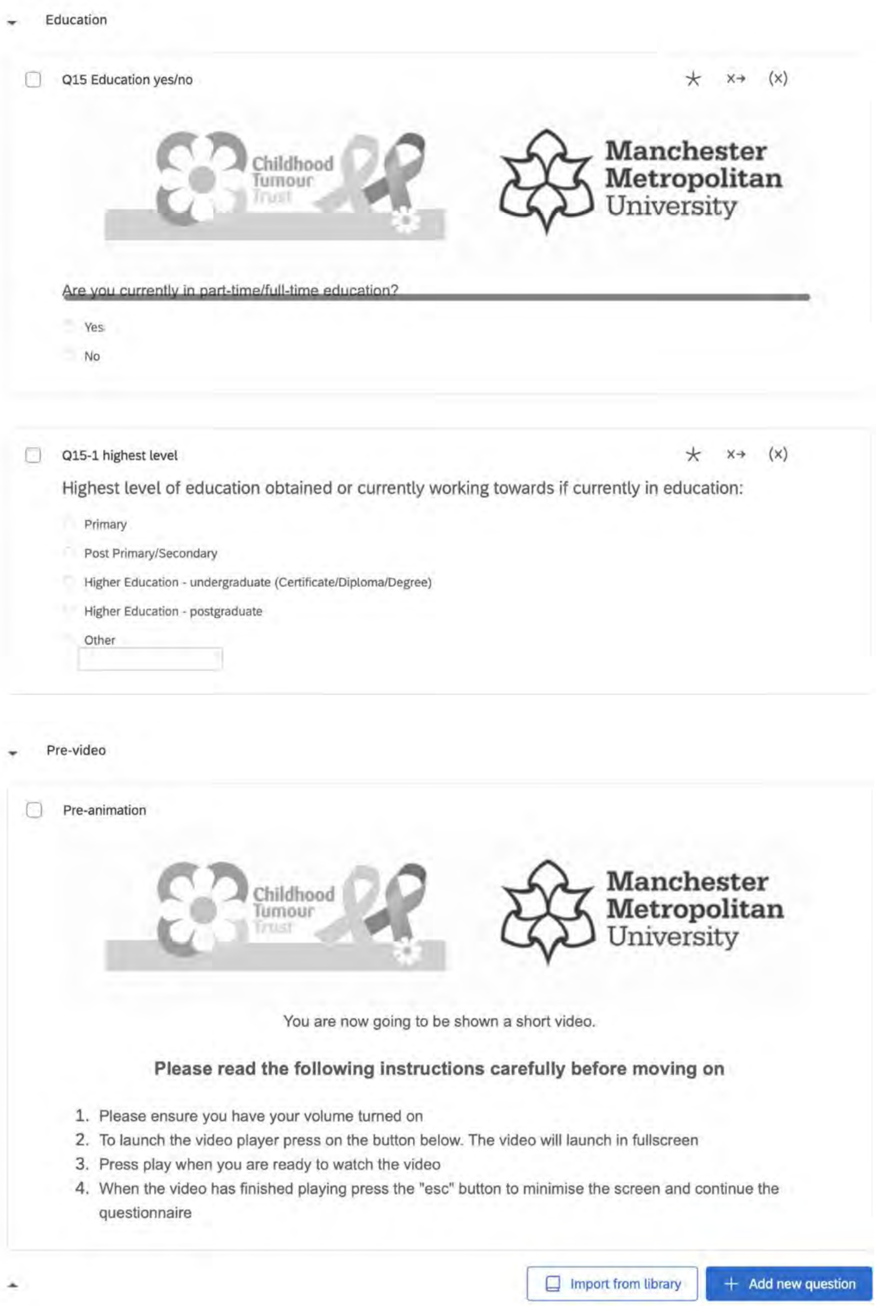
Mixed/multiple ethnic groups
- ○ White and Black Caribbean
- ○ White and Black African
- ○ White and Asian
- ○ Any other mixed background

Asian/Asian British
- ○ Indian
- ○ Pakistani
- ○ Bangladeshi
- ○ Chinese
- ○ Any other Asian background

Black/African/Caribbean/Black British
- ○ African
- ○ Caribbean
- ○ Any other Black/African/Caribbean background

Other
- ○ Arab
- ○ * Any other ethnic group (please describe)

○ Prefer not to say



☐ Q15 Education yes/no

Are you currently in part-time/full-time education?

○ Yes
○ No

☐ Q15-1 highest level

Highest level of education obtained or currently working towards if currently in education:

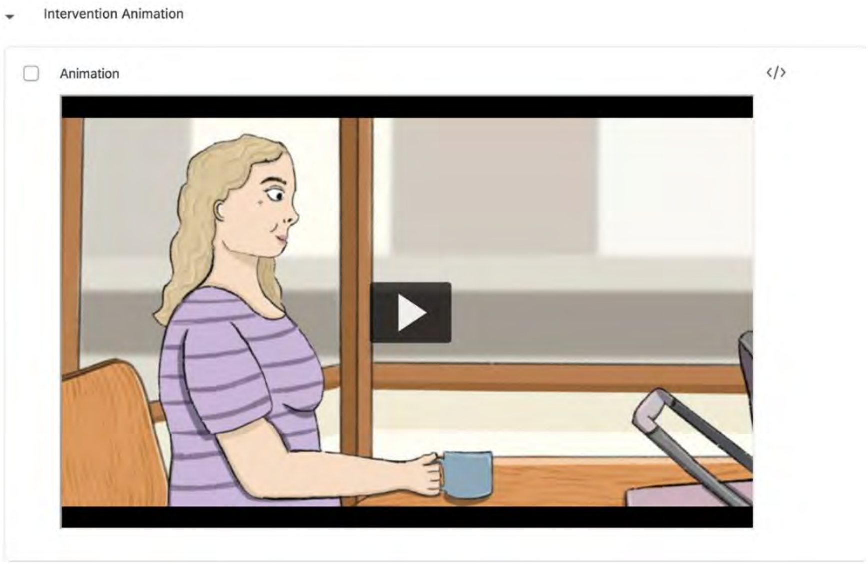
○ Primary
○ Post Primary/Secondary
○ Higher Education - undergraduate (Certificate/Diploma/Degree)
○ Higher Education - postgraduate
○ Other

☐ Pre-animation

You are now going to be shown a short video.

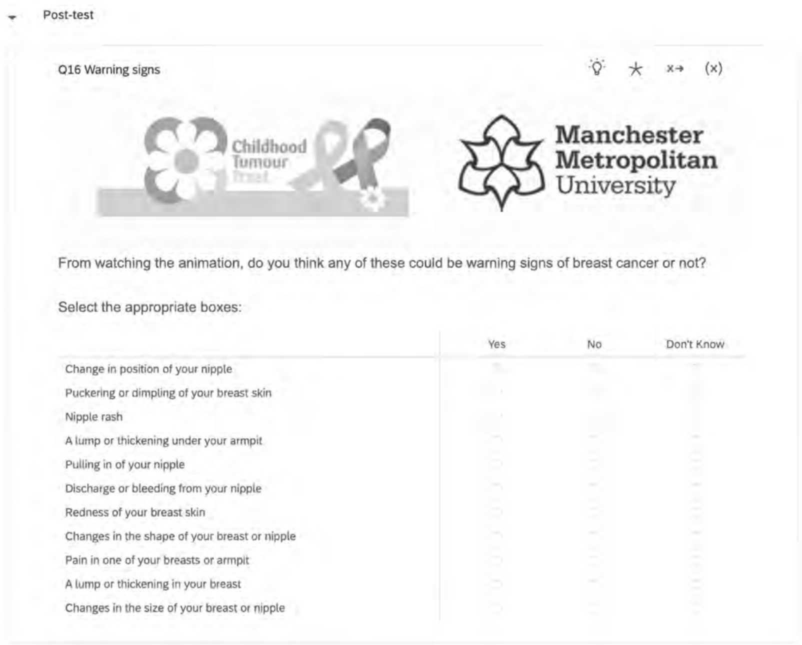
Please read the following instructions carefully before moving on

1. Please ensure you have your volume turned on
2. To launch the video player press on the button below. The video will launch in fullscreen
3. Press play when you are ready to watch the video
4. When the video has finished playing press the "esc" button to minimise the screen and continue the questionnaire



Intervention Animation

☐ Animation



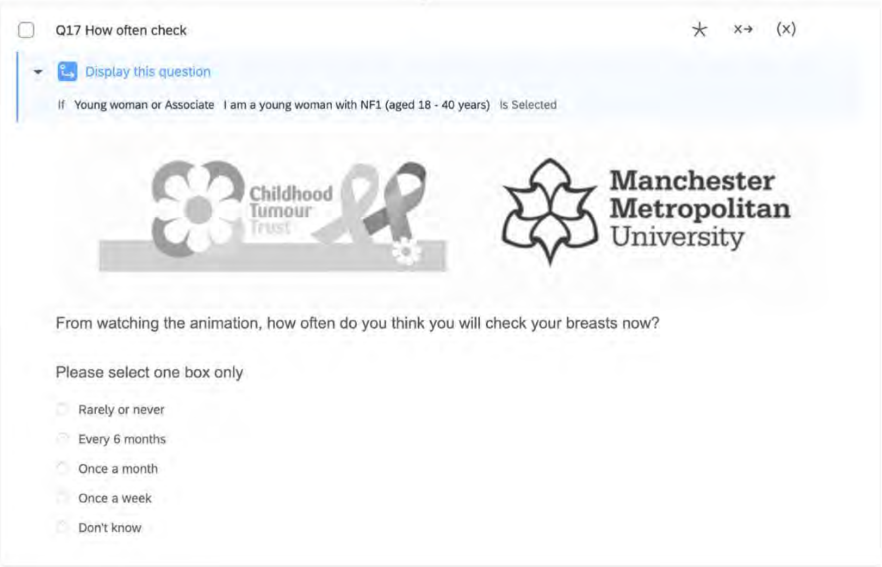
Post-test

Q16 Warning signs

From watching the animation, do you think any of these could be warning signs of breast cancer or not?

Select the appropriate boxes:

	Yes	No	Don't Know
Change in position of your nipple	○	○	○
Puckering or dimpling of your breast skin	○	○	○
Nipple rash	○	○	○
A lump or thickening under your armpit	○	○	○
Pulling in of your nipple	○	○	○
Discharge or bleeding from your nipple	○	○	○
Redness of your breast skin	○	○	○
Changes in the shape of your breast or nipple	○	○	○
Pain in one of your breasts or armpit	○	○	○
A lump or thickening in your breast	○	○	○
Changes in the size of your breast or nipple	○	○	○



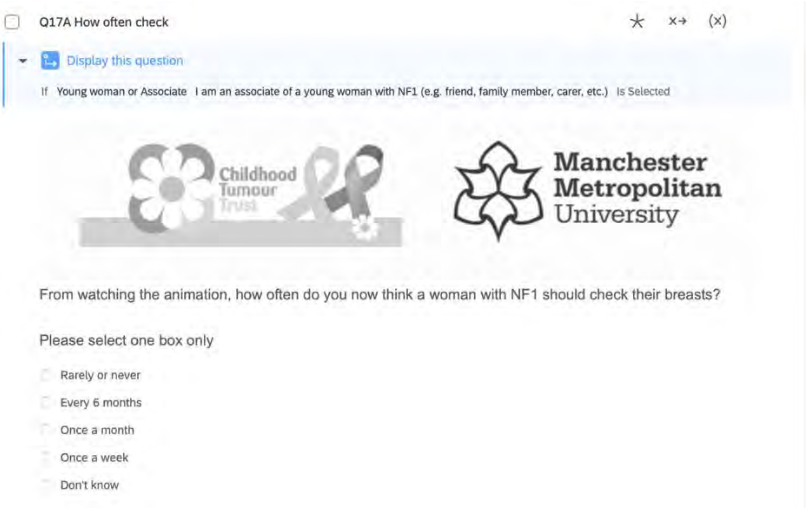
☐ Q17 How often check

If Young woman or Associate I am a young woman with NF1 (aged 18 - 40 years) Is Selected

From watching the animation, how often do you think you will check your breasts now?

Please select one box only

○ Rarely or never
○ Every 6 months
○ Once a month
○ Once a week
○ Don't know



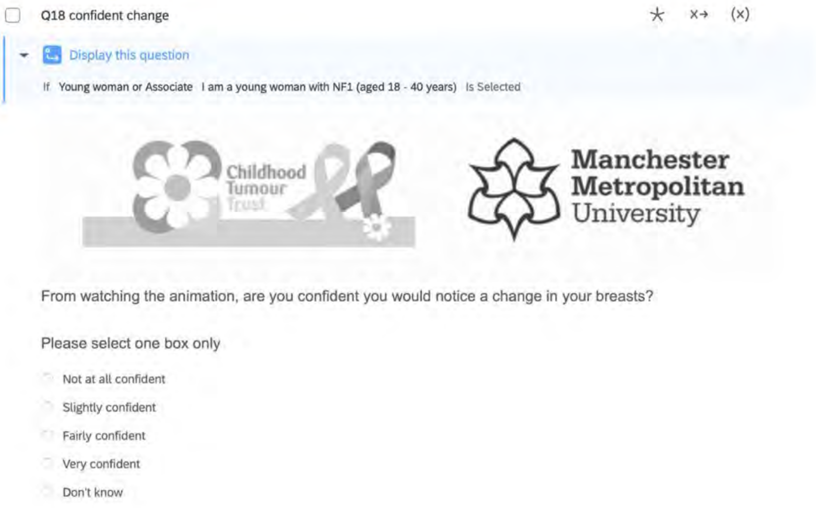
☐ Q17A How often check

If Young woman or Associate I am an associate of a young woman with NF1 (e.g. friend, family member, carer, etc.) Is Selected

From watching the animation, how often do you now think a woman with NF1 should check their breasts?

Please select one box only

○ Rarely or never
○ Every 6 months
○ Once a month
○ Once a week
○ Don't know



☐ Q18 confident change

If Young woman or Associate I am a young woman with NF1 (aged 18 - 40 years) Is Selected

From watching the animation, are you confident you would notice a change in your breasts?

Please select one box only

○ Not at all confident
○ Slightly confident
○ Fairly confident
○ Very confident
○ Don't know

☐ Q19 next yr develop

In the next year who is most likely to develop breast cancer if they have NF1 (in comparison to general population risk)?

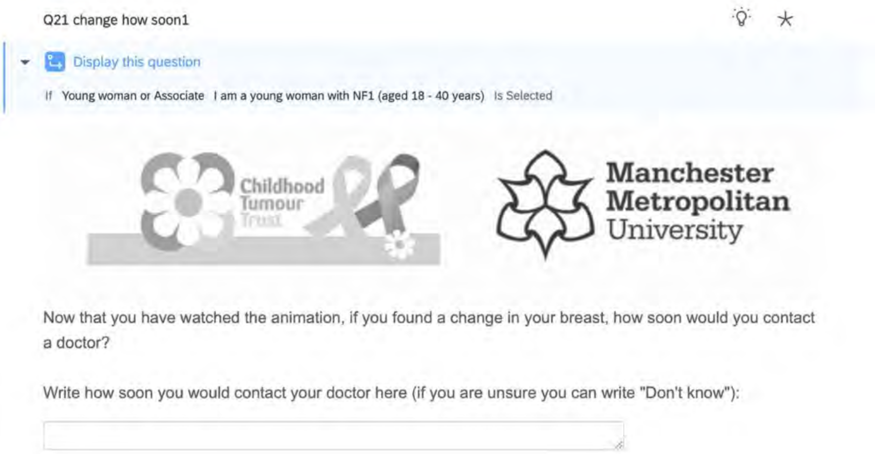
Please select one box only

○ A 40-year-old woman
○ A 60-year-old woman
○ A 80-year-old woman
○ A woman of any age
○ Don't know

☐ Q20 what age elig

At what age are women with NF1 eligible for breast screening in the UK and Ireland?

○ 20 years
○ 30 years
○ 40 years
○ 50 years
○ Don't know



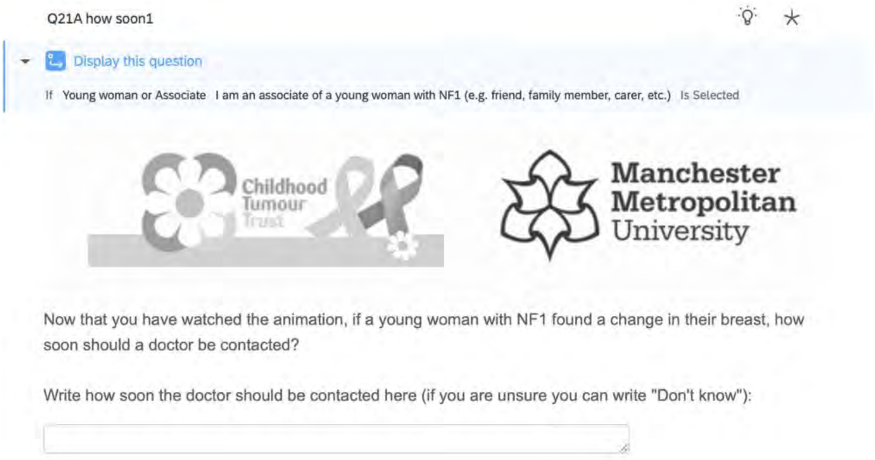
Q21 change how soon1

Display this question

If Young woman or Associate I am a young woman with NF1 (aged 18 - 40 years) Is Selected

Now that you have watched the animation, if you found a change in your breast, how soon would you contact a doctor?

Write how soon you would contact your doctor here (if you are unsure you can write "Don't know"):



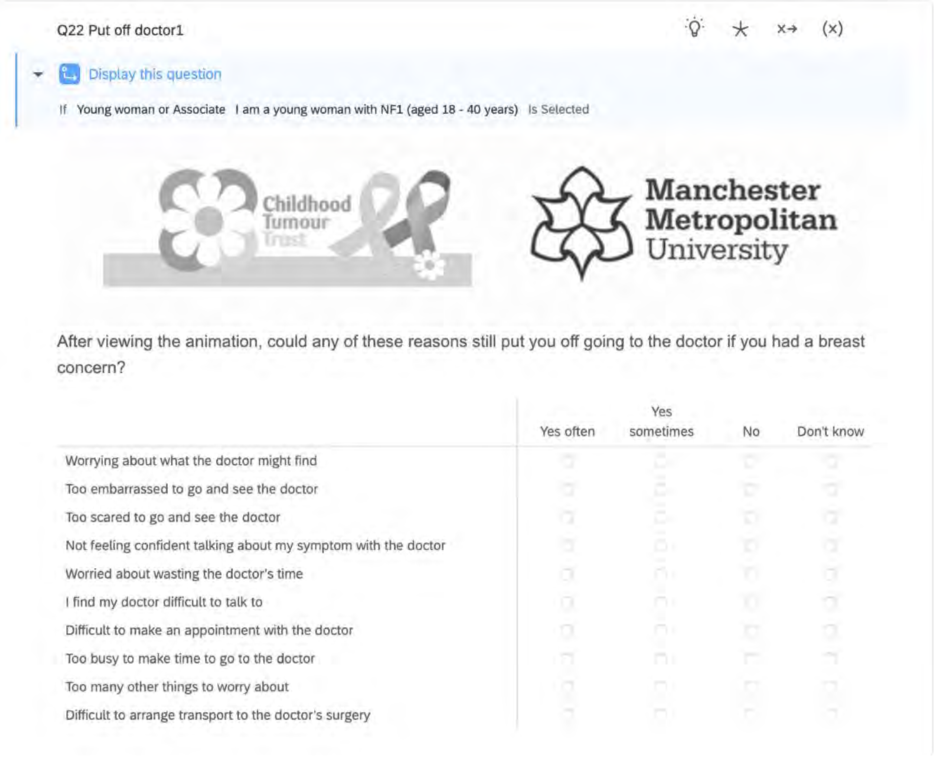
Q21A how soon1

Display this question

If Young woman or Associate I am an associate of a young woman with NF1 (e.g. friend, family member, carer, etc.) Is Selected

Now that you have watched the animation, if a young woman with NF1 found a change in their breast, how soon should a doctor be contacted?

Write how soon the doctor should be contacted here (if you are unsure you can write "Don't know"):



Q22 Put off doctor1

Display this question

If Young woman or Associate I am a young woman with NF1 (aged 18 - 40 years) Is Selected

After viewing the animation, could any of these reasons still put you off going to the doctor if you had a breast concern?

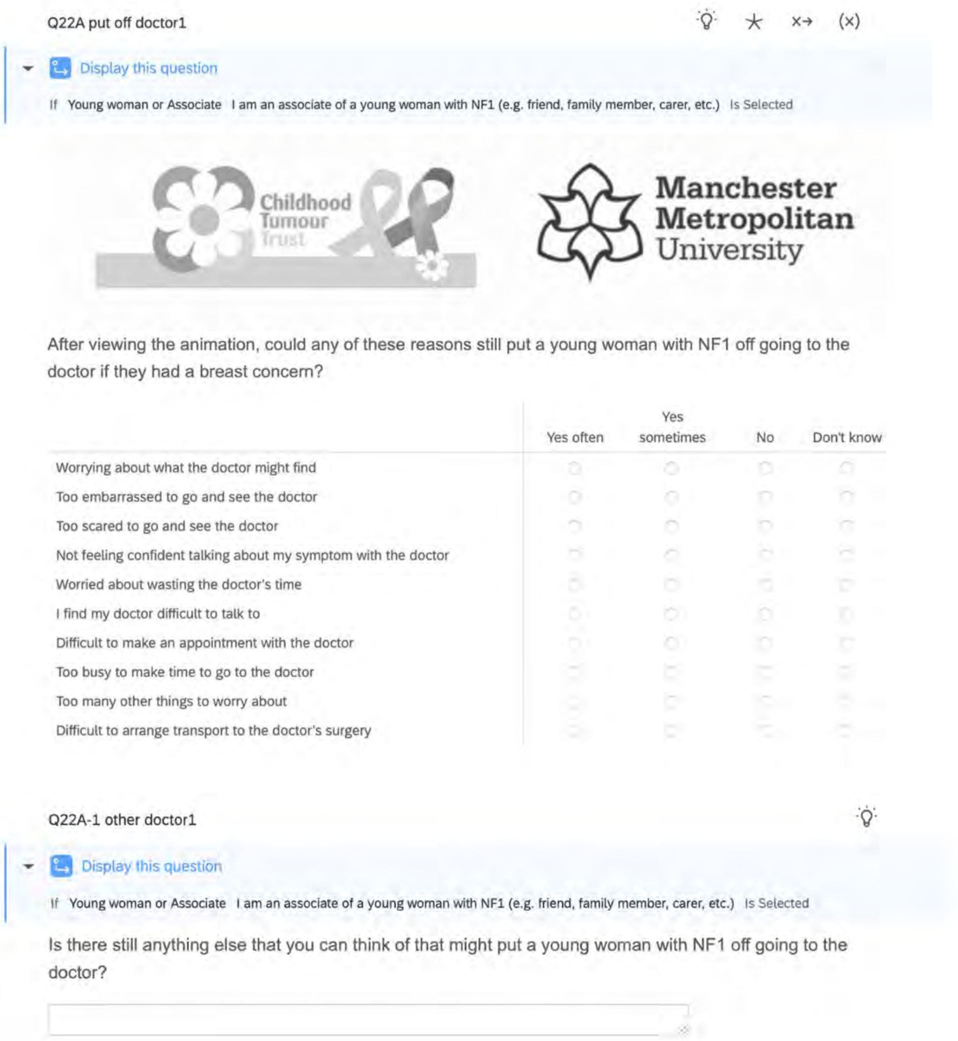
	Yes often	Yes sometimes	No	Don't know
Worrying about what the doctor might find	○	○	○	○
Too embarrassed to go and see the doctor	○	○	○	○
Too scared to go and see the doctor	○	○	○	○
Not feeling confident talking about my symptom with the doctor	○	○	○	○
Worried about wasting the doctor's time	○	○	○	○
I find my doctor difficult to talk to	○	○	○	○
Difficult to make an appointment with the doctor	○	○	○	○
Too busy to make time to go to the doctor	○	○	○	○
Too many other things to worry about	○	○	○	○
Difficult to arrange transport to the doctor's surgery	○	○	○	○

Q22-1 other put off1

Display this question

If Young woman or Associate I am a young woman with NF1 (aged 18 - 40 years) Is Selected

Is there still anything else that you can think of that might put you off going to the doctor?



Q22A put off doctor1

Display this question

If Young woman or Associate I am an associate of a young woman with NF1 (e.g. friend, family member, carer, etc.) Is Selected

After viewing the animation, could any of these reasons still put a young woman with NF1 off going to the doctor if they had a breast concern?

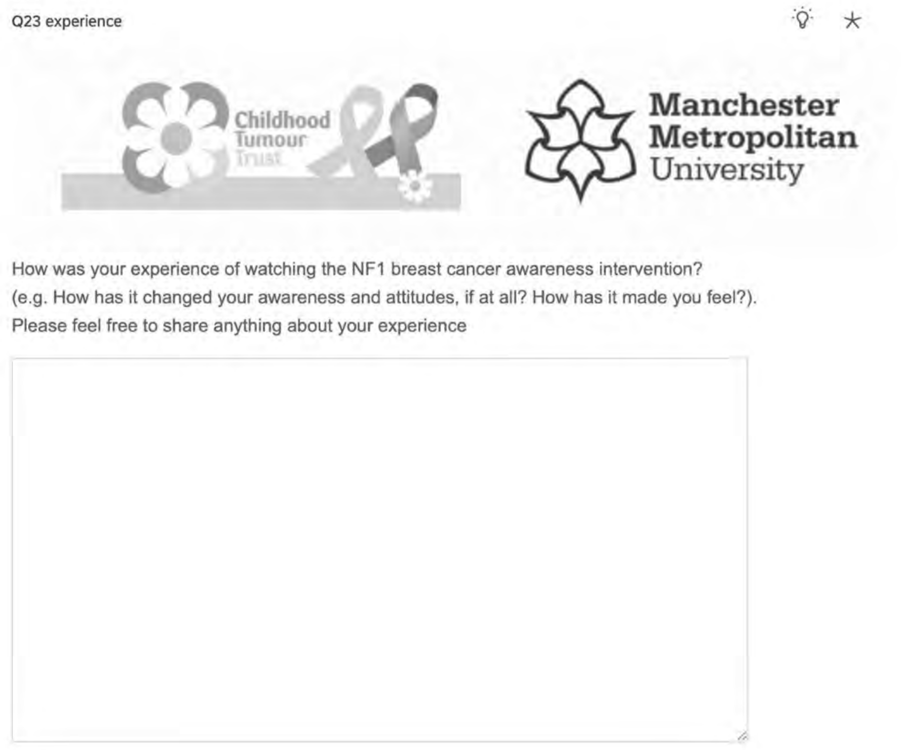
	Yes often	Yes sometimes	No	Don't know
Worrying about what the doctor might find	○	○	○	○
Too embarrassed to go and see the doctor	○	○	○	○
Too scared to go and see the doctor	○	○	○	○
Not feeling confident talking about my symptom with the doctor	○	○	○	○
Worried about wasting the doctor's time	○	○	○	○
I find my doctor difficult to talk to	○	○	○	○
Difficult to make an appointment with the doctor	○	○	○	○
Too busy to make time to go to the doctor	○	○	○	○
Too many other things to worry about	○	○	○	○
Difficult to arrange transport to the doctor's surgery	○	○	○	○

Q22A-1 other doctor1

Display this question

If Young woman or Associate I am an associate of a young woman with NF1 (e.g. friend, family member, carer, etc.) Is Selected

Is there still anything else that you can think of that might put a young woman with NF1 off going to the doctor?



Q23 experience

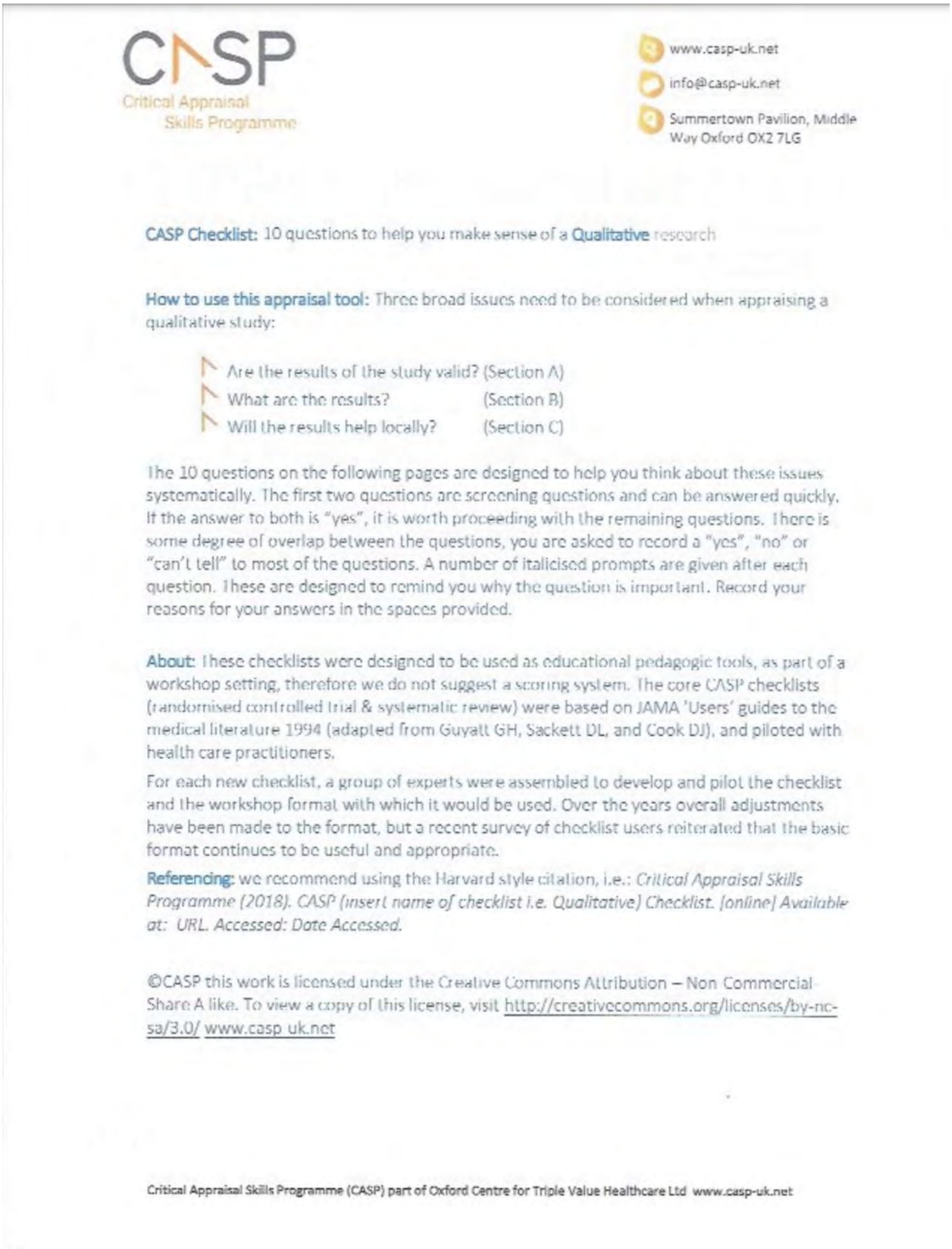
How was your experience of watching the NF1 breast cancer awareness intervention?
(e.g. How has it changed your awareness and attitudes, if at all? How has it made you feel?).
Please feel free to share anything about your experience

End of Survey

Please click on the link below where you will be asked to provide contact details and arrange a follow up interview with our project lead

Appendix L

Critical Appraisal Skills Programme (CASP, 2018) Completed Checklist



CASP
Critical Appraisal
Skills Programme

www.casp-uk.net
info@casp-uk.net
Summertown Pavilion, Middle Way Oxford OX2 7LG

CASP Checklist: 10 questions to help you make sense of a **Qualitative** research

How to use this appraisal tool: Three broad issues need to be considered when appraising a qualitative study:

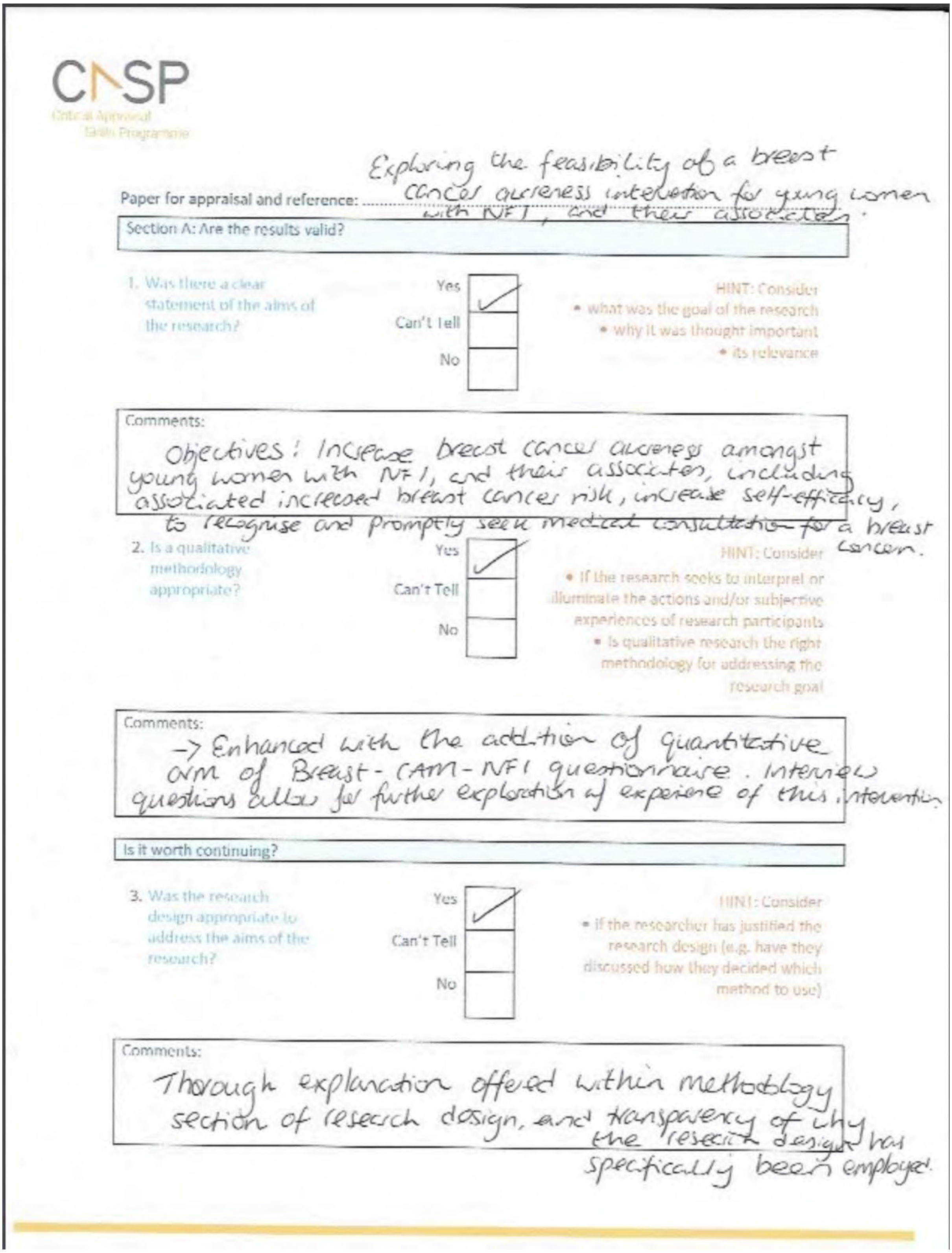
- Are the results of the study valid? (Section A)
- What are the results? (Section B)
- Will the results help locally? (Section C)

The 10 questions on the following pages are designed to help you think about these issues systematically. The first two questions are screening questions and can be answered quickly. If the answer to both is "yes", it is worth proceeding with the remaining questions. There is some degree of overlap between the questions, you are asked to record a "yes", "no" or "can't tell" to most of the questions. A number of italicised prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.

About: These checklists were designed to be used as educational pedagogic tools, as part of a workshop setting, therefore we do not suggest a scoring system. The core CASP checklists (randomised controlled trial & systematic review) were based on JAMA 'Users' guides to the medical literature 1994 (adapted from Guyatt GH, Sackett DL, and Cook DJ), and piloted with health care practitioners.

For each new checklist, a group of experts were assembled to develop and pilot the checklist and the workshop format with which it would be used. Over the years overall adjustments have been made to the format, but a recent survey of checklist users reiterated that the basic format continues to be useful and appropriate.

Referencing: we recommend using the Harvard style citation, i.e.: *Critical Appraisal Skills Programme (2018). CASP (insert name of checklist i.e. Qualitative) Checklist. [online] Available at: URL. Accessed: Date Accessed.*



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Paper for appraisal and reference: Exploring the feasibility of a breast cancer awareness intervention for young women with NF1, and their associates.

Section A: Are the results valid?

1. Was there a clear statement of the aims of the research?

Yes ☑
Can't Tell ☐
No ☐

HINT: Consider
- what was the goal of the research
- why it was thought important
- its relevance

Comments:
Objectives: Increase breast cancer awareness amongst young women with NF1, and their associates, including associated increased breast cancer risk, increase self-efficacy, to recognise and promptly seek medical consultation for a breast cancer.

2. Is a qualitative methodology appropriate?

Yes ☑
Can't Tell ☐
No ☐

HINT: Consider
- If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants
- Is qualitative research the right methodology for addressing the research goal

Comments:
-> Enhanced with the addition of quantitative arm of Breast-CAM-NF1 questionnaire. Interview questions allow for further exploration of experience of this intervention

Is it worth continuing?

3. Was the research design appropriate to address the aims of the research?

Yes ☑
Can't Tell ☐
No ☐

HINT: Consider
- if the researcher has justified the research design (e.g. have they discussed how they decided which method to use)

Comments:
Thorough explanation offered within methodology section of research design, and transparency of why the research design has specifically been employed.

CASP
Critical Appraisal
Skills Programme

4. Was the recruitment strategy appropriate to the aims of the research?

Yes ☑
Can't Tell ☐
No ☐

HINT: Consider
- If the researcher has explained how the participants were selected
- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
- If there are any discussions around recruitment (e.g. why some people chose not to take part)

Comments: Full details provided of participant selection, why these particular individuals were chosen, with information on inclusion + exclusion criteria. Explanation given into why these were deemed most suitable for gaining knowledge.

5. Was the data collected in a way that addressed the research issue?

Yes ☑
Can't Tell ☐
No ☐

HINT: Consider
- If the setting for the data collection was justified
- If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
- If the researcher has justified the methods chosen
- If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide)
- If methods were modified during the study. If so, has the researcher explained how and why
- If the form of data is clear (e.g. tape recordings, video material, notes etc.)
- If the researcher has discussed saturation of data ✗

Comments:
Thorough explanation provided on how data collection was performed, including methods used. Data saturation unsuitable for this research.
Full details provided within methodology to explain why, and why employing 'information power' is deemed most appropriate..

6. Has the relationship between researcher and participants been adequately considered?

Yes ☑
Can't Tell ☐
No ☐

HINT: Consider

- If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

Comments:
Reflexive accounts from me are provided within and throughout the thesis, as is suitable for reflexive thematic analysis

Section B: What are the results?

7. Have ethical issues been taken into consideration?

Yes ☑
Can't Tell ☐
No ☐

HINT: Consider

- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- If approval has been sought from the ethics committee

Comments:
- A thorough consideration of ethical issues are provided and discussed.
- Approval has been granted for the research

8. Was the data analysis sufficiently rigorous?

Yes ☑
Can't Tell ☐
No ☐

HINT: Consider
- If there is an in depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
- To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

Comments: Detailed explanation and transparency provided of the data analysis process, including appendices.

9. Is there a clear statement of findings?

Yes ☑
Can't Tell ☐
No ☐

HINT: Consider whether
- If the findings are explicit
- If there is adequate discussion of the evidence both for and against the researcher's arguments
- If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
- If the findings are discussed in relation to the original research question

Comments: - Thorough discussion provided alongside analysis (suitable for reflexive thematic analysis)

- Findings clearly discussed in relation to the original research question.

Section C: Will the results help locally?

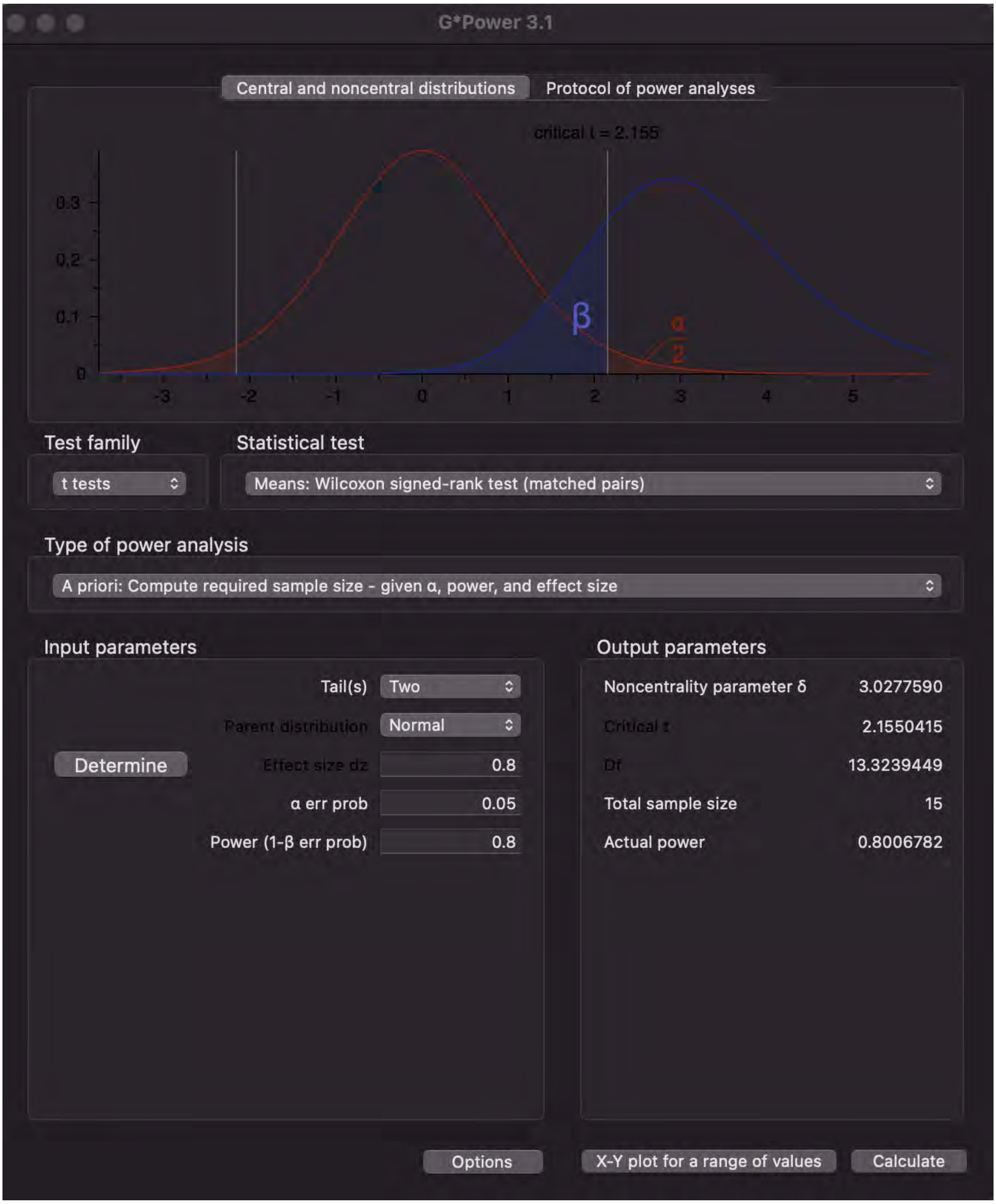
10. How valuable is the research?

HINT: Consider
- If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature
- If they identify new areas where research is necessary
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

Comments:
- Contribution discussed by inclusion within clinical recommendations, and conclusion.
- Catching breast cancer early can mean a better prognosis. Knowing risk factors, screening age eligibility also is important.
- Having the self-efficacy to seek medical help promptly, will potentially save lives.

Appendix M

G*Power (Faul et al., 2009) Output



Test family: t tests

Statistical test: Means: Wilcoxon signed-rank test (matched pairs)

Type of power analysis: A priori: Compute required sample size - given α, power, and effect size

Input parameters

Tail(s): Two

Parent distribution: Normal

Effect size dz: 0.8

α err prob: 0.05

Power (1-β err prob): 0.8

Output parameters

Noncentrality parameter δ: 3.0277590

Critical t: 2.1550415

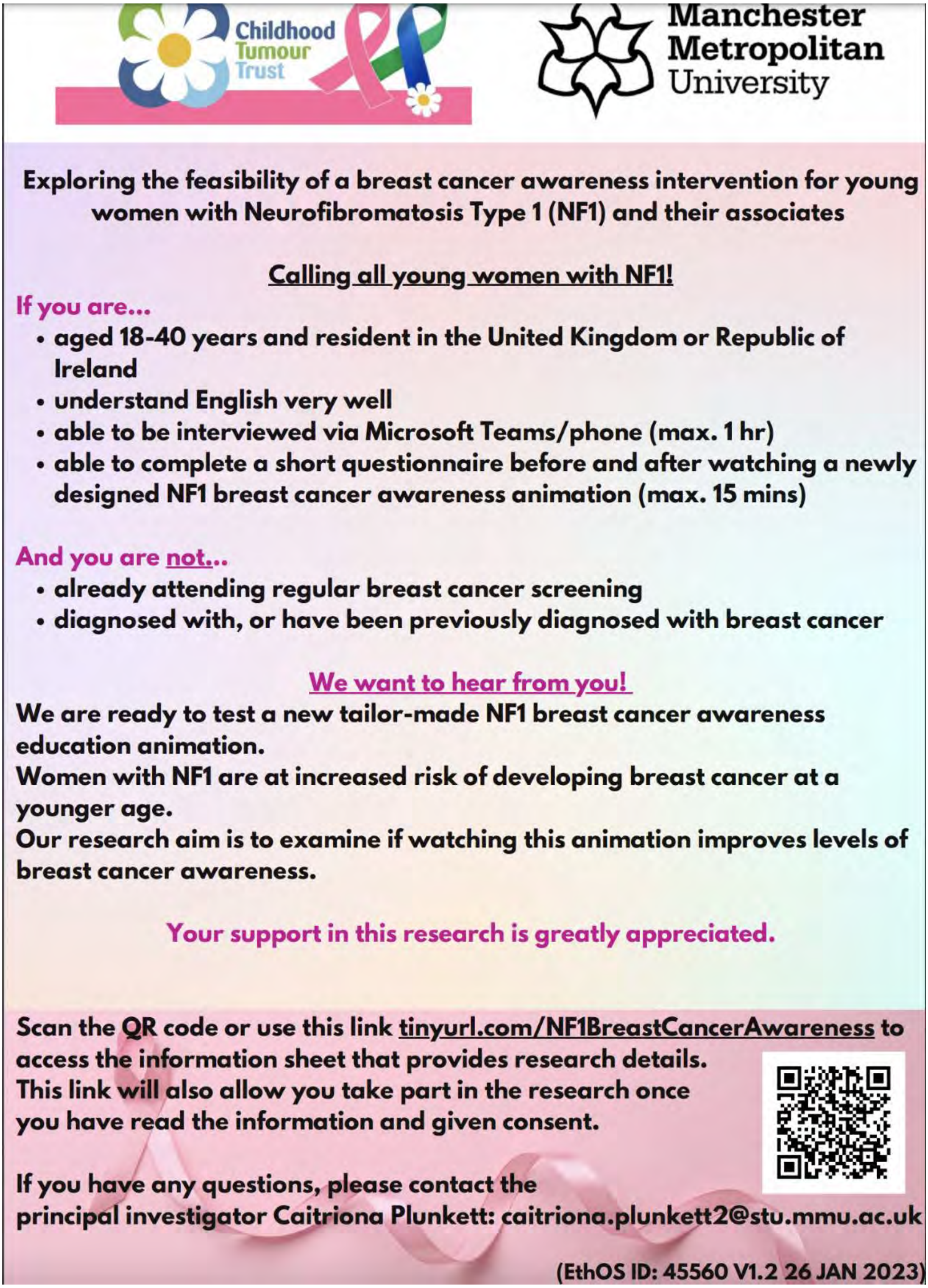
Df: 13.3239449

Total sample size: 15

Actual power: 0.8006782

Appendix N

Digital Recruitment Poster – Young Women with NF1



Childhood Tumour Trust

Manchester Metropolitan University

Exploring the feasibility of a breast cancer awareness intervention for young women with Neurofibromatosis Type 1 (NF1) and their associates

Calling all young women with NF1!

If you are…

- aged 18-40 years and resident in the United Kingdom or Republic of Ireland
- understand English very well
- able to be interviewed via Microsoft Teams/phone (max. 1 hr)
- able to complete a short questionnaire before and after watching a newly designed NF1 breast cancer awareness animation (max. 15 mins)

And you are not…

- already attending regular breast cancer screening
- diagnosed with, or have been previously diagnosed with breast cancer

We want to hear from you!

We are ready to test a new tailor-made NF1 breast cancer awareness education animation.
Women with NF1 are at increased risk of developing breast cancer at a younger age.
Our research aim is to examine if watching this animation improves levels of breast cancer awareness.

Your support in this research is greatly appreciated.

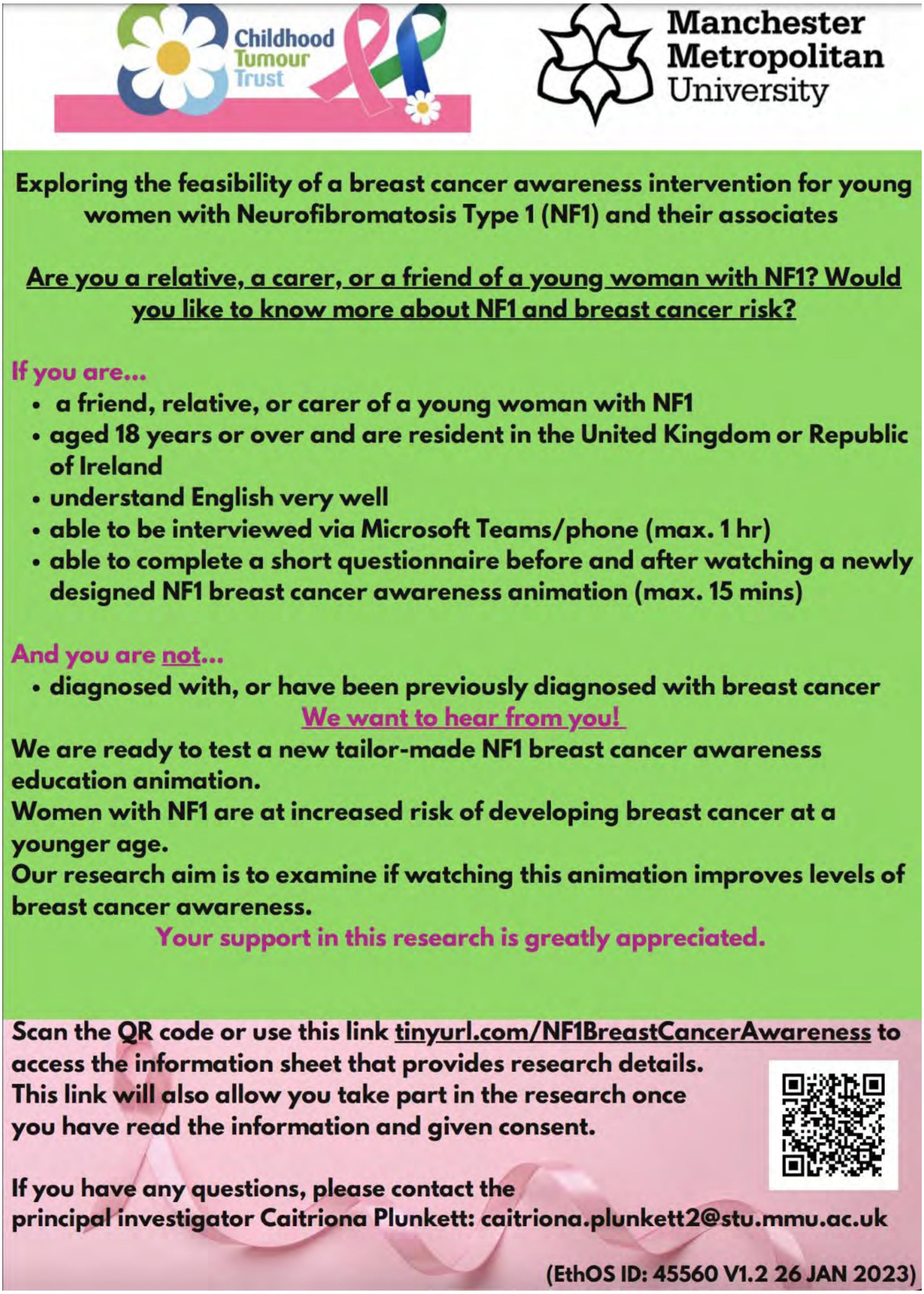
Scan the QR code or use this link tinyurl.com/NF1BreastCancerAwareness to access the information sheet that provides research details.
This link will also allow you take part in the research once you have read the information and given consent.

If you have any questions, please contact the principal investigator Caitriona Plunkett: caitriona.plunkett2@stu.mmu.ac.uk

(EthOS ID: 45560 V1.2 26 JAN 2023)

Appendix O

Digital Recruitment Poster – Associates



Exploring the feasibility of a breast cancer awareness intervention for young women with Neurofibromatosis Type 1 (NF1) and their associates

Are you a relative, a carer, or a friend of a young woman with NF1? Would you like to know more about NF1 and breast cancer risk?

If you are…

- a friend, relative, or carer of a young woman with NF1
- aged 18 years or over and are resident in the United Kingdom or Republic of Ireland
- understand English very well
- able to be interviewed via Microsoft Teams/phone (max. 1 hr)
- able to complete a short questionnaire before and after watching a newly designed NF1 breast cancer awareness animation (max. 15 mins)

And you are not…

- diagnosed with, or have been previously diagnosed with breast cancer

We want to hear from you!

We are ready to test a new tailor-made NF1 breast cancer awareness education animation.
Women with NF1 are at increased risk of developing breast cancer at a younger age.
Our research aim is to examine if watching this animation improves levels of breast cancer awareness.

Your support in this research is greatly appreciated.

Scan the QR code or use this link tinyurl.com/NF1BreastCancerAwareness to access the information sheet that provides research details.
This link will also allow you take part in the research once you have read the information and given consent.

If you have any questions, please contact the principal investigator Caitriona Plunkett: caitriona.plunkett2@stu.mmu.ac.uk

(EthOS ID: 45560 V1.2 26 JAN 2023)

Appendix P

Participant Information Sheet

Exploring the feasibility of a breast cancer awareness intervention for young women with Neurofibromatosis Type 1 (NF1) and their associates.

Invitation to research

My name is Caitriona Plunkett, and I am a PhD Researcher, at Manchester Metropolitan University. My PhD is sponsored by Childhood Tumour Trust. The research that I am conducting explores the feasibility of a breast cancer intervention for young women with NF1 and their associates, targeting breast cancer awareness, and breast cancer risk.

Why have I been invited?

You have been invited as you have been diagnosed with NF1 and are between the ages of 18 and 40 years. You are also resident in the United Kingdom or the Republic of Ireland. You are not attending regular breast cancer screening, diagnosed with, or have been previously diagnosed with breast cancer.

It is estimated that 25 individuals in total, of young women with NF1 and associates of young women with NF1 (e.g. carers, families, partners etc.) will participate within this research.

Do I have to take part?

It is up to you to decide whether or not to take part. Taking part is therefore voluntary. Before participating, please feel free to contact the Principal Investigator directly at caitriona.plunkett2@stu.mmu.ac.uk if you have any questions, or if you would like someone to go through the information sheet with you.

What will I be asked to do?

You will firstly be asked to complete an online Breast-CAM-NF1 questionnaire that examines your current level of breast cancer awareness. This questionnaire is an adapted measure of the Breast-CAM developed by Cancer Research UK, King's College London, and University College London in 2009. It was validated with the support of Breast Cancer Care and Breakthrough Breast Cancer. The Breast-CAM-NF1 questionnaire has been especially designed to measure breast cancer awareness that is specific to NF1 risk. This will take approximately 15 minutes to complete. You will then watch a short NF1 breast cancer awareness animation of approximately 3 minutes in length. On completion of this video, you will then answer similar, but fewer, questions to what you were previously asked, with a section to reflect on your experience of watching the animation. This is to determine if there are any changes in your knowledge of breast cancer awareness specific to NF1.

After this, on a day and time that suits you, you will be interviewed by me (Caitríona Plunkett) where you will be asked to share your opinions of the intervention, and to explore more about breast cancer awareness for women with NF1. The interview will take a maximum of 1 hour of your time and will take place online by Microsoft Teams or by telephone. It is your decision what method you choose.

Are there any risks if I participate?

All efforts will be taken to minimise risks to you. If you feel unhappy or uncomfortable at any point during the process, please let the principal investigator know so this can be rectified. Please remember that you can stop at any time.

If the subject of breast cancer, awareness to it, or the condition of NF1 has brought up difficult feelings, or left you feeling distressed, I would encourage you to contact one of the services listed below:

- Breast Cancer Now: https://breastcancernow.org/

Talk to a breast care nurse on 0808 800 6000

- Macmillan Cancer Support: www.macmillan.org.uk

  Phone Support Line: 0808 808 00 00
- Childhood Tumour Trust: https://www.childhoodtumourtrust.org.uk/
- Nerve Tumours UK: https://nervetumours.org.uk/

  Phone Helpline: 07939 046 030

If you are concerned about any symptoms that you may have, please discuss these with your doctor or with a trusted healthcare professional.

Are there any advantages if I participate?

Your contribution is greatly appreciated in this research and will give a better insight into breast cancer awareness of young women with NF1 to aid in developing ways to improve cancer services and education programmes within this specific population.

Informed consent

Your informed consent will be obtained at different stages throughout. This is to ensure that you are happy to continue within the different parts of this research. By agreeing to informed consent, you are agreeing that you:

- had the opportunity to consider the information, ask questions, and have had these answered satisfactorily.
- understand that participation is voluntary and that you are free to withdraw within the specified period of 2 weeks following data collection parts without giving any reason, and without legal rights affected.
- agree to participate in the research to the extent of the activities described within this participant information sheet.
- agree to the interview being audio recorded for analysis. No audio clips will be published without your express consent.
- give permission for information collected from the Breast-CAM-NF1 survey (although not your name or contact details) to be stored in the UK Data Archive for research purposes.
- understand and agree that words may be quoted anonymously in research

outputs.

Consent will be asked from you before any data (information) is asked of you. Consent will be requested:

- before completing questionnaires via Qualtrics, an online platform (digital consent).
- to contact you to be interviewed and for you to provide contact information such as an email address and a telephone number if you wish to be interviewed by telephone, rather than Microsoft Teams (digital consent via Qualtrics).
- to supply an email address if you wish to be informed of the outcomes of the research (Digital consent via Qualtrics).
- immediately before interviews (verbal consent to be recorded by Dictaphone).

What information about me will you collect and why?

Before beginning any data collection, and once you have given your consent to take part in the research you will be asked to set up a participant identification code (PIC) that is unique to you. This consists of 6 characters made up of your date of birthday, first and last letters of birthday month, and first and last letters of favourite colour (e.g., 28th May Purple is 28MYPE). This will be used with data to ensure that your responses are kept anonymous (not identified to you). No identifiable information such as your name or contact details will be kept with the research data that you provide.

Your answers from the questionnaires will be used to examine if there are any changes in your NF1 breast cancer awareness knowledge. Details of your experience of participating within this part of the research will also be collected.

Interviews are recorded and typed up to allow me to analyse information about your experiences of having watched the animation, to discuss any changes you have experienced in relation to your awareness levels, and to explore potential barriers to being breast cancer aware with NF1. You can choose a pseudonym (different name) for interviews to protect your identity.

All of this information is necessary to analyse whether the intervention was of benefit, and to explore what could be developed or adapted for future interventions concerning NF1 and breast cancer awareness.

How will my information be stored and how will you look after it?

All data will be stored on my (Principal Investigator's) password protected MMU OneDrive that is a storage facility provided by the university. Identifiable information such as your name, email address, or telephone number will be kept separate from any research information obtained by questionnaires, and interviews. This will be achieved by using your PIC and pseudonym with collected research data.

How will you use my information?

The data supplied by you will solely be used to meet the research purposes as part of a PhD in psychology. Data may be used for publication in academic journals and presented at academic conferences. Information pertaining to findings within this research may also be published on platforms that are used for educational resources for health professionals, within clinics, and charity platforms. Any identifiable information will not be published within these publications. A pseudonym will be used in published outputs to protect your identity.

Will my data be sent anywhere else, or shared with other people or organisations?

Non-identifiable data from the questionnaires will be uploaded to the UK Data Archive which is a secure platform as per the requirements set out by Cancer Research UK. Data will not be transferred outside of the UK or EU. No third party processors will be utilised.

When will you destroy my information?

Data can be held for 10 years in accordance with Manchester Metropolitan University's retention policy.

Data Protection Law

The way we look after your information is ruled by UK law. Under UK law, we need to have a very good reason for using your information (this is called a 'lawful basis'). Sometimes, we might also want to use sensitive information about you, like information about your health, religion and ethnic background. This is called 'special category information'. We collect all this information from you to help with our research, which aims to benefit everyone (this means that it is in the 'public interest').

You have the right to make choices about your information under UK law. If you have any questions or would like to ask us to do something with your information, you can ask the researcher or a parent or guardian, or someone else at the University. Contact details are shown towards the bottom of this document.

You can stop being a part of the study at any time, without giving a reason. You can ask us to delete your data at any time, but it might not always be possible. If you ask us to delete information within 2 weeks of completing parts of the research such as the survey or the interview, we will make sure this is done. If you ask us to delete data after this point, we might not be able to. If your data is anonymised (where we take out your name and any other information that lets us know the information is about you), we will not be able to delete it, because we will not know which data is yours.

What will happen to the results of the research study?

The project report will be submitted as part of a PhD in psychology and may be used for publication in academic journals and presented at academic conferences. The results will also be shared with the Childhood Tumour Trust.

Who has reviewed this research project?

This research project has been reviewed by the Faculty of Health and Education's Research Ethics Committee, of Manchester Metropolitan University.

Who do I contact if I have concerns about this study or I wish to complain?

Project Lead: If you have any concerns regarding this study, you can contact Caitríona Plunkett at caitriona.plunkett2@stu.mmu.ac.uk, or in writing to: The Department of Psychology, Manchester Metropolitan University, 53 Bonsall Street, Manchester, M15 6GX.

Principal Supervisor: Dr Melissa Pilkington: M.Pilkington@mmu.ac.uk, Department of Psychology, Manchester Metropolitan University, 53 Bonsall Street, Manchester, M15 6GX.

Manchester Metropolitan Faculty of Health and Education's Research Ethics and Governance Lead: Dr Clare Fox via email: FOHE-Ethics@mmu.ac.uk.

Manchester Metropolitan Data Protection Officer: dataprotection@mmu.ac.uk
Tel: 0161 247 3331 Legal Services, All Saints Building, Manchester Metropolitan University, Manchester, M15 6BH

UK Information Commissioner's Office: You have the right to complain directly to the Information Commissioner's Office if you would like to complain about how we process your personal data: https://ico.org.uk/global/contact-us/

THANK YOU FOR CONSIDERING PARTICIPATING IN THIS PROJECT

Appendix Q

Participant Information Sheet – Associates

Participant Information Sheet

Exploring the feasibility of a breast cancer awareness intervention for young women with Neurofibromatosis Type 1 (NF1) and their associates.

Invitation to research

My name is Caitriona Plunkett, and I am a PhD Researcher, at Manchester Metropolitan University. My PhD is sponsored by Childhood Tumour Trust. The research that I am conducting explores the feasibility of a breast cancer intervention for young women with NF1 and their associates, targeting breast cancer awareness, and breast cancer risk.

Why have I been invited?

You have been invited as you are an associate of a woman with NF1, such as a relative, a friend, or a carer. Raising breast cancer awareness among associates may also aid in educating young women with NF1. You are also resident in the United Kingdom or the Republic of Ireland. You are not currently diagnosed with or have been previously diagnosed with breast cancer.

It is estimated that 25 individuals in total, of young women with NF1 and associates of young women with NF1 (e.g. carers, families, partners etc.) will participate within this research.

Do I have to take part?

It is up to you to decide whether or not to take part. Taking part is therefore voluntary. Before participating, please feel free to contact the Principal Investigator directly at caitriona.plunkett2@stu.mmu.ac.uk if you have any questions, or if you would like someone to go through the information sheet with you.

What will I be asked to do?

You will firstly be asked to complete an online Breast-CAM-NF1 questionnaire that examines your current level of breast cancer awareness. This questionnaire is an adapted measure of the Breast-CAM developed by Cancer Research UK, King's College London, and University College London in 2009. It was validated with the support of Breast Cancer Care and Breakthrough Breast Cancer. The Breast-CAM-NF1 questionnaire has been especially designed to measure breast cancer awareness that is specific to NF1 risk. This will take approximately 15 minutes to complete. You will then watch a short NF1 breast cancer awareness animation of approximately 3 minutes in length. On completion of this video, you will then answer similar, but fewer, questions to what you were previously asked, with a section to reflect on your experience of watching the animation. This is to determine if there are any changes in your knowledge of breast cancer awareness specific to NF1.

After this, on a day and time that suits you, you will be interviewed by me (Caitríona Plunkett) where you will be asked to share your opinions of the intervention, and to explore more about breast cancer awareness for women with NF1. The interview will take a maximum of 1 hour of your time and will take place online by Microsoft Teams or by telephone. It is your decision what method you choose.

Are there any risks if I participate?

All efforts will be taken to minimise risks to you. If you feel unhappy or uncomfortable at any point during the process, please let the principal investigator know so this can be rectified. Please remember that you can stop at any time.

If the subject of breast cancer, awareness to it, or the condition of NF1 has brought up difficult feelings, or left you feeling distressed, I would encourage you to contact one of the services listed below:

- Breast Cancer Now: https://breastcancernow.org/

Talk to a breast care nurse on 0808 800 6000

- Macmillan Cancer Support: www.macmillan.org.uk

Phone Support Line: 0808 808 00 00

- Childhood Tumour Trust: https://www.childhoodtumourtrust.org.uk/
- Nerve Tumours UK: https://nervetumours.org.uk/

Phone Helpline: 07939 046 030

If you are concerned about any symptoms that you may have, please discuss these with your doctor or with a trusted healthcare professional.

Are there any advantages if I participate?

Your contribution is greatly appreciated in this research and will give a better insight into breast cancer awareness of young women with NF1 to aid in developing ways to improve cancer services and education programmes within this specific population.

Informed consent

Your informed consent will be obtained at different stages throughout. This is to ensure that you are happy to continue within the different parts of this research. By agreeing to informed consent, you are agreeing that you:

- had the opportunity to consider the information, ask questions, and have had these answered satisfactorily.
- understand that participation is voluntary and that you are free to withdraw within the specified period of 2 weeks following data collection parts without giving any reason, and without legal rights affected.
- agree to participate in the research to the extent of the activities described within this participant information sheet.
- agree to the interview being audio recorded for analysis. No audio clips will be published without your express consent.

- give permission for information collected from the Breast-CAM-NF1 survey (although not your name or contact details) to be stored in the UK Data Archive for research purposes.
- understand and agree that words may be quoted anonymously in research outputs.

Consent will be asked from you before any data (information) is asked of you. Consent will be requested:

- before completing questionnaires via Qualtrics, an online platform (digital consent).
- to contact you to be interviewed and for you to provide contact information such as an email address and a telephone number if you wish to be interviewed by telephone, rather than Microsoft Teams (digital consent via Qualtrics).
- to supply an email address if you wish to be informed of the outcomes of the research (Digital consent via Qualtrics).
- immediately before interviews (verbal consent to be recorded by Dictaphone).

What information about me will you collect and why?

Before beginning any data collection, and once you have given your consent to take part in the research you will be asked to set up a participant identification code (PIC) that is unique to you. This consists of 6 characters made up of your date of birthday, first and last letters of birthday month, and first and last letters of favourite colour (e.g., 28th May Purple is 28MYPE). This will be used with data to ensure that your responses are kept anonymous (not identified to you). No identifiable information such as your name or contact details will be kept with the research data that you provide.

Your answers from the questionnaires will be used to examine if there are any changes in your NF1 breast cancer awareness knowledge. Details of your experience of participating within this part of the research will also be collected.

Interviews are recorded and typed up to allow me to analyse information about your experiences of having watched the animation, to discuss any changes you have experienced in relation to your awareness levels, and to explore potential barriers to being breast cancer aware with NF1. You can choose a pseudonym (different name) for interviews to protect your identity.

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How will my information be stored and how will you look after it?

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How will you use my information?

The data supplied by you will solely be used to meet the research purposes as part of a PhD in psychology. Data may be used for publication in academic journals and presented at academic conferences. Information pertaining to findings within this research may also be published on platforms that are used for educational resources for health professionals, within clinics, and charity platforms. Any identifiable information will not be published within these publications. A pseudonym will be used in published outputs to protect your identity.

Will my data be sent anywhere else, or shared with other people or organisations?

Non-identifiable data from the questionnaires will be uploaded to the UK Data Archive which is a secure platform as per the requirements set out by Cancer Research UK. Data will not be transferred outside of the UK or EU. No third party processors will be utilised.

When will you destroy my information?

Data can be held for 10 years in accordance with Manchester Metropolitan University's retention policy.

Data Protection Law

The way we look after your information is ruled by UK law. Under UK law, we need to have a very good reason for using your information (this is called a 'lawful basis'). Sometimes, we might also want to use sensitive information about you, like information about your health, religion and ethnic background. This is called 'special category information'. We collect all this information from you to help with our research, which aims to benefit everyone (this means that it is in the 'public interest').

You have the right to make choices about your information under UK law. If you have any questions or would like to ask us to do something with your information, you can ask the researcher or a parent or guardian, or someone else at the University. Contact details are shown towards the bottom of this document.

You can stop being a part of the study at any time, without giving a reason. You can ask us to delete your data at any time, but it might not always be possible. If you ask us to delete information within 2 weeks of completing parts of the research such as the survey or the interview, we will make sure this is done. If you ask us to delete data after this point, we might not be able to. If your data is anonymised (where we take out your name and any other information that lets us know the information is about you), we will not be able to delete it, because we will not know which data is yours.

What will happen to the results of the research study?

The project report will be submitted as part of a PhD in psychology and may be used for publication in academic journals and presented at academic conferences. The results will also be shared with the Childhood Tumour Trust.

Who has reviewed this research project?

This research project has been reviewed by the Faculty of Health and Education's Research Ethics Committee, of Manchester Metropolitan University.

Who do I contact if I have concerns about this study or I wish to complain?

Project Lead: If you have any concerns regarding this study, you can contact Caitríona Plunkett at caitriona.plunkett2@stu.mmu.ac.uk, or in writing to: The Department of Psychology, Manchester Metropolitan University, 53 Bonsall Street, Manchester, M15 6GX.

Principal Supervisor: Dr Melissa Pilkington: M.Pilkington@mmu.ac.uk, Department of Psychology, Manchester Metropolitan University, 53 Bonsall Street, Manchester, M15 6GX.

Manchester Metropolitan Faculty of Health and Education's Research Ethics and Governance Lead: Dr Clare Fox via email: FOHE-Ethics@mmu.ac.uk.

Manchester Metropolitan Data Protection Officer: dataprotection@mmu.ac.uk
Tel: 0161 247 3331 Legal Services, All Saints Building, Manchester Metropolitan University, Manchester, M15 6BH

UK Information Commissioner's Office:
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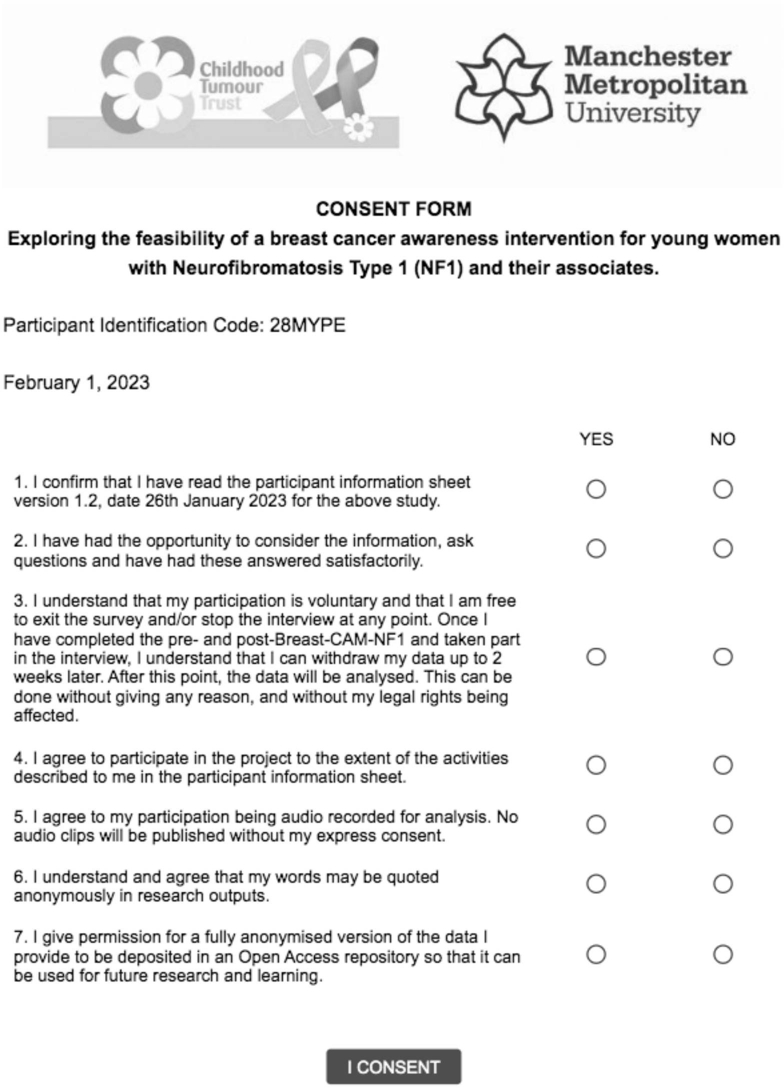
https://ico.org.uk/global/contact-us/

THANK YOU FOR CONSIDERING PARTICIPATING IN THIS PROJECT

Appendix R

Consent Form



CONSENT FORM

Exploring the feasibility of a breast cancer awareness intervention for young women with Neurofibromatosis Type 1 (NF1) and their associates.

Participant Identification Code: 28MYPE

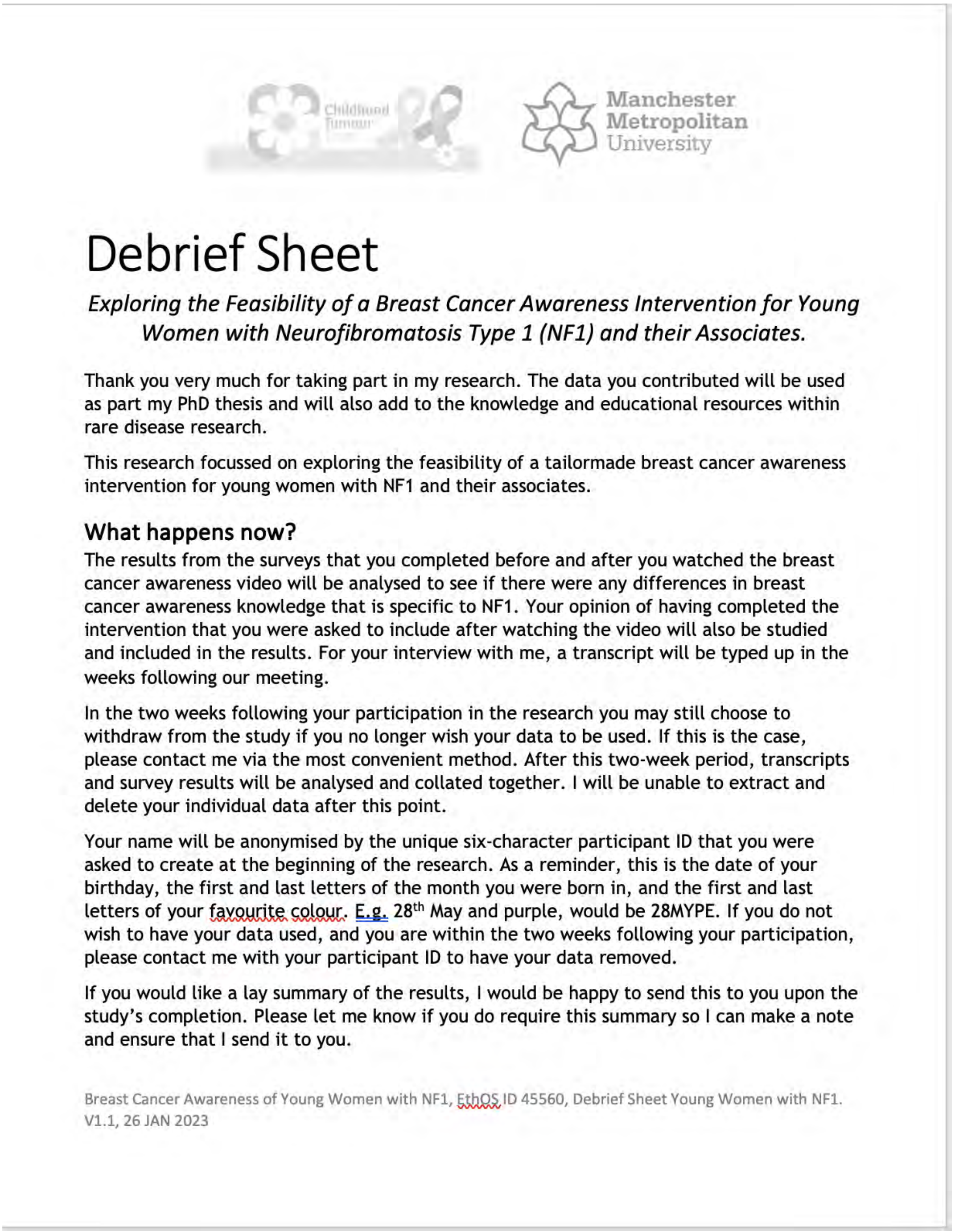
February 1, 2023

	YES	NO
1. I confirm that I have read the participant information sheet version 1.2, date 26th January 2023 for the above study.	○	○
2. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	○	○
3. I understand that my participation is voluntary and that I am free to exit the survey and/or stop the interview at any point. Once I have completed the pre- and post-Breast-CAM-NF1 and taken part in the interview, I understand that I can withdraw my data up to 2 weeks later. After this point, the data will be analysed. This can be done without giving any reason, and without my legal rights being affected.	○	○
4. I agree to participate in the project to the extent of the activities described to me in the participant information sheet.	○	○
5. I agree to my participation being audio recorded for analysis. No audio clips will be published without my express consent.	○	○
6. I understand and agree that my words may be quoted anonymously in research outputs.	○	○
7. I give permission for a fully anonymised version of the data I provide to be deposited in an Open Access repository so that it can be used for future research and learning.	○	○

I CONSENT

Appendix S

Debrief Sheet - Young Women with NF1



Debrief Sheet

Exploring the Feasibility of a Breast Cancer Awareness Intervention for Young Women with Neurofibromatosis Type 1 (NF1) and their Associates.

Thank you very much for taking part in my research. The data you contributed will be used as part my PhD thesis and will also add to the knowledge and educational resources within rare disease research.

This research focussed on exploring the feasibility of a tailormade breast cancer awareness intervention for young women with NF1 and their associates.

What happens now?

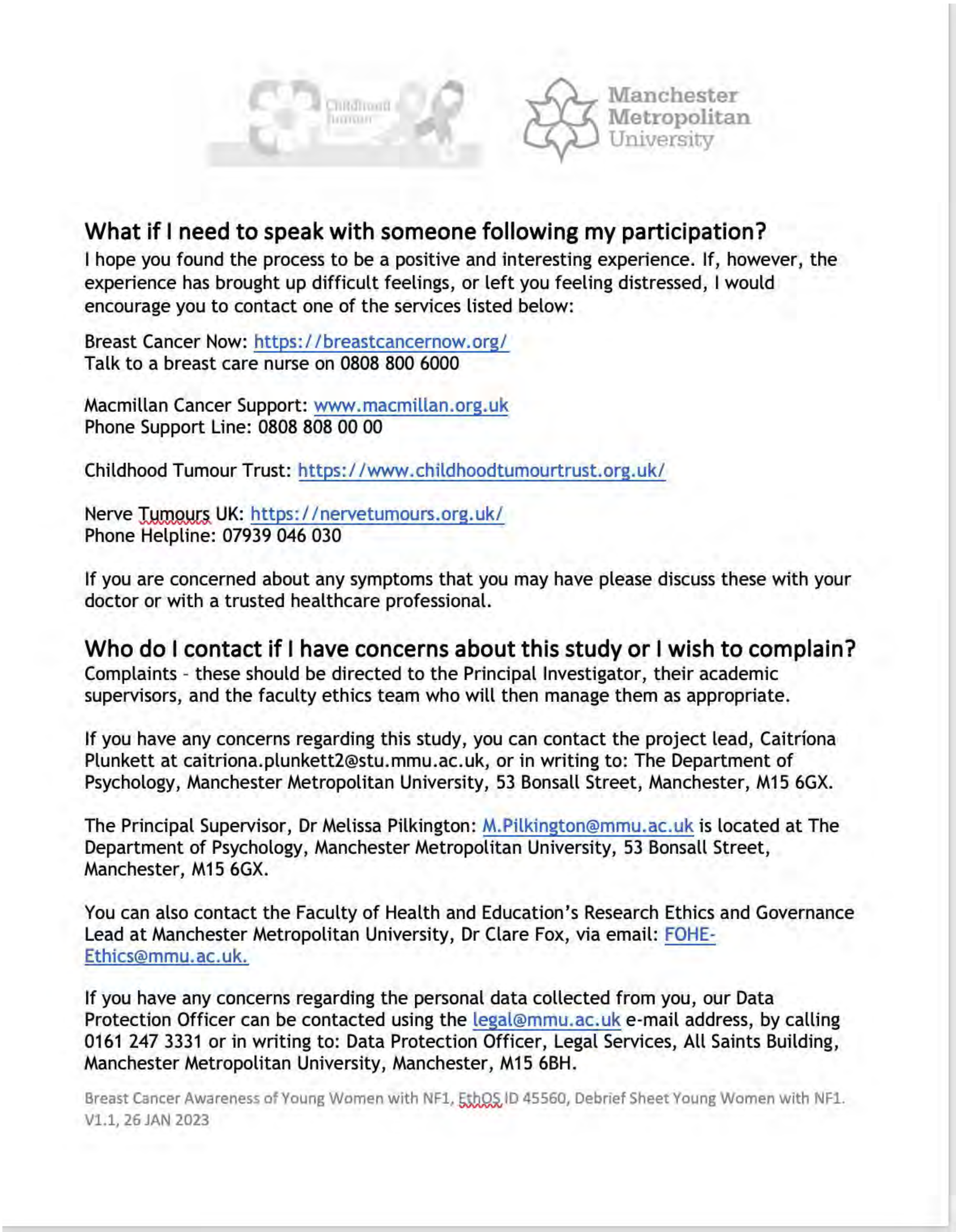
The results from the surveys that you completed before and after you watched the breast cancer awareness video will be analysed to see if there were any differences in breast cancer awareness knowledge that is specific to NF1. Your opinion of having completed the intervention that you were asked to include after watching the video will also be studied and included in the results. For your interview with me, a transcript will be typed up in the weeks following our meeting.

In the two weeks following your participation in the research you may still choose to withdraw from the study if you no longer wish your data to be used. If this is the case, please contact me via the most convenient method. After this two-week period, transcripts and survey results will be analysed and collated together. I will be unable to extract and delete your individual data after this point.

Your name will be anonymised by the unique six-character participant ID that you were asked to create at the beginning of the research. As a reminder, this is the date of your birthday, the first and last letters of the month you were born in, and the first and last letters of your favourite colour. E.g. 28th May and purple, would be 28MYPE. If you do not wish to have your data used, and you are within the two weeks following your participation, please contact me with your participant ID to have your data removed.

If you would like a lay summary of the results, I would be happy to send this to you upon the study's completion. Please let me know if you do require this summary so I can make a note and ensure that I send it to you.

Breast Cancer Awareness of Young Women with NF1, EthOS ID 45560, Debrief Sheet Young Women with NF1. V1.1, 26 JAN 2023



What if I need to speak with someone following my participation?

I hope you found the process to be a positive and interesting experience. If, however, the experience has brought up difficult feelings, or left you feeling distressed, I would encourage you to contact one of the services listed below:

Breast Cancer Now: https://breastcancernow.org/
Talk to a breast care nurse on 0808 800 6000

Macmillan Cancer Support: www.macmillan.org.uk
Phone Support Line: 0808 808 00 00

Childhood Tumour Trust: https://www.childhoodtumourtrust.org.uk/

Nerve Tumours UK: https://nervetumours.org.uk/
Phone Helpline: 07939 046 030

If you are concerned about any symptoms that you may have please discuss these with your doctor or with a trusted healthcare professional.

Who do I contact if I have concerns about this study or I wish to complain?

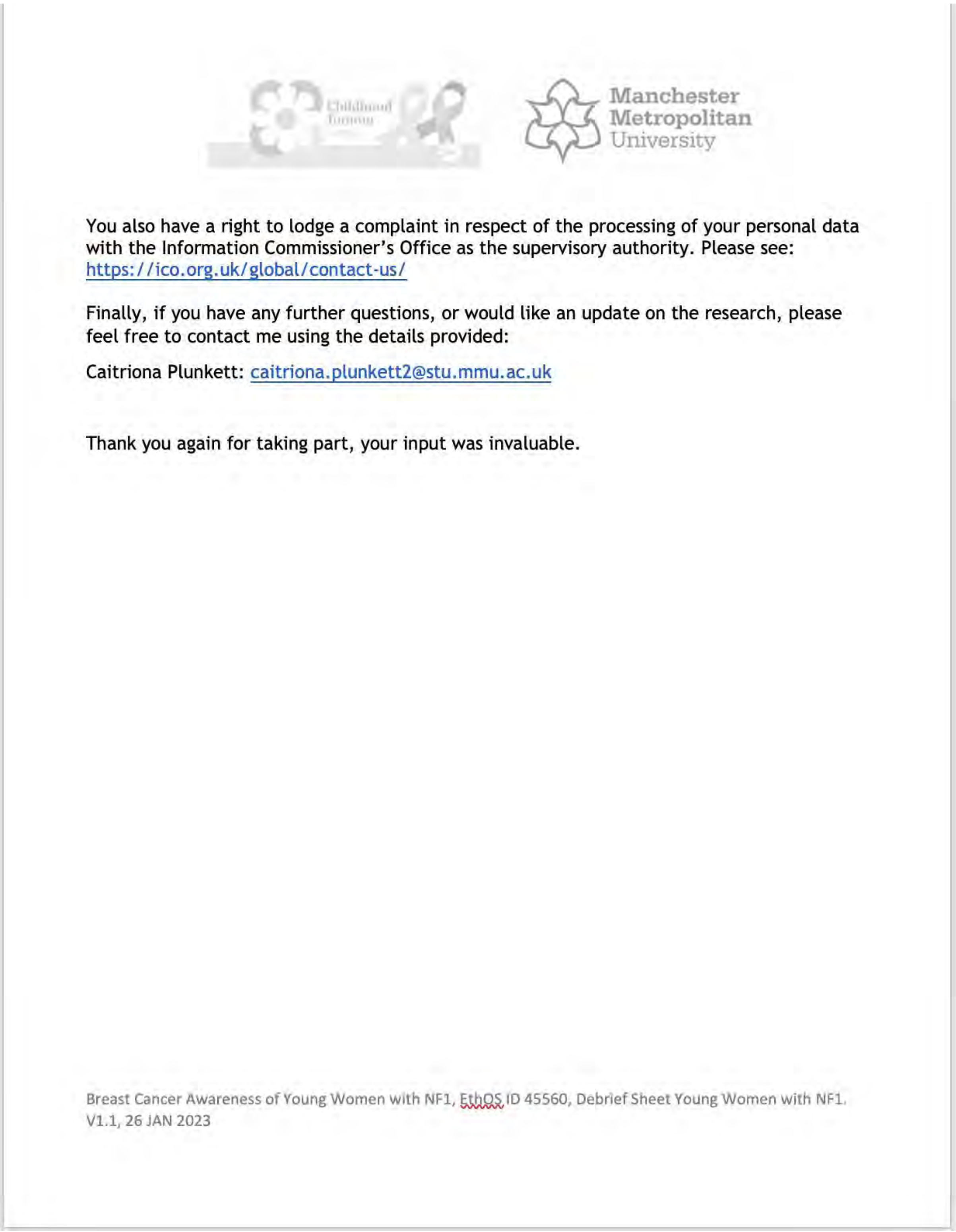
Complaints - these should be directed to the Principal Investigator, their academic supervisors, and the faculty ethics team who will then manage them as appropriate.

If you have any concerns regarding this study, you can contact the project lead, Caitríona Plunkett at caitriona.plunkett2@stu.mmu.ac.uk, or in writing to: The Department of Psychology, Manchester Metropolitan University, 53 Bonsall Street, Manchester, M15 6GX.

The Principal Supervisor, Dr Melissa Pilkington: M.Pilkington@mmu.ac.uk is located at The Department of Psychology, Manchester Metropolitan University, 53 Bonsall Street, Manchester, M15 6GX.

You can also contact the Faculty of Health and Education's Research Ethics and Governance Lead at Manchester Metropolitan University, Dr Clare Fox, via email: FOHE-Ethics@mmu.ac.uk.

If you have any concerns regarding the personal data collected from you, our Data Protection Officer can be contacted using the legal@mmu.ac.uk e-mail address, by calling 0161 247 3331 or in writing to: Data Protection Officer, Legal Services, All Saints Building, Manchester Metropolitan University, Manchester, M15 6BH.



You also have a right to lodge a complaint in respect of the processing of your personal data with the Information Commissioner's Office as the supervisory authority. Please see: https://ico.org.uk/global/contact-us/

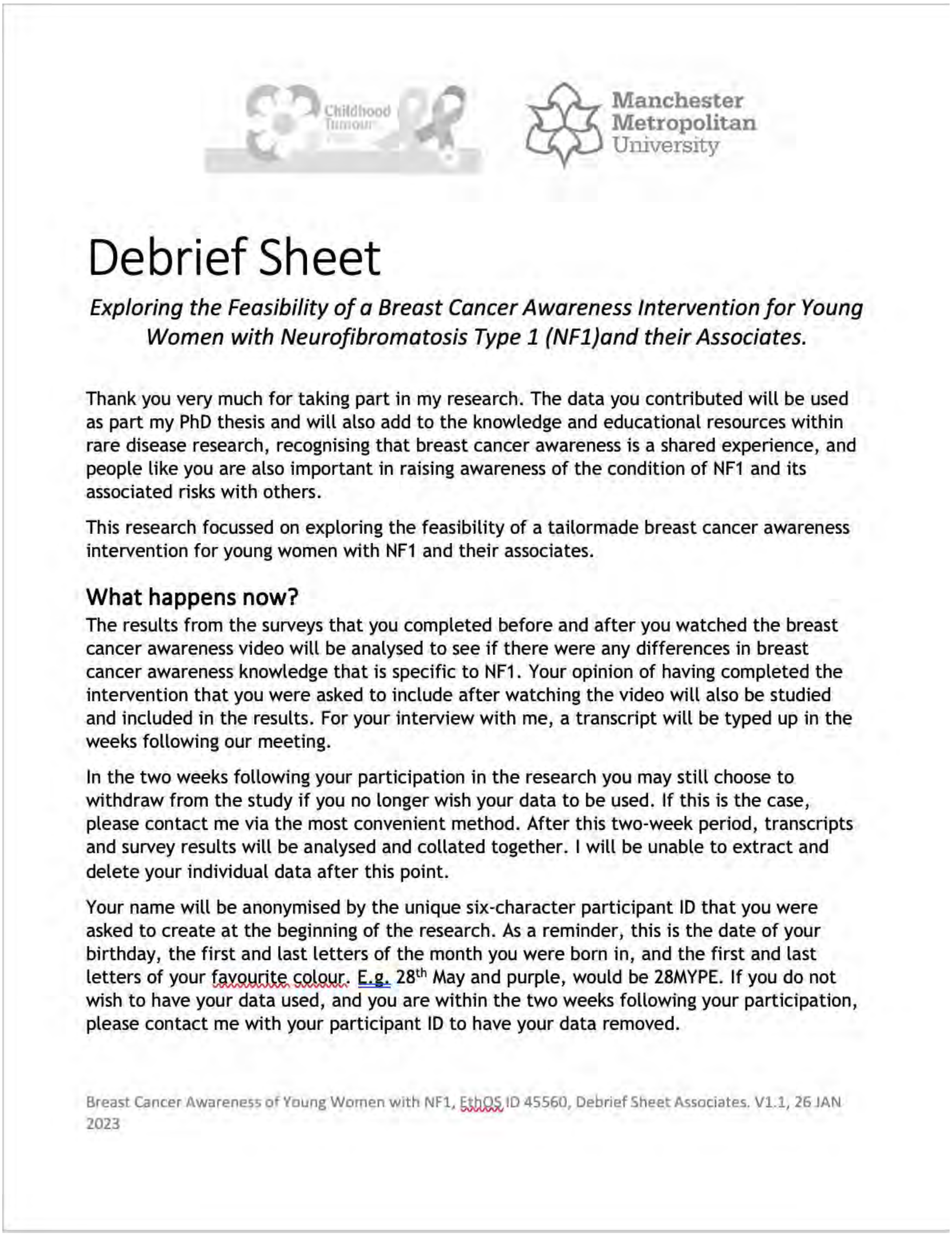
Finally, if you have any further questions, or would like an update on the research, please feel free to contact me using the details provided:

Caitriona Plunkett: caitriona.plunkett2@stu.mmu.ac.uk

Thank you again for taking part, your input was invaluable.

Appendix T

Debrief Sheet – Associates



Debrief Sheet

Exploring the Feasibility of a Breast Cancer Awareness Intervention for Young Women with Neurofibromatosis Type 1 (NF1)and their Associates.

Thank you very much for taking part in my research. The data you contributed will be used as part my PhD thesis and will also add to the knowledge and educational resources within rare disease research, recognising that breast cancer awareness is a shared experience, and people like you are also important in raising awareness of the condition of NF1 and its associated risks with others.

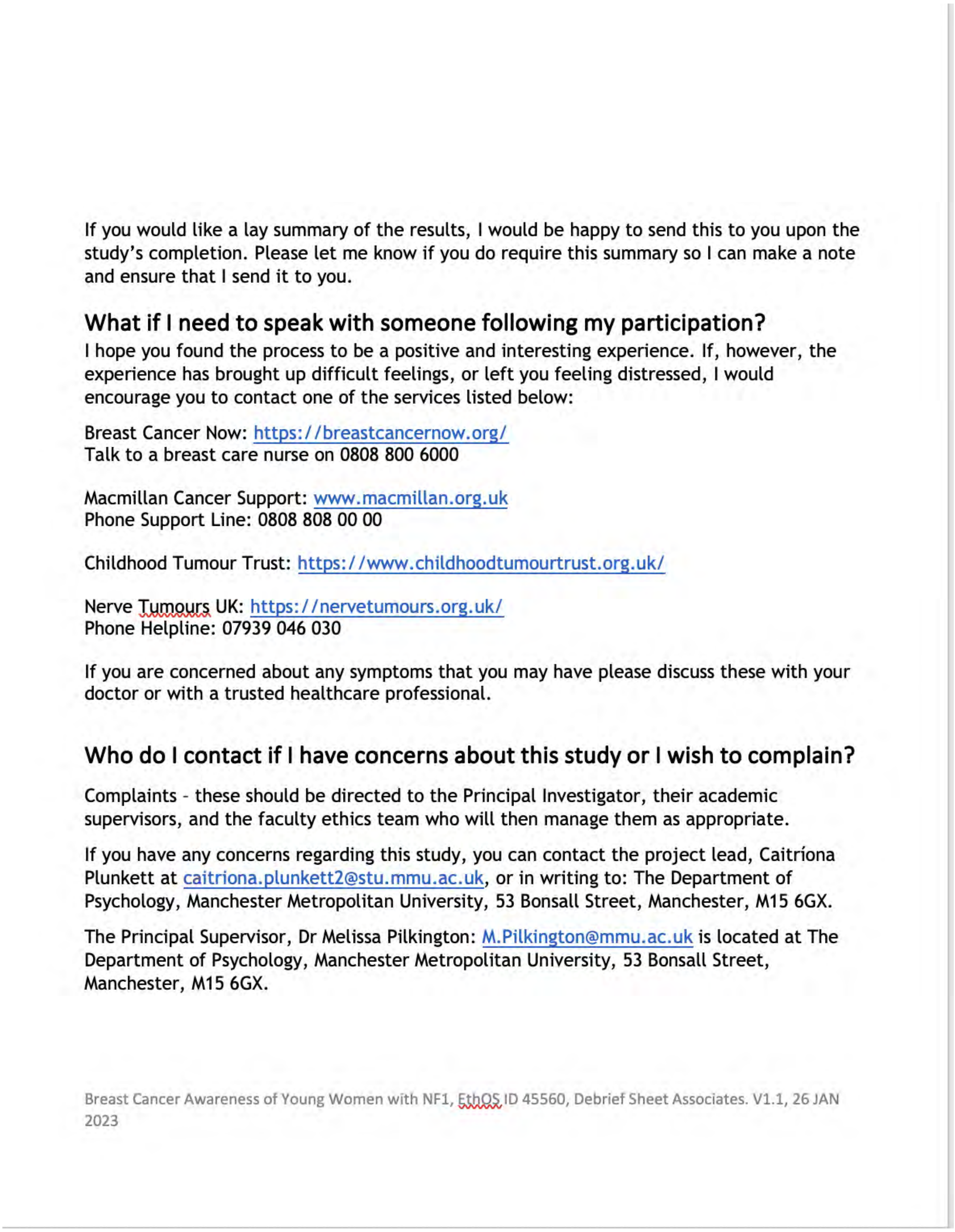
This research focussed on exploring the feasibility of a tailormade breast cancer awareness intervention for young women with NF1 and their associates.

What happens now?

The results from the surveys that you completed before and after you watched the breast cancer awareness video will be analysed to see if there were any differences in breast cancer awareness knowledge that is specific to NF1. Your opinion of having completed the intervention that you were asked to include after watching the video will also be studied and included in the results. For your interview with me, a transcript will be typed up in the weeks following our meeting.

In the two weeks following your participation in the research you may still choose to withdraw from the study if you no longer wish your data to be used. If this is the case, please contact me via the most convenient method. After this two-week period, transcripts and survey results will be analysed and collated together. I will be unable to extract and delete your individual data after this point.

Your name will be anonymised by the unique six-character participant ID that you were asked to create at the beginning of the research. As a reminder, this is the date of your birthday, the first and last letters of the month you were born in, and the first and last letters of your favourite colour. E.g. 28th May and purple, would be 28MYPE. If you do not wish to have your data used, and you are within the two weeks following your participation, please contact me with your participant ID to have your data removed.



If you would like a lay summary of the results, I would be happy to send this to you upon the study's completion. Please let me know if you do require this summary so I can make a note and ensure that I send it to you.

What if I need to speak with someone following my participation?

I hope you found the process to be a positive and interesting experience. If, however, the experience has brought up difficult feelings, or left you feeling distressed, I would encourage you to contact one of the services listed below:

Breast Cancer Now: https://breastcancernow.org/
Talk to a breast care nurse on 0808 800 6000

Macmillan Cancer Support: www.macmillan.org.uk
Phone Support Line: 0808 808 00 00

Childhood Tumour Trust: https://www.childhoodtumourtrust.org.uk/

Nerve Tumours UK: https://nervetumours.org.uk/
Phone Helpline: 07939 046 030

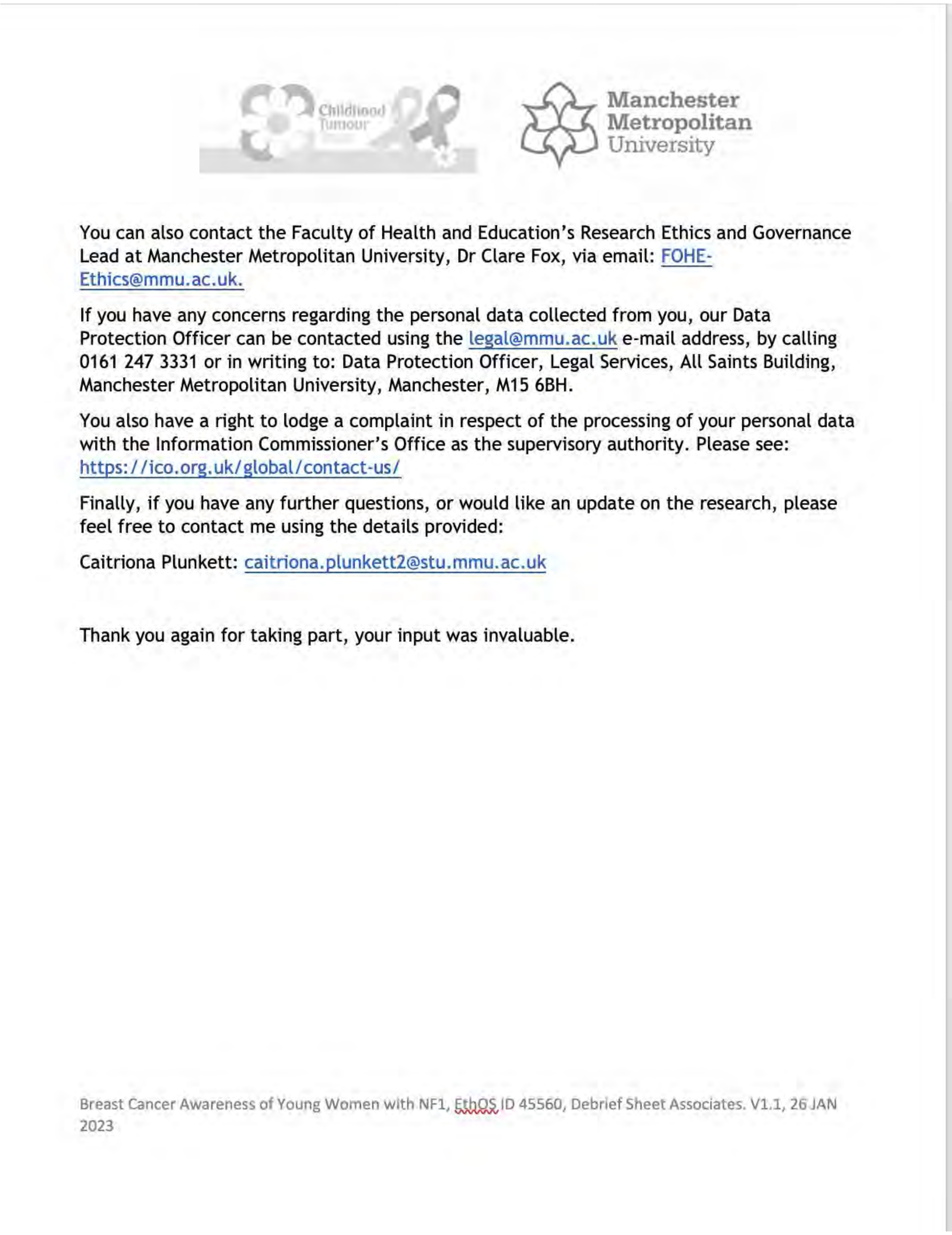
If you are concerned about any symptoms that you may have please discuss these with your doctor or with a trusted healthcare professional.

Who do I contact if I have concerns about this study or I wish to complain?

Complaints – these should be directed to the Principal Investigator, their academic supervisors, and the faculty ethics team who will then manage them as appropriate.

If you have any concerns regarding this study, you can contact the project lead, Caitríona Plunkett at caitriona.plunkett2@stu.mmu.ac.uk, or in writing to: The Department of Psychology, Manchester Metropolitan University, 53 Bonsall Street, Manchester, M15 6GX.

The Principal Supervisor, Dr Melissa Pilkington: M.Pilkington@mmu.ac.uk is located at The Department of Psychology, Manchester Metropolitan University, 53 Bonsall Street, Manchester, M15 6GX.



You can also contact the Faculty of Health and Education's Research Ethics and Governance Lead at Manchester Metropolitan University, Dr Clare Fox, via email: FOHE-Ethics@mmu.ac.uk.

If you have any concerns regarding the personal data collected from you, our Data Protection Officer can be contacted using the legal@mmu.ac.uk e-mail address, by calling 0161 247 3331 or in writing to: Data Protection Officer, Legal Services, All Saints Building, Manchester Metropolitan University, Manchester, M15 6BH.

You also have a right to lodge a complaint in respect of the processing of your personal data with the Information Commissioner's Office as the supervisory authority. Please see: https://ico.org.uk/global/contact-us/

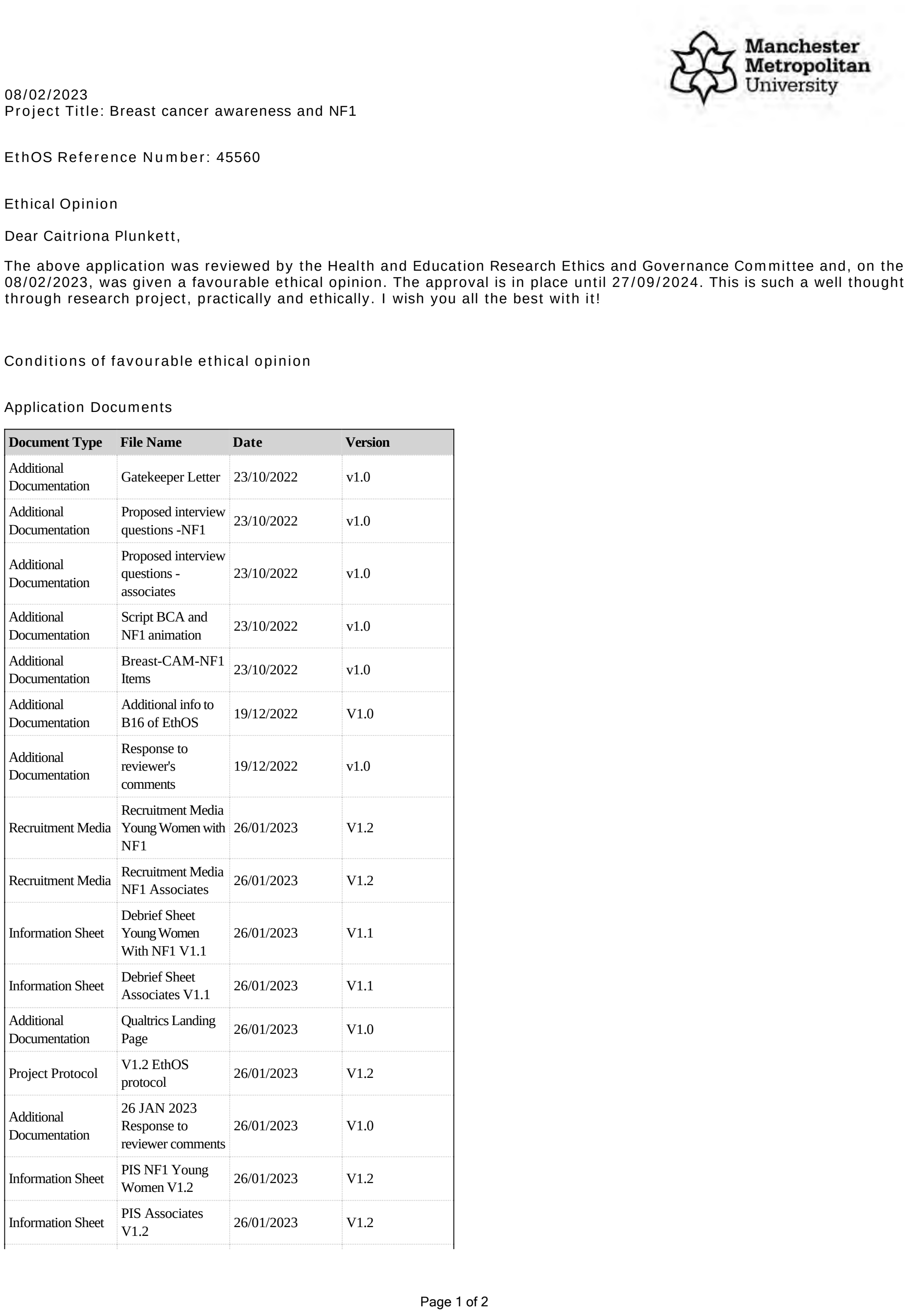
Finally, if you have any further questions, or would like an update on the research, please feel free to contact me using the details provided:

Caitriona Plunkett: caitriona.plunkett2@stu.mmu.ac.uk

Thank you again for taking part, your input was invaluable.

Appendix U

Evidence of Ethical Approval



Manchester Metropolitan University

08/02/2023
Project Title: Breast cancer awareness and NF1

EthOS Reference Number: 45560

Ethical Opinion

Dear Caitriona Plunkett,

The above application was reviewed by the Health and Education Research Ethics and Governance Committee and, on the 08/02/2023, was given a favourable ethical opinion. The approval is in place until 27/09/2024. This is such a well thought through research project, practically and ethically. I wish you all the best with it!

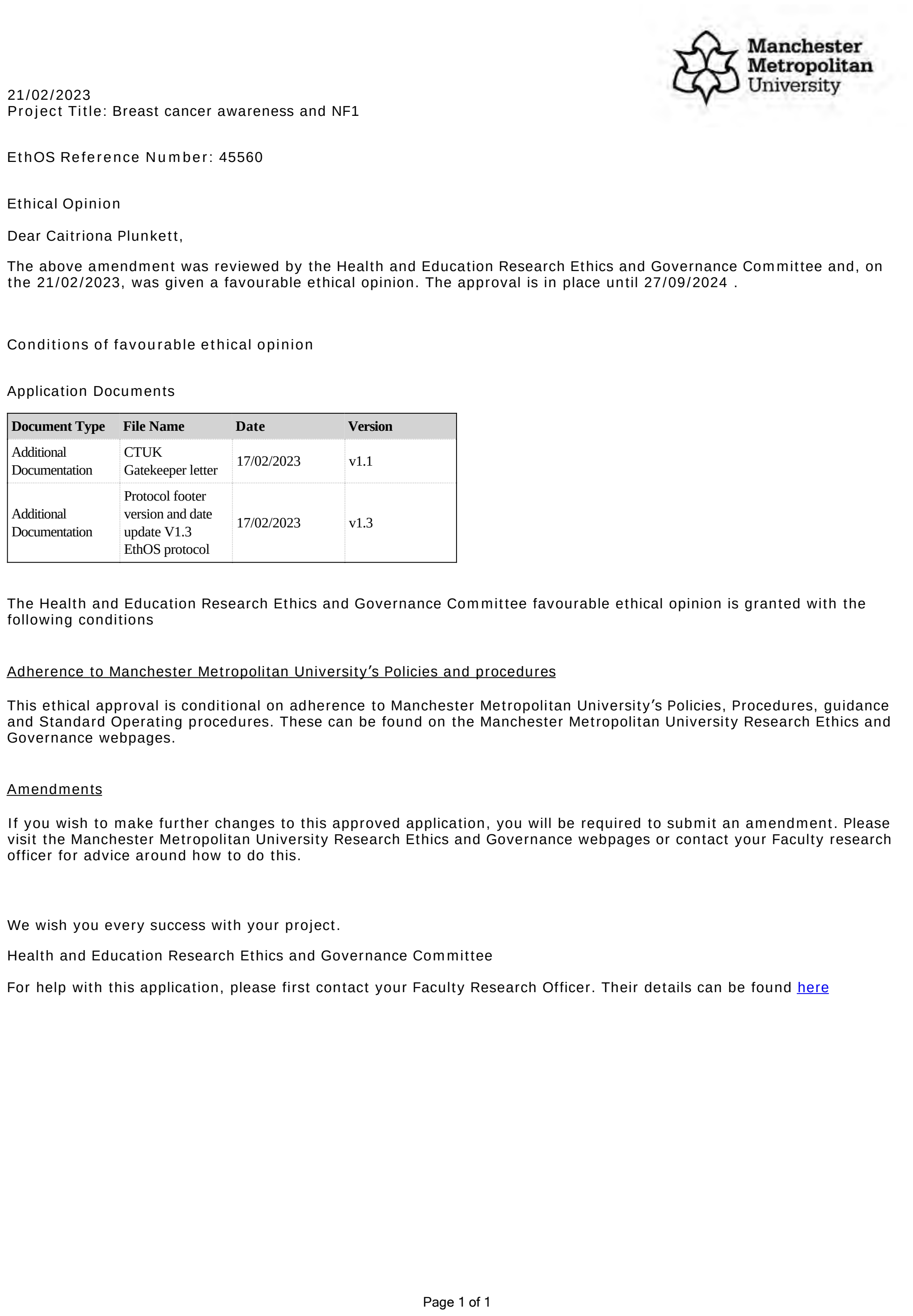
Conditions of favourable ethical opinion

Application Documents

Document Type	File Name	Date	Version
Additional Documentation	Gatekeeper Letter	23/10/2022	v1.0
Additional Documentation	Proposed interview questions -NF1	23/10/2022	v1.0
Additional Documentation	Proposed interview questions - associates	23/10/2022	v1.0
Additional Documentation	Script BCA and NF1 animation	23/10/2022	v1.0
Additional Documentation	Breast-CAM-NF1 Items	23/10/2022	v1.0
Additional Documentation	Additional info to B16 of EthOS	19/12/2022	V1.0
Additional Documentation	Response to reviewer's comments	19/12/2022	v1.0
Recruitment Media	Recruitment Media Young Women with NF1	26/01/2023	V1.2
Recruitment Media	Recruitment Media NF1 Associates	26/01/2023	V1.2
Information Sheet	Debrief Sheet Young Women With NF1 V1.1	26/01/2023	V1.1
Information Sheet	Debrief Sheet Associates V1.1	26/01/2023	V1.1
Additional Documentation	Qualtrics Landing Page	26/01/2023	V1.0
Project Protocol	V1.2 EthOS protocol	26/01/2023	V1.2
Additional Documentation	26 JAN 2023 Response to reviewer comments	26/01/2023	V1.0
Information Sheet	PIS NF1 Young Women V1.2	26/01/2023	V1.2
Information Sheet	PIS Associates V1.2	26/01/2023	V1.2

Appendix V

Evidence of Amended Ethical Approval – Additional Gatekeepers



21/02/2023
Project Title: Breast cancer awareness and NF1

EthOS Reference Number: 45560

Ethical Opinion

Dear Caitriona Plunkett,

The above amendment was reviewed by the Health and Education Research Ethics and Governance Committee and, on the 21/02/2023, was given a favourable ethical opinion. The approval is in place until 27/09/2024 .

Conditions of favourable ethical opinion

Application Documents

Document Type	File Name	Date	Version
Additional Documentation	CTUK Gatekeeper letter	17/02/2023	v1.1
Additional Documentation	Protocol footer version and date update V1.3 EthOS protocol	17/02/2023	v1.3

The Health and Education Research Ethics and Governance Committee favourable ethical opinion is granted with the following conditions

Adherence to Manchester Metropolitan University’s Policies and procedures

This ethical approval is conditional on adherence to Manchester Metropolitan University’s Policies, Procedures, guidance and Standard Operating procedures. These can be found on the Manchester Metropolitan University Research Ethics and Governance webpages.

Amendments

If you wish to make further changes to this approved application, you will be required to submit an amendment. Please visit the Manchester Metropolitan University Research Ethics and Governance webpages or contact your Faculty research officer for advice around how to do this.

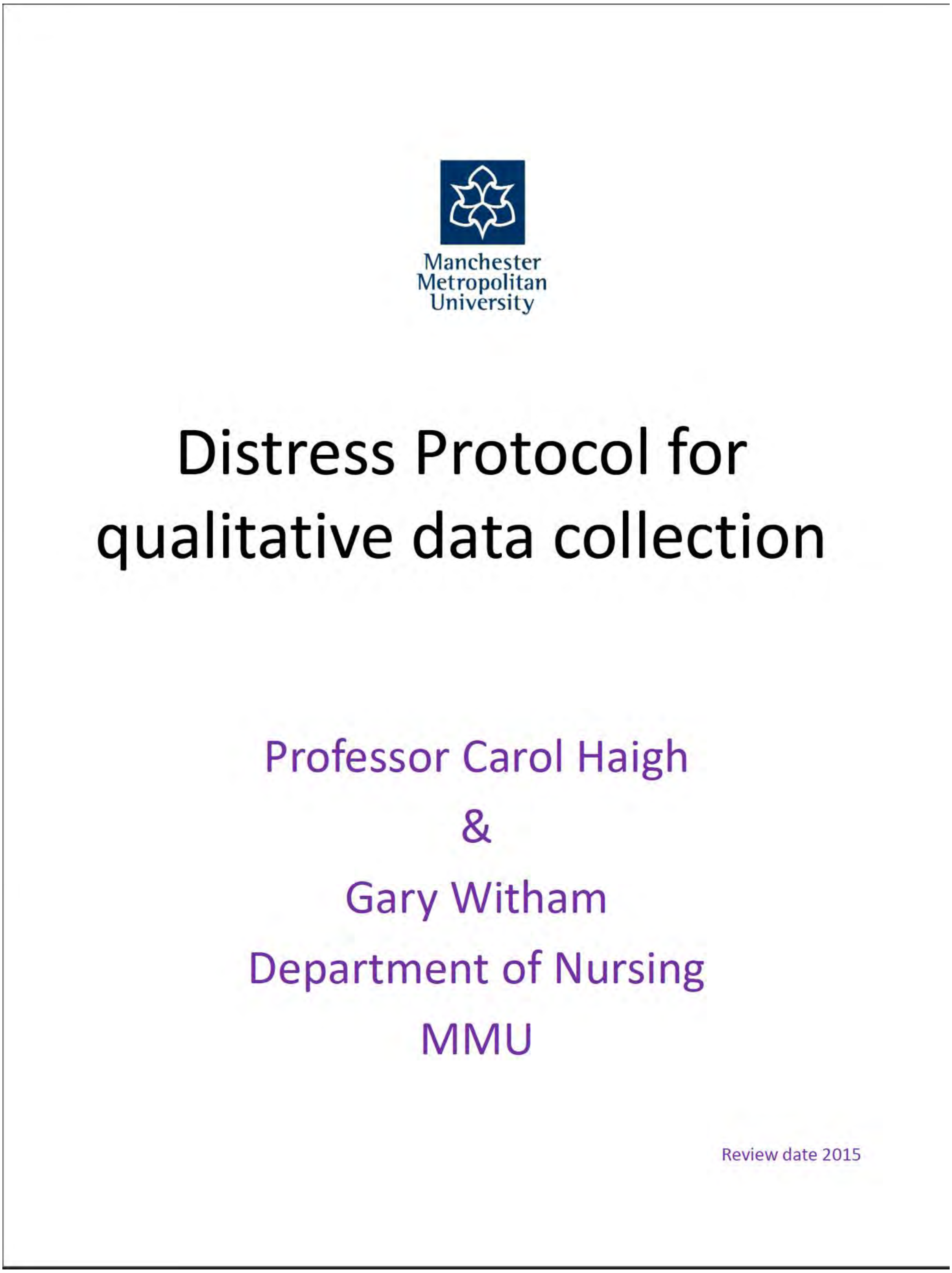
We wish you every success with your project.

Health and Education Research Ethics and Governance Committee

For help with this application, please first contact your Faculty Research Officer. Their details can be found here

Appendix W

Manchester Metropolitan University Distress Protocol (Haigh and Witham, 2015)



Manchester Metropolitan University

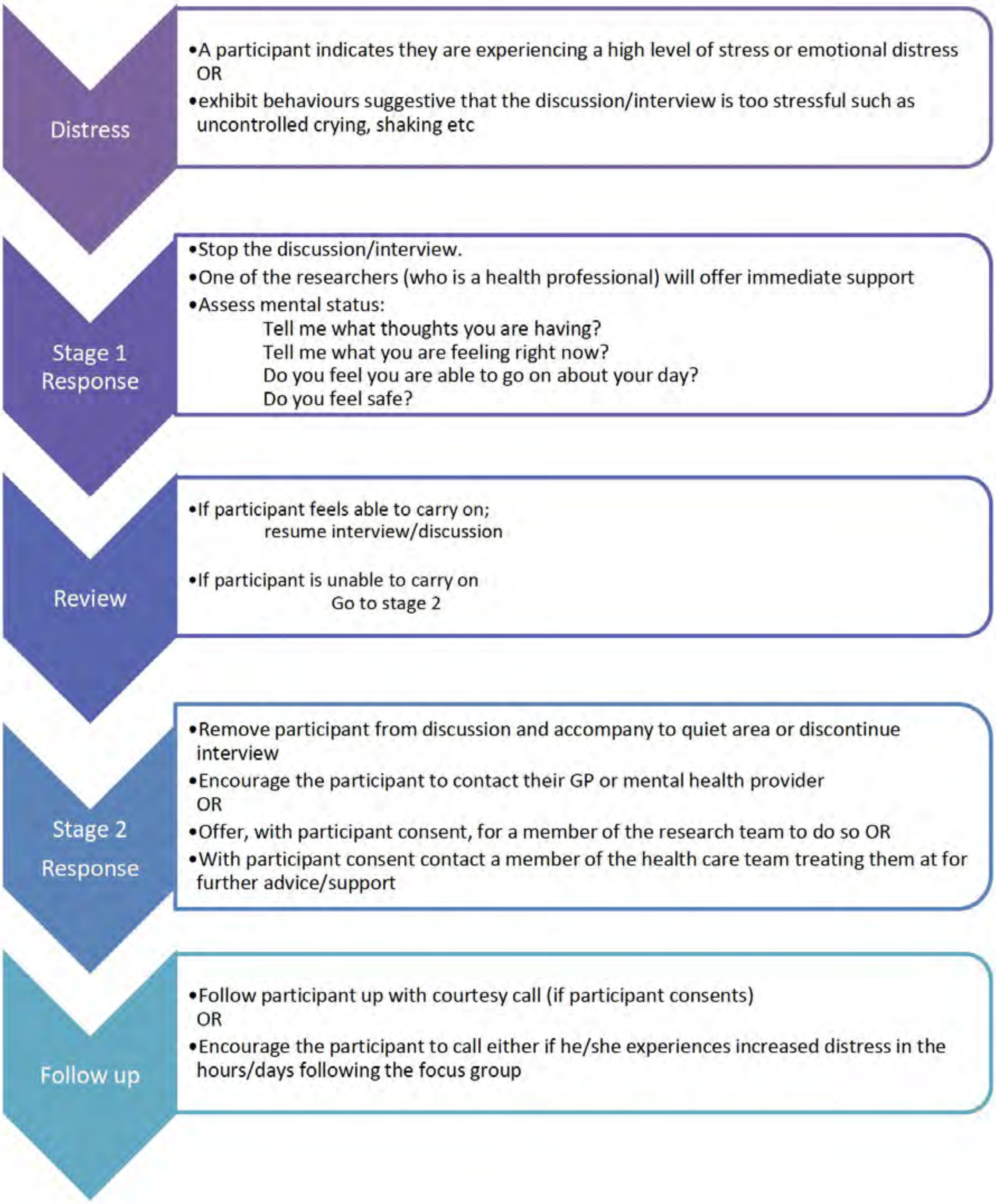
Distress Protocol for qualitative data collection

Professor Carol Haigh
&
Gary Witham
Department of Nursing
MMU

Review date 2015

Distress Protocol 1: The protocol for managing distress in the context of a research focus group /interview

(Modified from : Draucker C B, Martsolf D S and Poole C (2009) Developing Distress Protocols for research on Sensitive Topics. *Archives of Psychiatric Nursing* 23 (5) pp 343-350)



Distress

- A participant indicates they are experiencing a high level of stress or emotional distress
  OR
- exhibit behaviours suggestive that the discussion/interview is too stressful such as uncontrolled crying, shaking etc

Stage 1 Response

- Stop the discussion/interview.
- One of the researchers (who is a health professional) will offer immediate support
- Assess mental status:
    Tell me what thoughts you are having?
    Tell me what you are feeling right now?
    Do you feel you are able to go on about your day?
    Do you feel safe?

Review

- If participant feels able to carry on;
    resume interview/discussion
- If participant is unable to carry on
    Go to stage 2

Stage 2 Response

- Remove participant from discussion and accompany to quiet area or discontinue interview
- Encourage the participant to contact their GP or mental health provider
  OR
- Offer, with participant consent, for a member of the research team to do so OR
- With participant consent contact a member of the health care team treating them at for further advice/support

Follow up

- Follow participant up with courtesy call (if participant consents)
  OR
- Encourage the participant to call either if he/she experiences increased distress in the hours/days following the focus group

Distress Protocol 2: The protocol for managing distress in the context of a research focus group /interview management
McCosker,H Barnard, A Gerber, R (2001). Undertaking Sensitive Research: Issues and Strategies for Meeting the Safety Needs of All. Forum: Qualitative Social Research, 2(1)

Pre-data collection

- The researcher should consider the potential physical and psychological impact on the researcher of the participants description of life experiences
- The researcher should consider how many interviews could be undertaken in a week
- The researcher should be aware of the potential for emotional exhaustion

Data collection stage

- If the topic is potentially sensitive/distressing data collection to be undertaken by two members of the research team
- regular scheduled debriefing sessions with a named member of the research team
- may be encouraged to journal their thoughts and feelings which may then become part of fieldwork notes in some research approaches

Analysis

- is alerted prior to transcription review of potentially "challenging" or "difficult" interviews
- has regular scheduled debriefing sessions with a named member of the research team

Follow up

- Encourage the researcher to access a research mentor if he/she experiences increased distress in the hours/days following transcription

Distress Protocol 3: The protocol for managing distress in the context of a research focus group /interview transcription

(Gregory, D Russell, C Phillips, L (1997). Beyond textual perfection: transcribers as vulnerable persons. Qualitative Health Research, 7(2), 294-300.)

Pre-data collection

- The transcriber should be considered in any research proposal, with a clear indication of how this person will be provided with a "safe" working environment while also maintaining the "quality" of the research

ethical review stage

- be included in the ethical clearance process
- is informed of the nature of the research and the type of data

Pre-transcription

- is alerted prior to the transcription of potentially "challenging" or "difficult" interviews
- has regular scheduled debriefing sessions with a named member of the research team

During Transcription

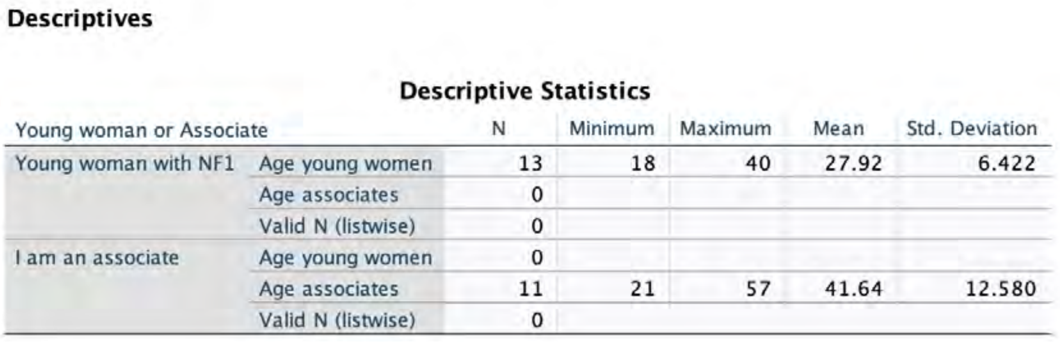
- has prompt access to an appropriate person for crisis counselling
- has a clearly documented termination from the transcription process that includes resolution of personal issues which arose as a consequence of the work
- may be encouraged to journal their thoughts and feelings which may then become part of fieldwork notes in some research approaches

Follow up

- Follow transcriber up with courtesy call (if transcriber consents)
  OR
- Encourage the transcriber to call if he/she experiences increased distress in the hours/days following transcription

Appendix X

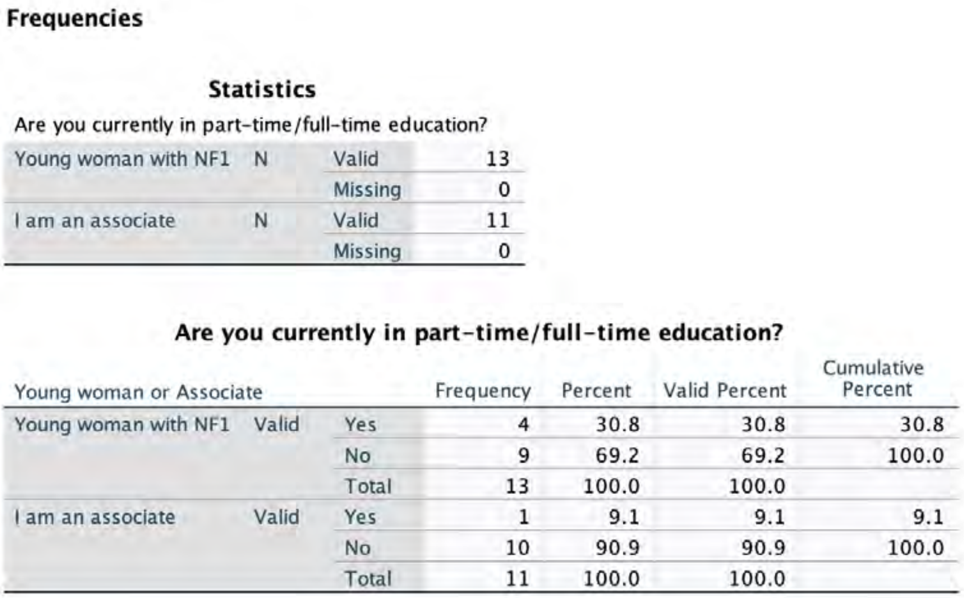
SPSS Descriptive and Inferential Outputs



Descriptives

Descriptive Statistics

Young woman or Associate		N	Minimum	Maximum	Mean	Std. Deviation
Young woman with NF1	Age young women	13	18	40	27.92	6.422
	Age associates	0				
	Valid N (listwise)	0				
I am an associate	Age young women	0				
	Age associates	11	21	57	41.64	12.580
	Valid N (listwise)	0				



Frequencies

Statistics

Are you currently in part-time/full-time education?

Young woman with NF1	N	Valid	13
		Missing	0
I am an associate	N	Valid	11
		Missing	0

Are you currently in part-time/full-time education?

Young woman or Associate			Frequency	Percent	Valid Percent	Cumulative Percent
Young woman with NF1	Valid	Yes	4	30.8	30.8	30.8
		No	9	69.2	69.2	100.0
		Total	13	100.0	100.0	
I am an associate	Valid	Yes	1	9.1	9.1	9.1
		No	10	90.9	90.9	100.0
		Total	11	100.0	100.0	

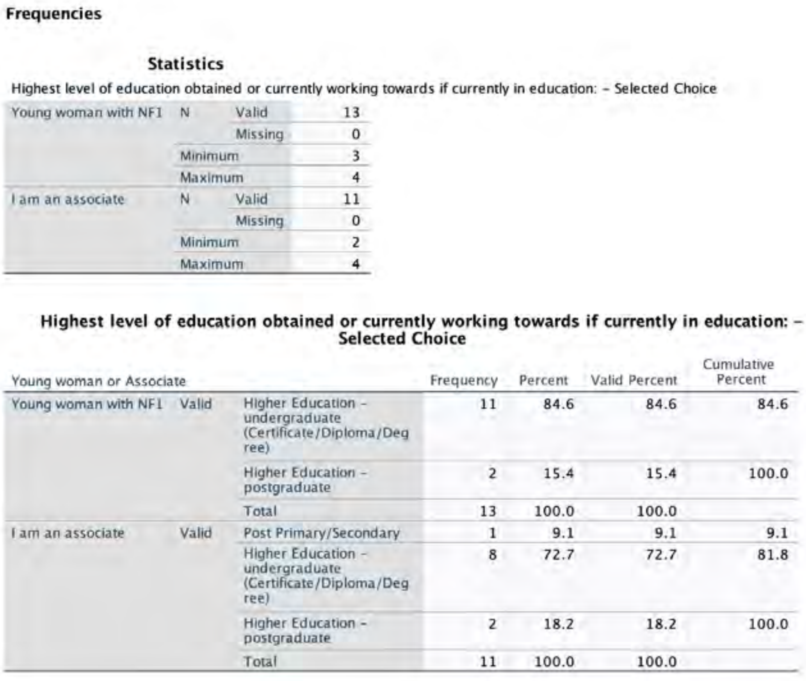
Frequency Table

Age young women

Young woman or Associate			Frequency	Percent	Valid Percent	Cumulative Percent
Young woman with NF1	Valid	18	1	7.7	7.7	7.7
		21	3	23.1	23.1	30.8
		26	1	7.7	7.7	38.5
		28	1	7.7	7.7	46.2
		29	2	15.4	15.4	61.5
		30	1	7.7	7.7	69.2
		31	1	7.7	7.7	76.9
		34	1	7.7	7.7	84.6
		35	1	7.7	7.7	92.3
		40	1	7.7	7.7	100.0
		Total	13	100.0	100.0	
I am an associate	Missing	System	11	100.0		

Age associates

Young woman or Associate			Frequency	Percent	Valid Percent	Cumulative Percent
Young woman with NF1	Missing	System	13	100.0		
I am an associate	Valid	21	1	9.1	9.1	9.1
		27	2	18.2	18.2	27.3
		35	1	9.1	9.1	36.4
		38	1	9.1	9.1	45.5
		46	1	9.1	9.1	54.5
		50	1	9.1	9.1	63.6
		51	1	9.1	9.1	72.7
		53	2	18.2	18.2	90.9
		57	1	9.1	9.1	100.0
		Total	11	100.0	100.0	



Frequencies

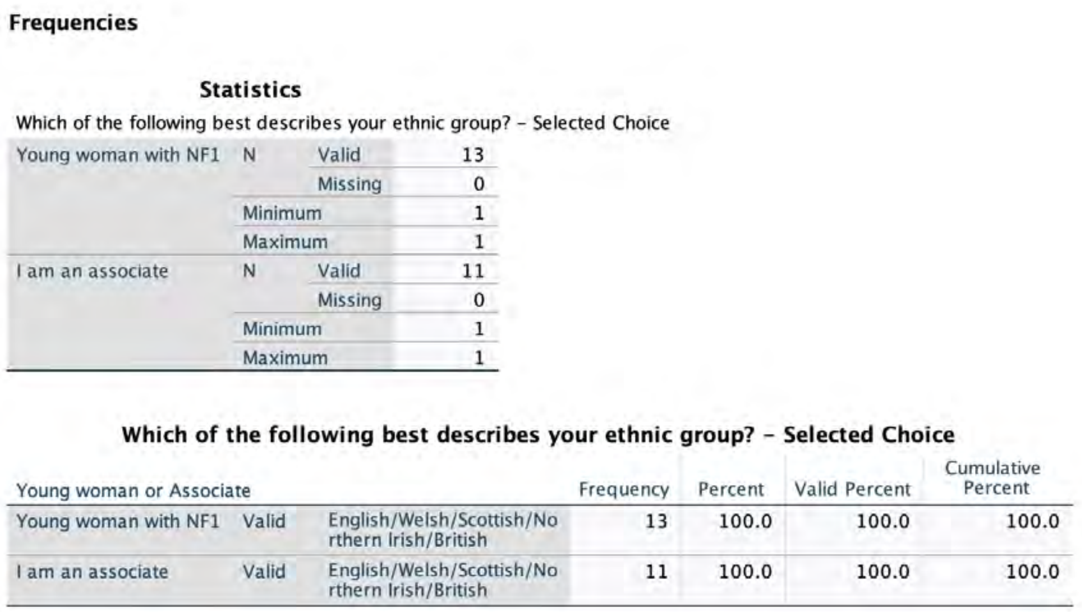
Statistics

Highest level of education obtained or currently working towards if currently in education: - Selected Choice

Young woman with NF1	N	Valid	13
		Missing	0
	Minimum		3
	Maximum		4
I am an associate	N	Valid	11
		Missing	0
	Minimum		2
	Maximum		4

Highest level of education obtained or currently working towards if currently in education: - Selected Choice

Young woman or Associate			Frequency	Percent	Valid Percent	Cumulative Percent
Young woman with NF1	Valid	Higher Education - undergraduate (Certificate/Diploma/Degree)	11	84.6	84.6	84.6
		Higher Education - postgraduate	2	15.4	15.4	100.0
		Total	13	100.0	100.0	
I am an associate	Valid	Post Primary/Secondary	1	9.1	9.1	9.1
		Higher Education - undergraduate (Certificate/Diploma/Degree)	8	72.7	72.7	81.8
		Higher Education - postgraduate	2	18.2	18.2	100.0
		Total	11	100.0	100.0	



Frequencies

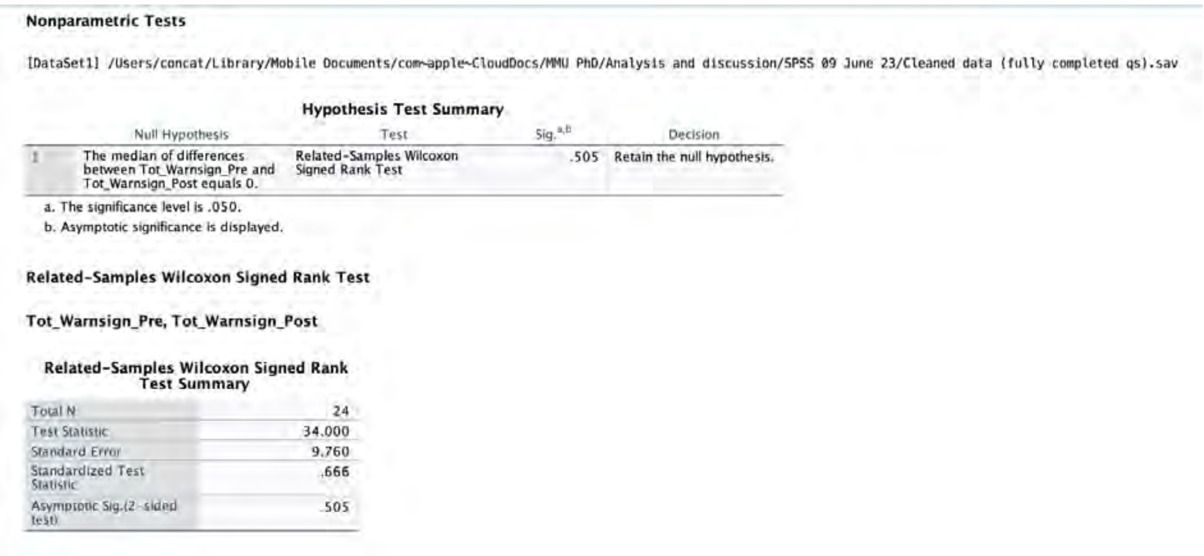
Statistics

Which of the following best describes your ethnic group? - Selected Choice

Young woman with NF1	N	Valid	13
		Missing	0
	Minimum		1
	Maximum		1
I am an associate	N	Valid	11
		Missing	0
	Minimum		1
	Maximum		1

Which of the following best describes your ethnic group? - Selected Choice

Young woman or Associate			Frequency	Percent	Valid Percent	Cumulative Percent
Young woman with NF1	Valid	English/Welsh/Scottish/Northern Irish/British	13	100.0	100.0	100.0
I am an associate	Valid	English/Welsh/Scottish/Northern Irish/British	11	100.0	100.0	100.0



Nonparametric Tests

```
[DataSet1] /Users/concat/Library/Mobile Documents/com~apple~CloudDocs/MMU PhD/Analysis and discussion/SPSS 09 June 23/Cleaned data (fully completed qs).sav
```

Hypothesis Test Summary

	Null Hypothesis	Test	Sig.[a,b]	Decision
1	The median of differences between Tot_Warnsign_Pre and Tot_Warnsign_Post equals 0.	Related-Samples Wilcoxon Signed Rank Test	.505	Retain the null hypothesis.

a. The significance level is .050.

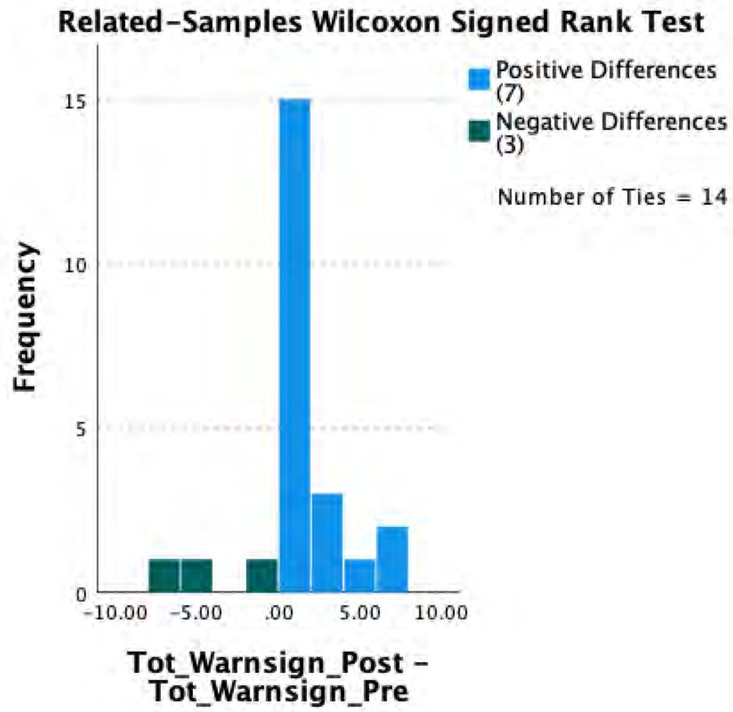
b. Asymptotic significance is displayed.

Related-Samples Wilcoxon Signed Rank Test

Tot_Warnsign_Pre, Tot_Warnsign_Post

Related-Samples Wilcoxon Signed Rank Test Summary

Total N	24
Test Statistic	34.000
Standard Error	9.760
Standardized Test Statistic	.666
Asymptotic Sig.(2-sided test)	.505


Related-Samples Wilcoxon Signed Rank Test
Positive Differences (7)
Negative Differences (3)
Number of Ties = 14
Frequency
15
10
5
0
-10.00
-5.00
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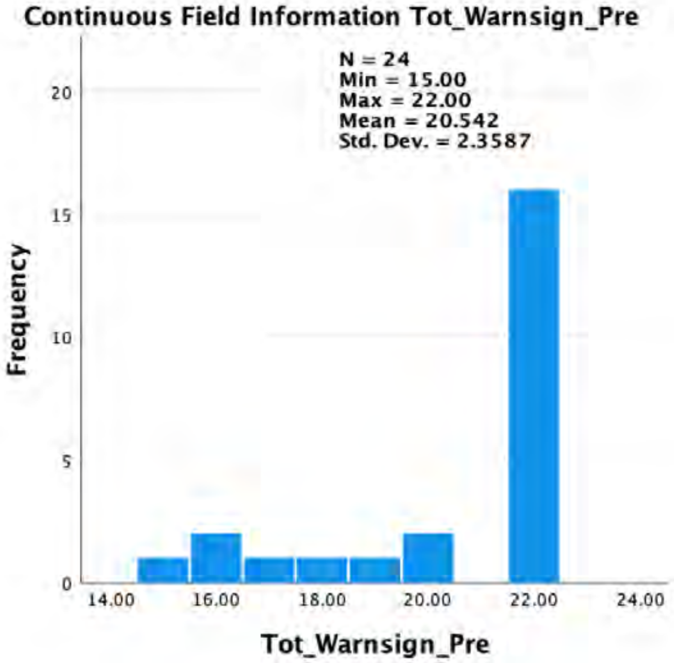
10.00
Tot_Warnsign_Post - Tot_Warnsign_Pre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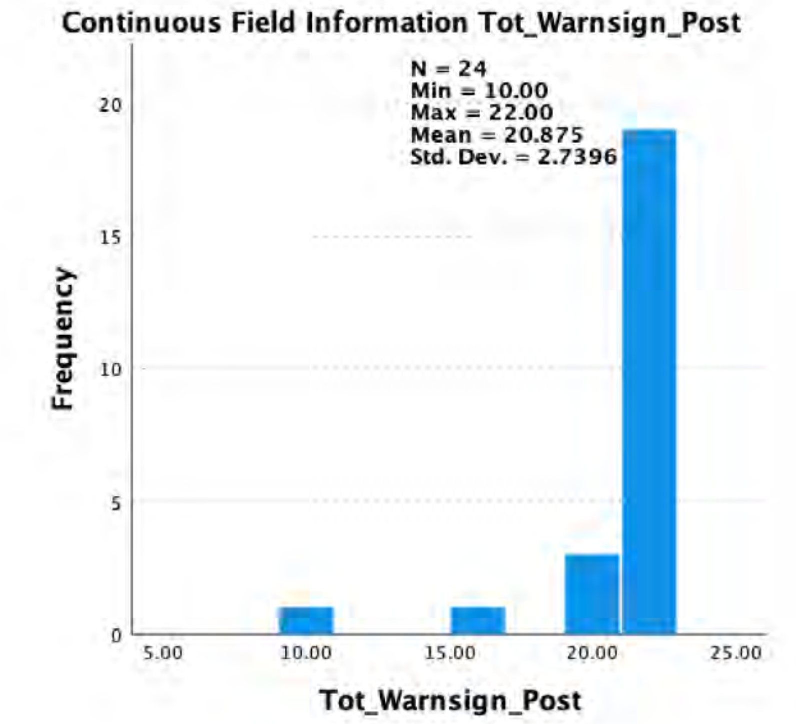
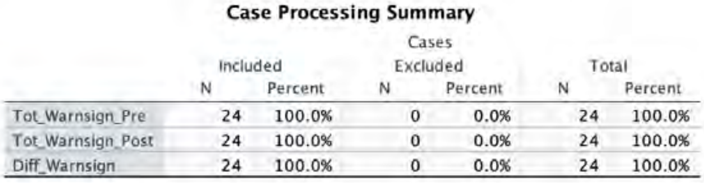


Means



Case Processing Summary

	Cases					
	Included		Excluded		Total	
	N	Percent	N	Percent	N	Percent
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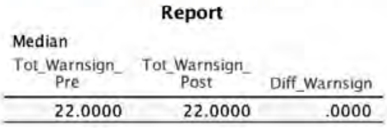
Tot_Warnsign_Post	24	100.0%	0	0.0%	24	100.0%
Diff_Warnsign	24	100.0%	0	0.0%	24	100.0%

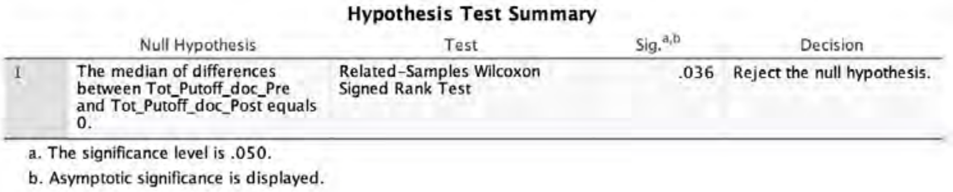


Report

Median

Tot_Warnsign_Pre	Tot_Warnsign_Post	Diff_Warnsign
22.0000	22.0000	.0000

Nonparametric Tests



Hypothesis Test Summary

	Null Hypothesis	Test	Sig.^{a,b}	Decision
1	The median of differences between Tot_Putoff_doc_Pre and Tot_Putoff_doc_Post equals 0.	Related-Samples Wilcoxon Signed Rank Test	.036	Reject the null hypothesis.

a. The significance level is .050.

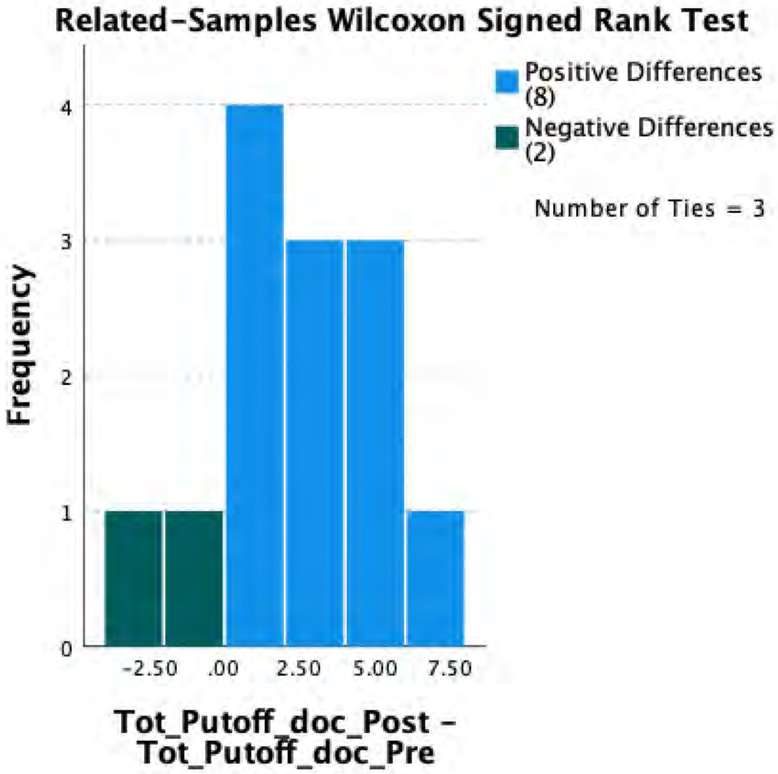
b. Asymptotic significance is displayed.

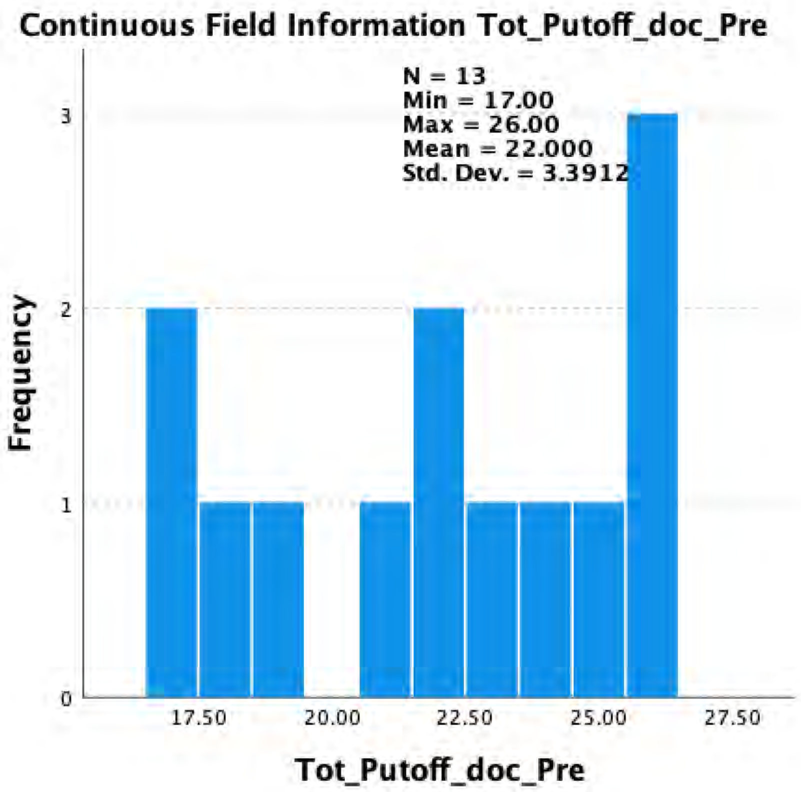
Related-Samples Wilcoxon Signed Rank Test

Tot_Putoff_doc_Pre, Tot_Putoff_doc_Post

Related-Samples Wilcoxon Signed Rank Test Summary

Total N	13
Test Statistic	48.000
Standard Error	9.766
Standardized Test Statistic	2.099
Asymptotic Sig.(2-sided test)	.036

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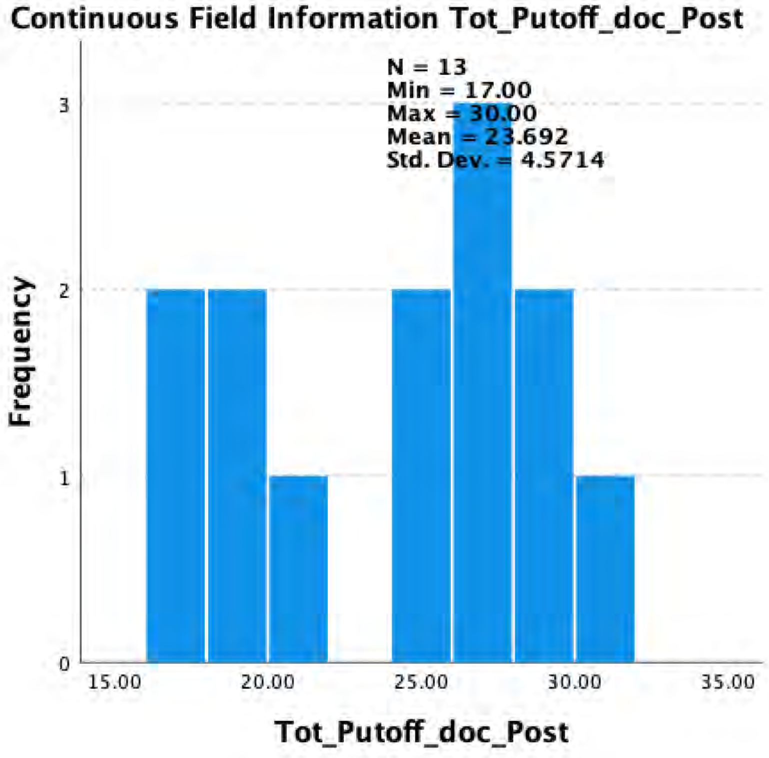
27.50
Tot_Putoff_doc_Pre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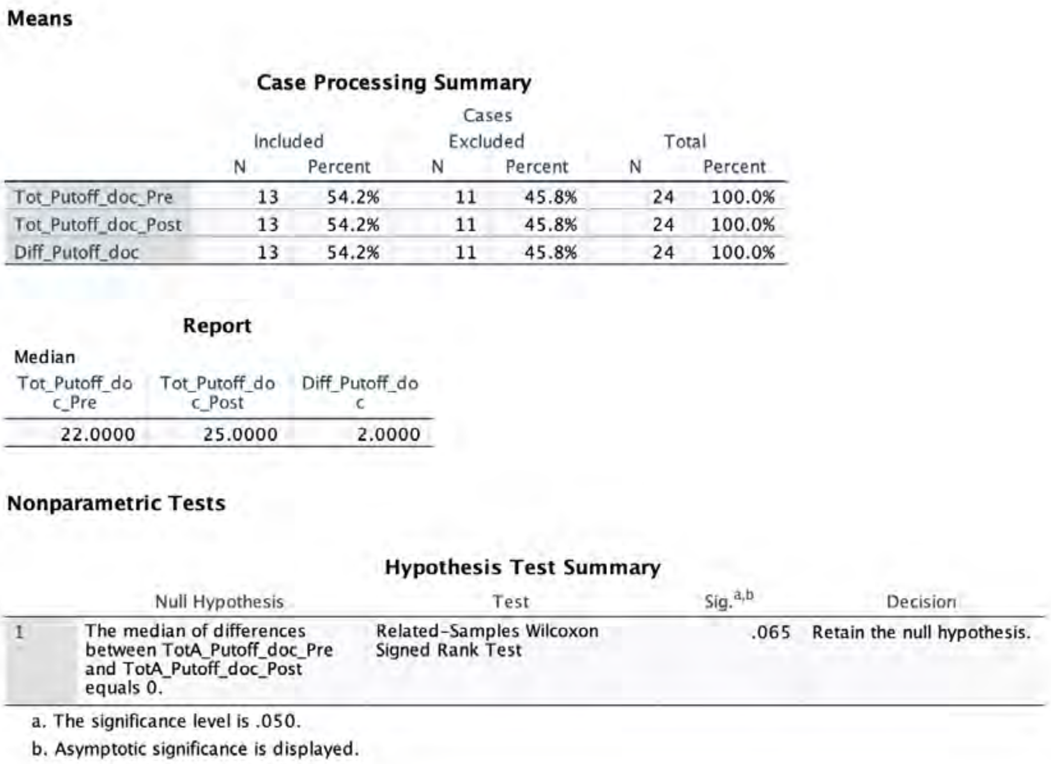


Means

Case Processing Summary

	Cases					
	Included		Excluded		Total	
	N	Percent	N	Percent	N	Percent
Tot_Putoff_doc_Pre	13	54.2%	11	45.8%	24	100.0%
Tot_Putoff_doc_Post	13	54.2%	11	45.8%	24	100.0%
Diff_Putoff_doc	13	54.2%	11	45.8%	24	100.0%

Report

Median

Tot_Putoff_doc_Pre	Tot_Putoff_doc_Post	Diff_Putoff_doc
22.0000	25.0000	2.0000

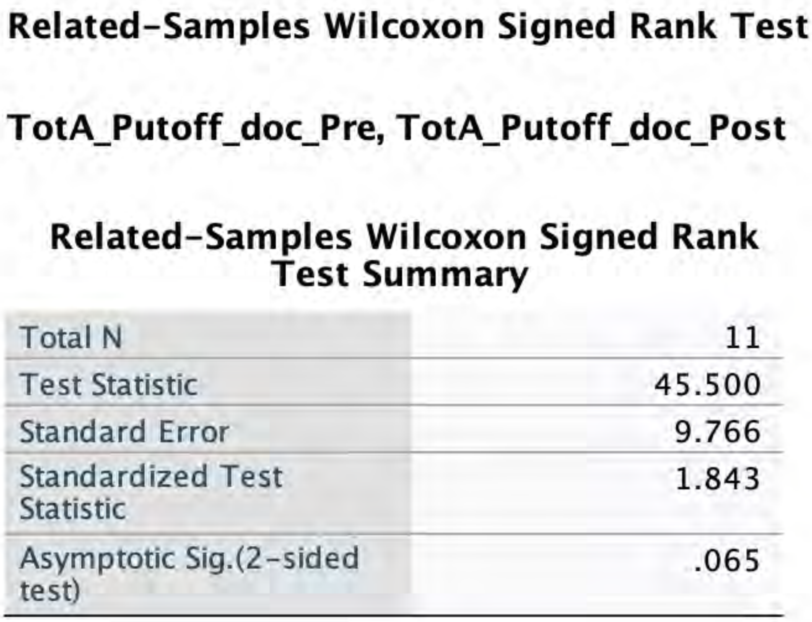
Nonparametric Tests

Hypothesis Test Summary

	Null Hypothesis	Test	Sig.^{a,b}	Decision
1	The median of differences between TotA_Putoff_doc_Pre and TotA_Putoff_doc_Post equals 0.	Related-Samples Wilcoxon Signed Rank Test	.065	Retain the null hypothesis.

a. The significance level is .050.

b. Asymptotic significance is displayed.

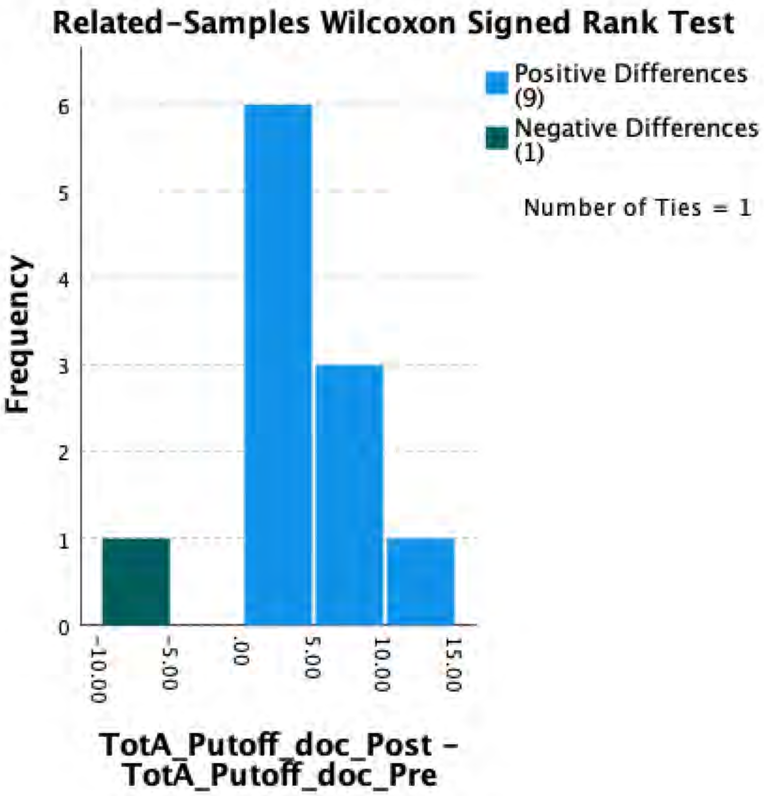


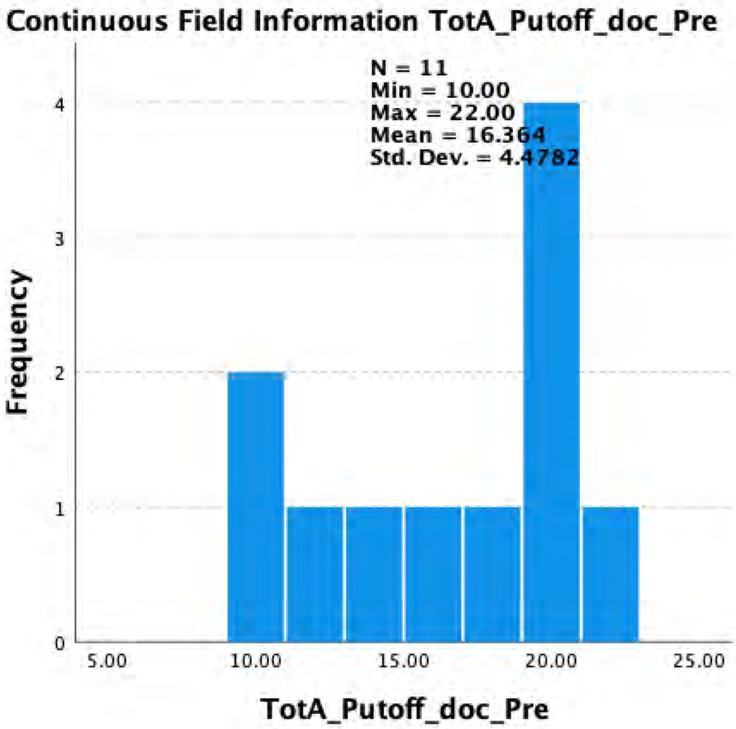
Related-Samples Wilcoxon Signed Rank Test

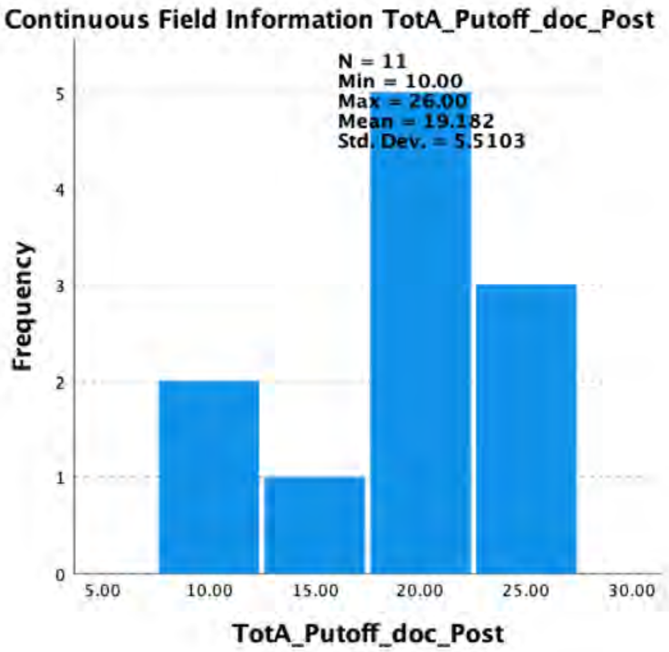
TotA_Putoff_doc_Pre, TotA_Putoff_doc_Post

Related-Samples Wilcoxon Signed Rank Test Summary

Total N	11
Test Statistic	45.500
Standard Error	9.766
Standardized Test Statistic	1.843
Asymptotic Sig.(2-sided test)	.065


Related-Samples Wilcoxon Signed Rank Test
Positive Differences (9)
Negative Differences (1)
Number of Ties = 1
Frequency
0
1
2
3
4
5
6
-10.00
-5.00
.00
5.00
10.00
15.00
TotA_Putoff_doc_Post - TotA_Putoff_doc_Pre


Continuous Field Information TotA_Putoff_doc_Pre
N = 11
Min = 10.00
Max = 22.00
Mean = 16.364
Std. Dev. = 4.4782
Frequency
0
1
2
3
4
5.00
10.00
15.00
20.00
25.00
TotA_Putoff_doc_Pre



Means

Case Processing Summary

	Cases					
	Included		Excluded		Total	
	N	Percent	N	Percent	N	Percent
TotA_Putoff_doc_Pre	11	45.8%	13	54.2%	24	100.0%
TotA_Putoff_doc_Post	11	45.8%	13	54.2%	24	100.0%
DiffA_Putoff_doc	11	45.8%	13	54.2%	24	100.0%

Report

Median

TotA_Putoff_doc_Pre	TotA_Putoff_doc_Post	DiffA_Putoff_doc
18.0000	20.0000	4.0000

Nonparametric Tests

Hypothesis Test Summary

	Null Hypothesis	Test	Sig.^{a,b}	Decision
1	The median of differences between How often do you check your breasts? Please select one box only a nd From watching the animatio n, how often do you think you wi ll check your breasts n ow? Please select one box only equ	Related-Samples Wilcoxon Signed Rank Test	.139	Retain the null hypothesis.

a. The significance level is .050.

b. Asymptotic significance is displayed.

Related-Samples Wilcoxon Signed Rank Test

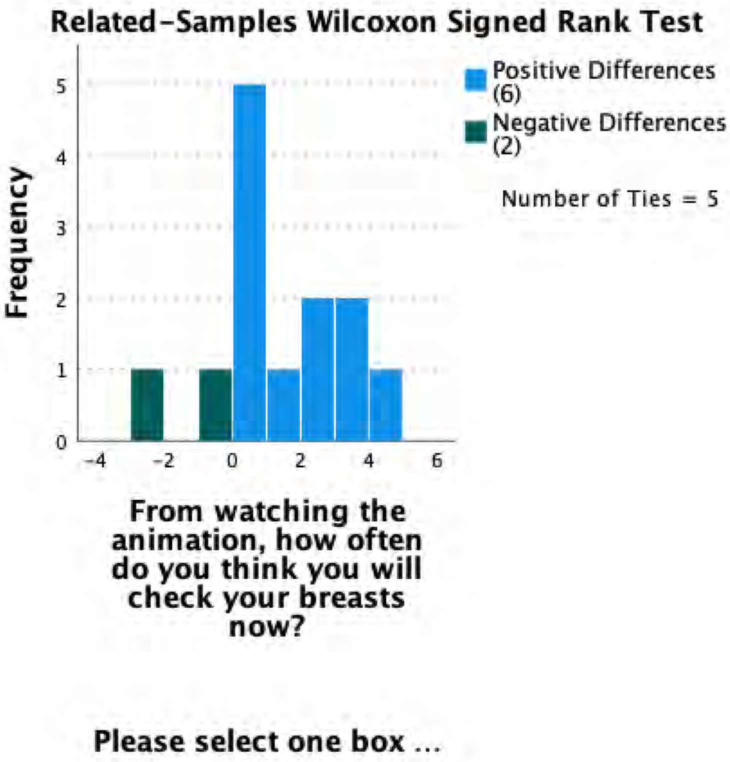
How often do you check your breasts?

Please select one box only, From watching the animation, how often do you think you will check your breasts now?

Please select one box only

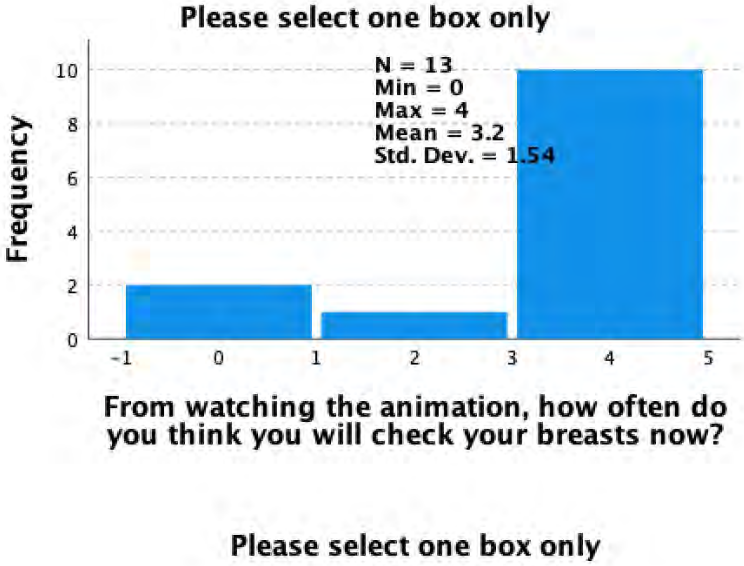
Related-Samples Wilcoxon Signed Rank Test Summary

Total N	13
Test Statistic	28.500
Standard Error	7.089
Standardized Test Statistic	1.481
Asymptotic Sig.(2-sided test)	.139



Continuous Field Information How often do you check your breasts?

Continuous Field Information From watching the animation, how often do you think you will check your breasts now?



Means

Case Processing Summary

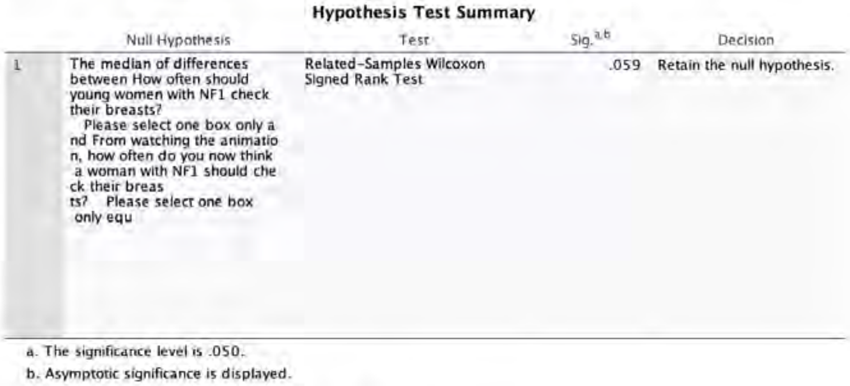
	Cases					
	Included		Excluded		Total	
	N	Percent	N	Percent	N	Percent
How often do you check your breasts? Please select one b ox o	13	54.2%	11	45.8%	24	100.0%
From watching the animation, how often do you think you will check your breasts now? Please select one b ox o	13	54.2%	11	45.8%	24	100.0%
Diff_breastcheck_freq	13	54.2%	11	45.8%	24	100.0%

Report

Median

How often do you check your breasts? Please sele ct one box o	From watching the animation, how often do you think you will check your breasts now? Please sele ct one box o	Diff_breastche ck_freq
2.00	4.00	.0000

Nonparametric Tests



Hypothesis Test Summary

	Null Hypothesis	Test	Sig.[a,b]	Decision
1	The median of differences between How often should young women with NF1 check their breasts? Please select one box only a nd From watching the animatio n, how often do you now think a woman with NF1 should che ck their breas ts? Please select one box only equ	Related-Samples Wilcoxon Signed Rank Test	.059	Retain the null hypothesis.

a. The significance level is .050.

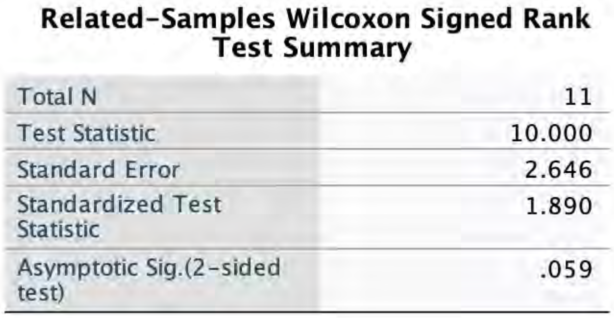
b. Asymptotic significance is displayed.

Related-Samples Wilcoxon Signed Rank Test

How often should young women with NF1 check their breasts?

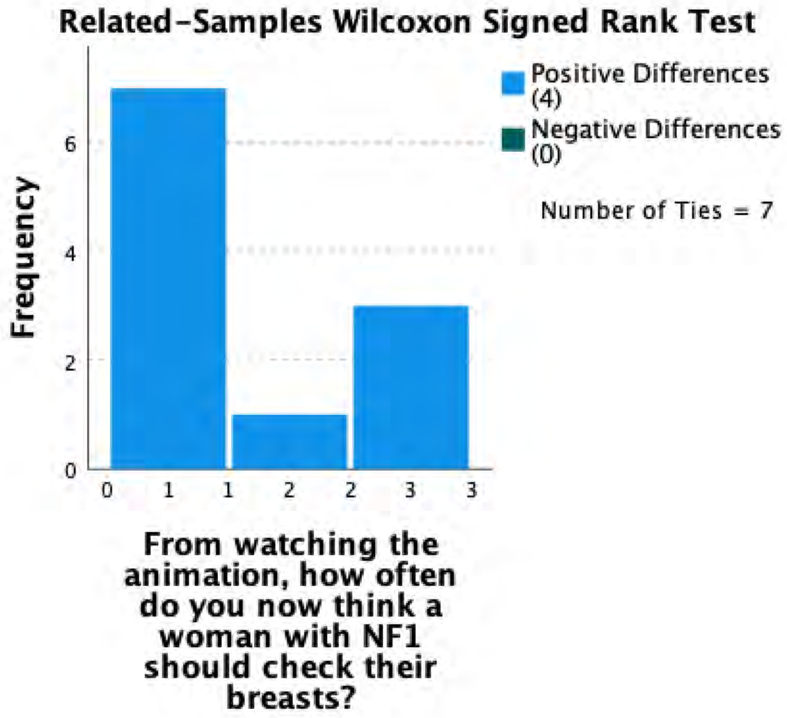
Please select one box only, From watching the animation, how often do you now think a woman with NF1 should check their breasts?

Please select one box only



Related-Samples Wilcoxon Signed Rank Test Summary

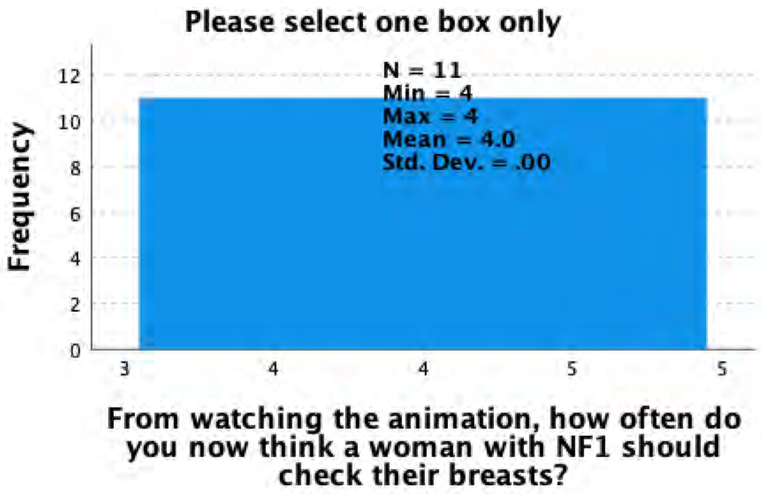
Total N	11
Test Statistic	10.000
Standard Error	2.646
Standardized Test Statistic	1.890
Asymptotic Sig.(2-sided test)	.059

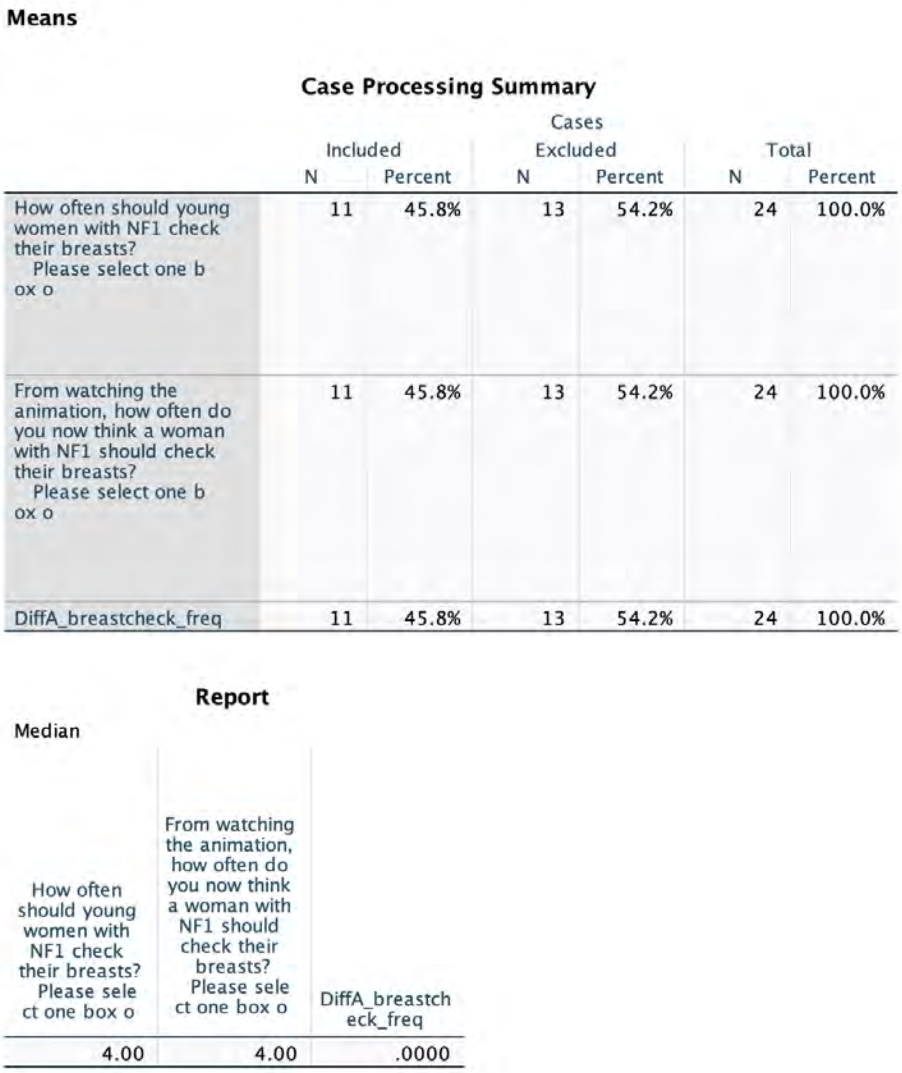


Continuous Field Information How often should young women with NF1 check their breasts?

Please select one box only

Continuous Field Information From watching the animation, how often do you now think a woman with NF1 should check their breasts?





Means

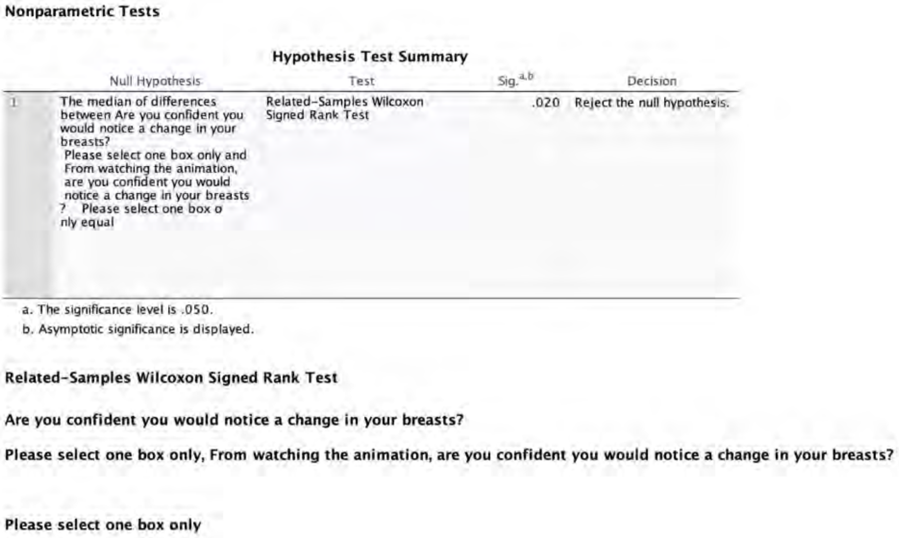
Case Processing Summary

	Cases					
	Included		Excluded		Total	
	N	Percent	N	Percent	N	Percent
How often should young women with NF1 check their breasts? Please select one b ox o	11	45.8%	13	54.2%	24	100.0%
From watching the animation, how often do you now think a woman with NF1 should check their breasts? Please select one b ox o	11	45.8%	13	54.2%	24	100.0%
DiffA_breastcheck_freq	11	45.8%	13	54.2%	24	100.0%

Report

Median

How often should young women with NF1 check their breasts? Please sele ct one box o	From watching the animation, how often do you now think a woman with NF1 should check their breasts? Please sele ct one box o	DiffA_breastch eck_freq
4.00	4.00	.0000



Nonparametric Tests

Hypothesis Test Summary

	Null Hypothesis	Test	Sig.[a,b]	Decision
1	The median of differences between Are you confident you would notice a change in your breasts? Please select one box only and From watching the animation, are you confident you would notice a change in your breasts ? Please select one box o nly equal	Related-Samples Wilcoxon Signed Rank Test	.020	Reject the null hypothesis.

a. The significance level is .050.

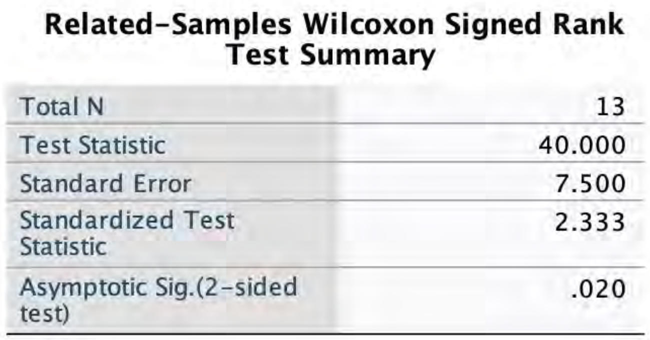
b. Asymptotic significance is displayed.

Related-Samples Wilcoxon Signed Rank Test

Are you confident you would notice a change in your breasts?

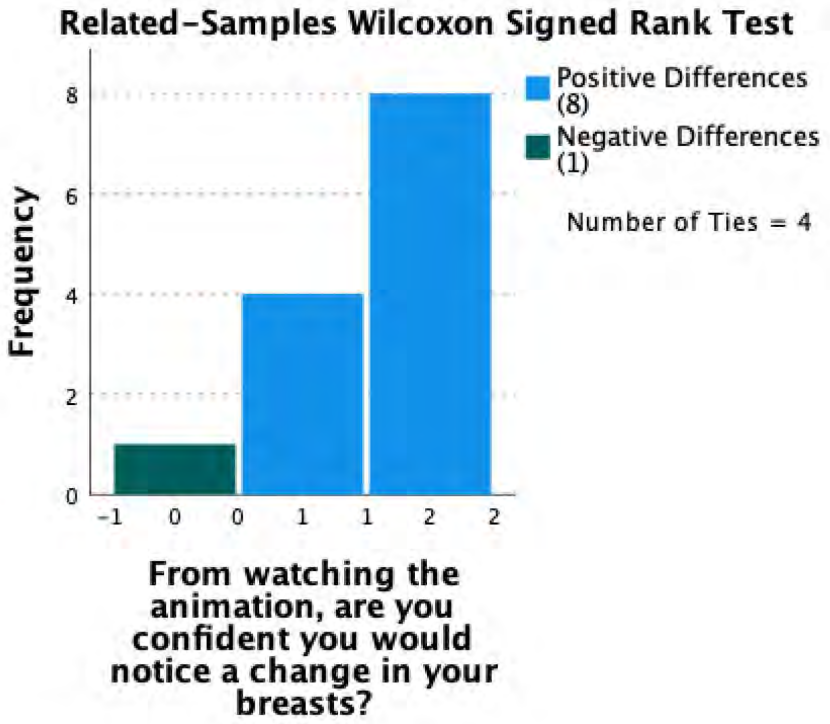
Please select one box only, From watching the animation, are you confident you would notice a change in your breasts?

Please select one box only

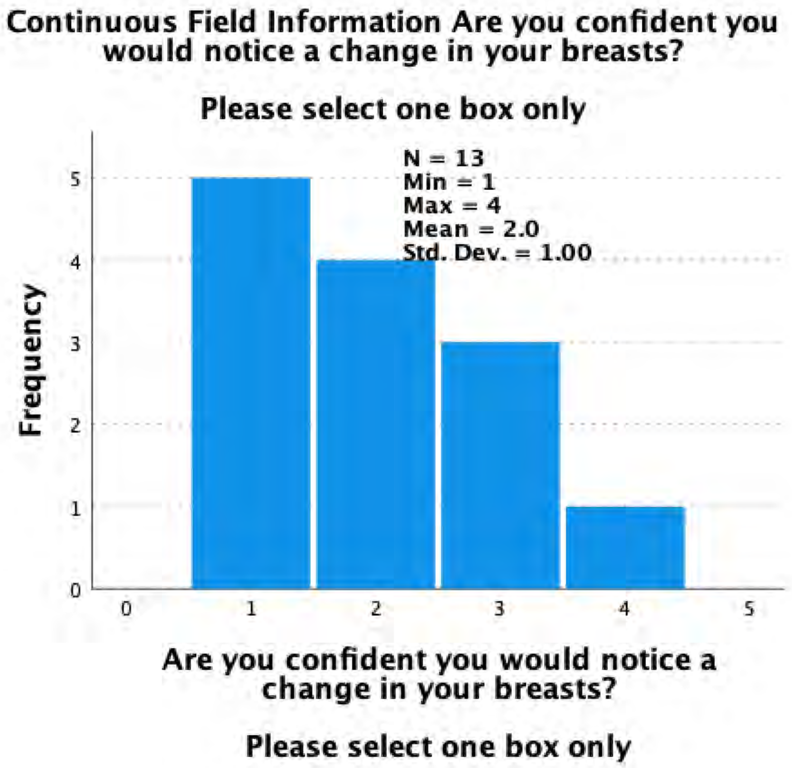


Related-Samples Wilcoxon Signed Rank Test Summary

Total N	13
Test Statistic	40.000
Standard Error	7.500
Standardized Test Statistic	2.333
Asymptotic Sig.(2-sided test)	.020

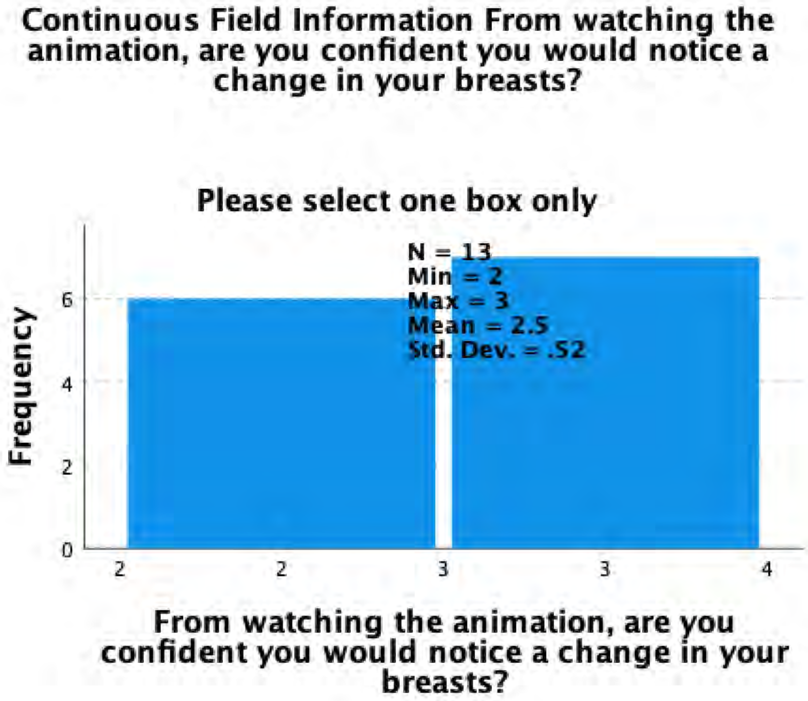


Please select one box ...



Continuous Field Information Are you confident you would notice a change in your breasts?

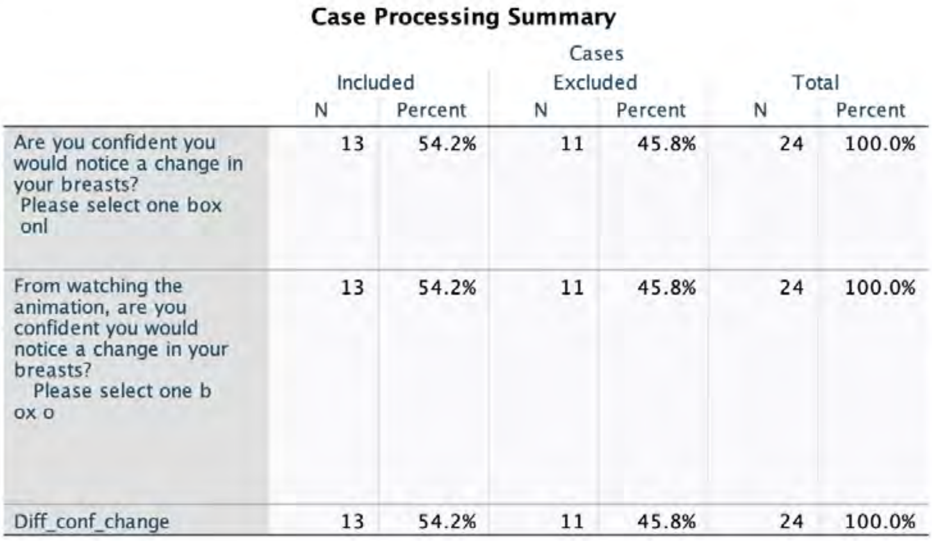
Please select one box only



Continuous Field Information From watching the animation, are you confident you would notice a change in your breasts?

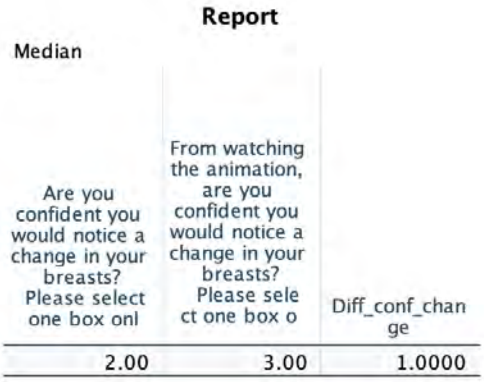
Please select one box only

Means



Case Processing Summary

	Cases					
	Included		Excluded		Total	
	N	Percent	N	Percent	N	Percent
Are you confident you would notice a change in your breasts? Please select one box onl	13	54.2%	11	45.8%	24	100.0%
From watching the animation, are you confident you would notice a change in your breasts? Please select one b ox o	13	54.2%	11	45.8%	24	100.0%
Diff_conf_change	13	54.2%	11	45.8%	24	100.0%

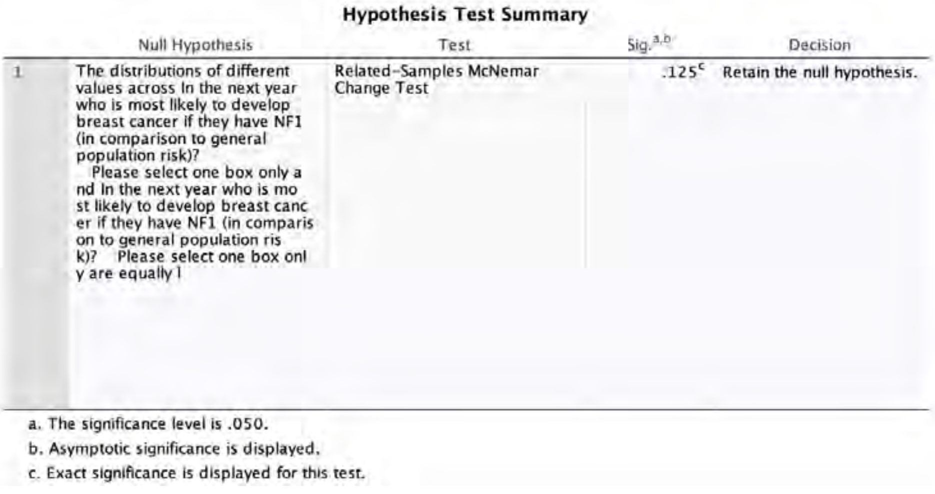


Report

Median

Are you confident you would notice a change in your breasts? Please select one box onl	From watching the animation, are you confident you would notice a change in your breasts? Please sele ct one box o	Diff_conf_chan ge
2.00	3.00	1.0000

Nonparametric Tests



Hypothesis Test Summary

	Null Hypothesis	Test	Sig.[a,b]	Decision
1	The distributions of different values across In the next year who is most likely to develop breast cancer if they have NF1 (in comparison to general population risk)? Please select one box only a nd In the next year who is mo st likely to develop breast canc er if they have NF1 (in comparis on to general population ris k)? Please select one box onl y are equally l	Related-Samples McNemar Change Test	.125[c]	Retain the null hypothesis.

a. The significance level is .050.

b. Asymptotic significance is displayed.

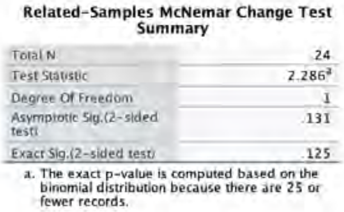
c. Exact significance is displayed for this test.

Related-Samples McNemar Change Test

In the next year who is most likely to develop breast cancer if they have NF1 (in comparison to general population risk)?

Please select one box only, In the next year who is most likely to develop breast cancer if they have NF1 (in comparison to general population risk)?

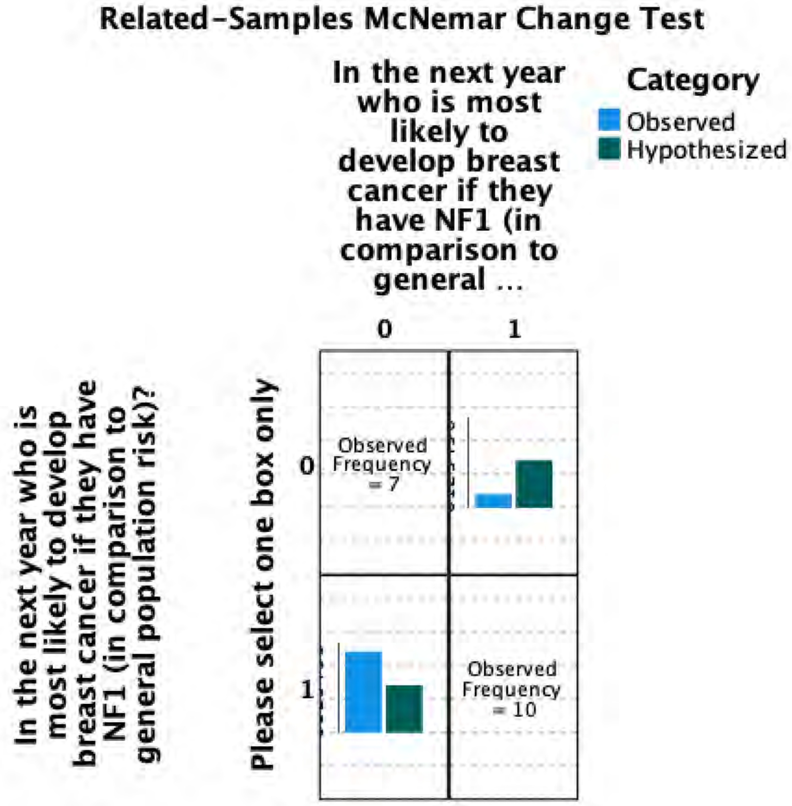
Please select one box only



Related-Samples McNemar Change Test Summary

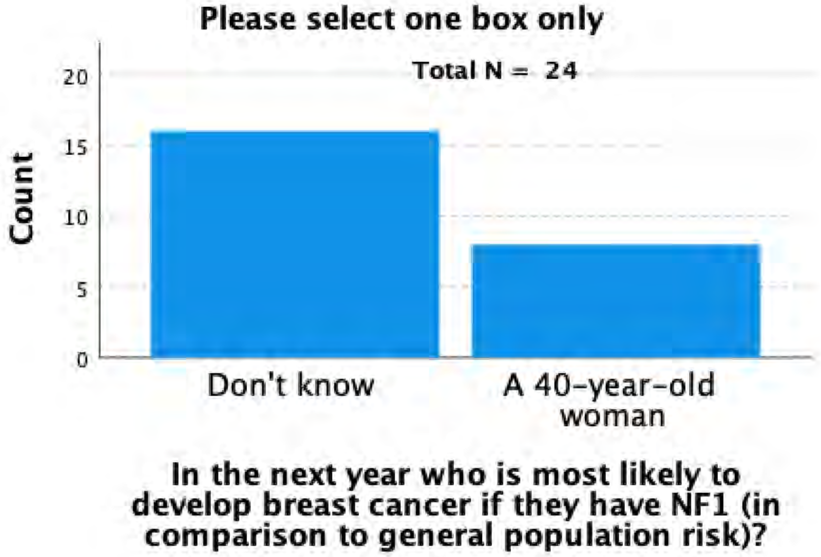
Total N	24
Test Statistic	2.286[a]
Degree Of Freedom	1
Asymptotic Sig.(2-sided test)	.131
Exact Sig.(2-sided test)	.125

a. The exact p-value is computed based on the binomial distribution because there are 25 or fewer records.



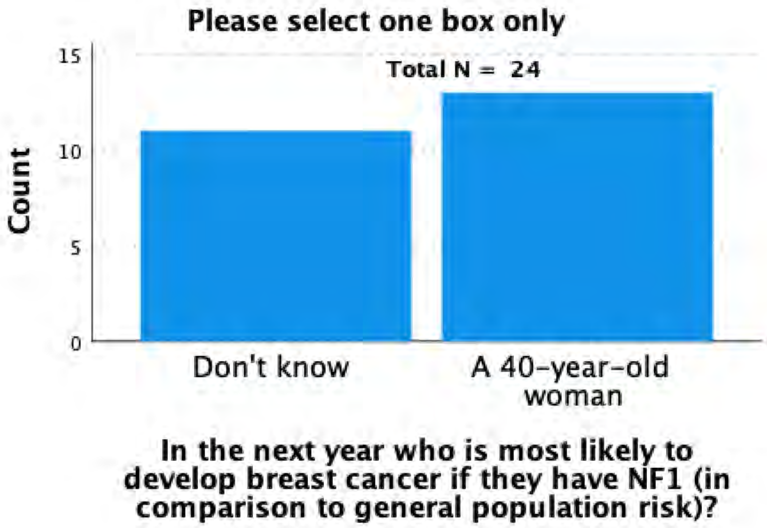
Related-Samples McNemar Change Test

Categorical Field Information In the next year who is most likely to develop breast cancer if they have NF1 (in comparison to general population risk)?

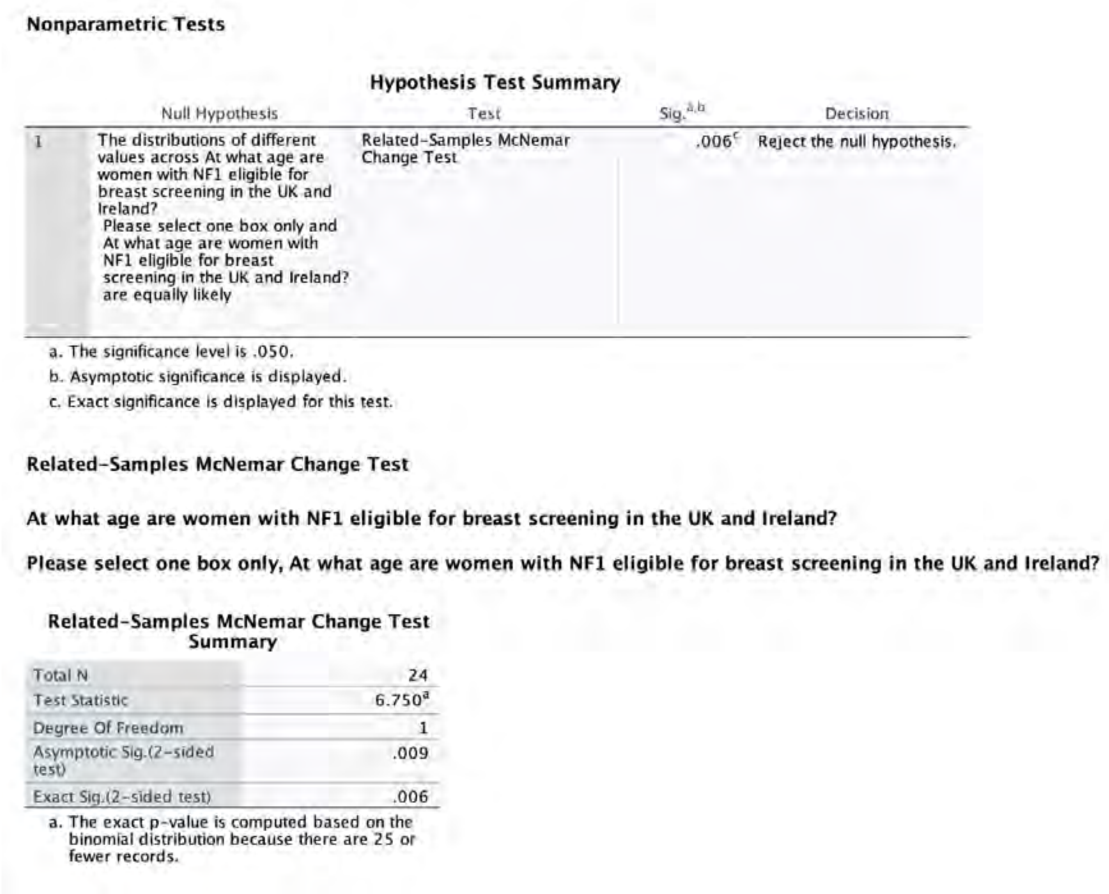


Please note that 'Don't know' in McNemar tests is exported as the SPSS label, but denotes total for all incorrect answers.

Categorical Field Information In the next year who is most likely to develop breast cancer if they have NF1 (in comparison to general population risk)?



Please note that 'Don't know' in McNemar tests is exported as the SPSS label, but denotes total for all incorrect answers.



Nonparametric Tests

Hypothesis Test Summary

	Null Hypothesis	Test	Sig.[a,b]	Decision
1	The distributions of different values across At what age are women with NF1 eligible for breast screening in the UK and Ireland? Please select one box only and At what age are women with NF1 eligible for breast screening in the UK and Ireland? are equally likely	Related-Samples McNemar Change Test	.006[c]	Reject the null hypothesis.

a. The significance level is .050.

b. Asymptotic significance is displayed.

c. Exact significance is displayed for this test.

Related-Samples McNemar Change Test

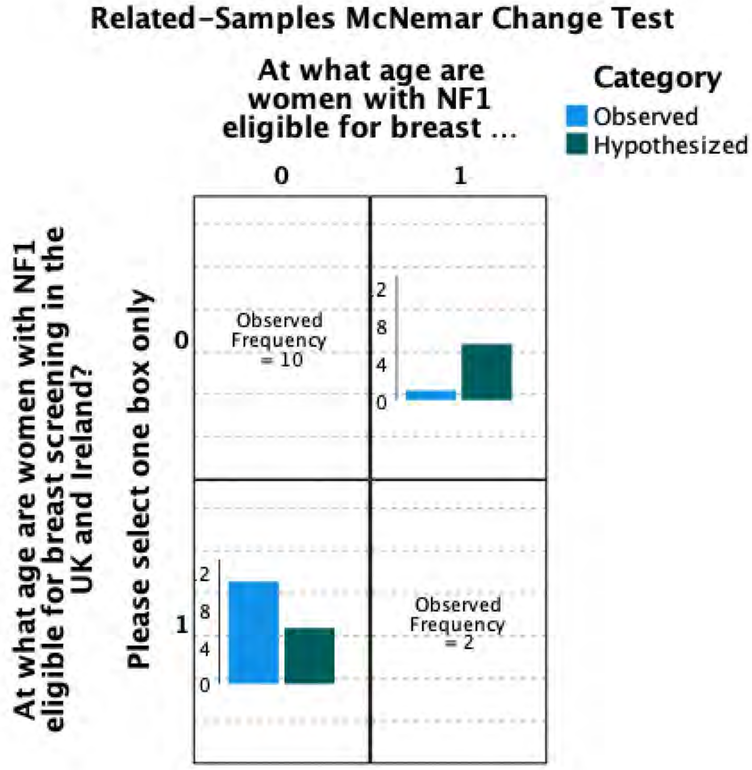
At what age are women with NF1 eligible for breast screening in the UK and Ireland?

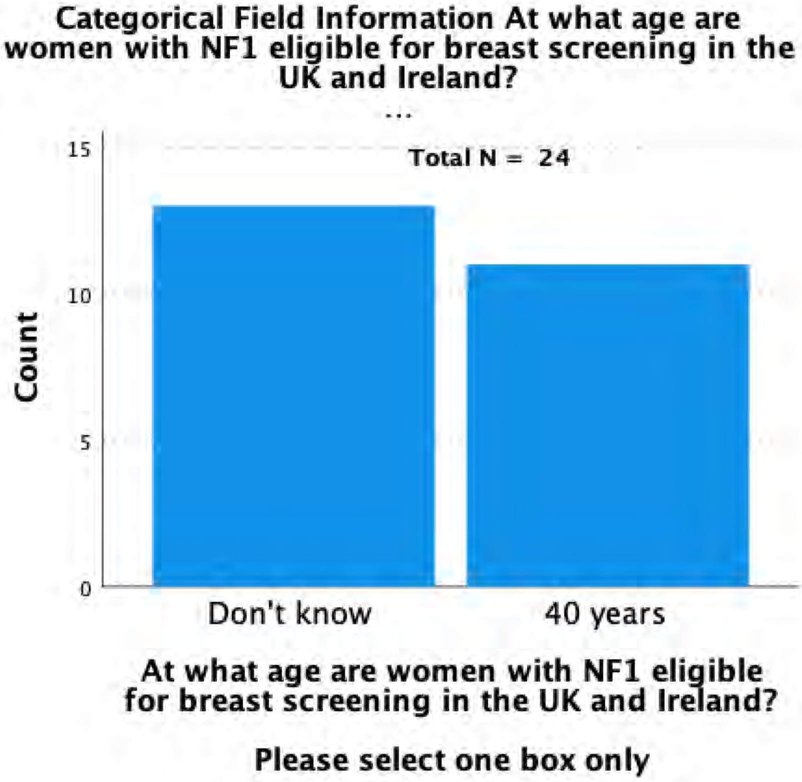
Please select one box only, At what age are women with NF1 eligible for breast screening in the UK and Ireland?

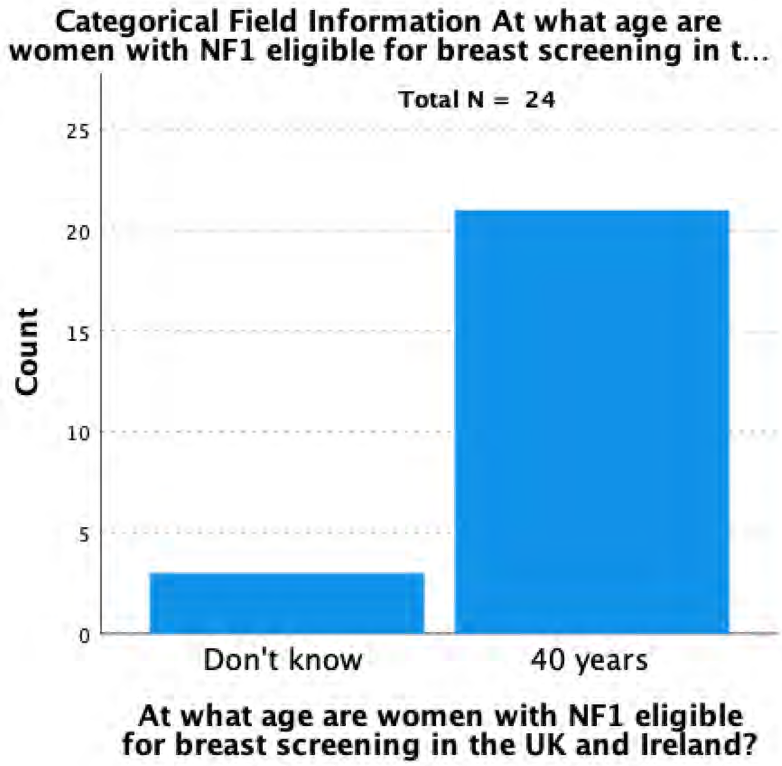
Related-Samples McNemar Change Test Summary

Total N	24
Test Statistic	6.750[a]
Degree Of Freedom	1
Asymptotic Sig.(2-sided test)	.009
Exact Sig.(2-sided test)	.006

a. The exact p-value is computed based on the binomial distribution because there are 25 or fewer records.


Related-Samples McNemar Change Test
At what age are women with NF1 eligible for breast ...
Category
Observed
Hypothesized
0
1
At what age are women with NF1 eligible for breast screening in the UK and Ireland?
Please select one box only
0
1
Observed Frequency = 10
2
8
4
0
2
8
4
0
Observed Frequency = 2


Categorical Field Information At what age are women with NF1 eligible for breast screening in the UK and Ireland?
...
Total N = 24
15
10
5
0
Count
Don't know
40 years
At what age are women with NF1 eligible for breast screening in the UK and Ireland?
Please select one box only



Appendix Y

Reflexive Thematic Analysis on Own Reflexive/Familiarisation Accounts

Mavis (A)	
Precocious puberty a surprise Limitations of knowledge Curiosity within breast cancer links	Mavis is very knowledgeable about NF1. She listed off all that she knew about NF1. I was familiar with all, except for precocious puberty. I went away and researched this straight after. I was really surprised to learn that this is not uncommon among children with NF1, particularly those that may have optic gliomas or other tumours in the brain, in particular. This is where puberty signs present themselves at a much younger age. For girls it's before 8, and for boys it’s before 9. So, getting a period and having breasts develop would be the signs in

	young girls. This is really important and particularly pertinent within this research.
Thanking a parent	Thank you Mavis for mentioning this! It’s already known that women are at
The mother connection	increased risk of developing breast cancer if they started their periods earlier. The
Experience is ‘the mother’ of wisdom	earlier the period, the higher the risk of breast cancer. So, if precocious puberty is not uncommon in children with NF1, then this would also play into the already increased risk of developing breast cancer at a younger age. Wow, I’ve read A LOT and I never came across this, but a bit of researching confirms that yep, it’s an
Importance of talking to participants	important consideration to apply within this research. So, breast cancer awareness probably becomes that bit more important for parents and guardians in particular with their daughters. It’s important to have those conversations in the family, about breast concerns. I know having gone through cancer myself, my kids are certainly that bit more aware, more open
The ‘parent hat’	to talking about their bodies. I’ve been advised that my daughter should start
Talking bodies with kids	attending breast scans from 25 years, most probably ultrasounds due to the younger
Effecting children	age. I was very open with my own experience of having gone through breast
The mother connection	cancer and they’ve heard me being interviewed about breast cancer awareness

Experience is ‘the mother’ of wisdom Kids as advocates Proud mum Mum bond Creating bonds The mother connection Experience is ‘the mother’ of wisdom	within my patient advocacy and peer support roles. They too have happily been in photos on TV, websites, and in newspapers. I know that’s not everyone’s cup of tea and I respect that, but they are happy to be involved. They have already had helpful and supportive conversations with classmates that have parents or grandparents going through cancer. I’m incredibly proud of them. Mavis is the same with her daughter, and for her the animation really helped in this regard, with talking about breast cancer awareness. I really loved what Mavis said when describing how it has helped. ‘It’s helped me feel more confident in speaking to my daughter about checking, em and also knowing what we should be looking for, em (.) so, and it-, I think that the animation is quite simple to understand em and quite clear and something that we could watch together’. I never had really thought about it in this way, as an education tool for younger individuals, and interestingly and how lovely, as something that could be a shared experience too.
Stopping rumours Getting people talking about the facts	I really love this idea that it can open up a conversation. That’s really what awareness should have, well, in that it is factual stuff and not just opening up some conversation

Making breast cancer awareness personal, to personally make breast cancer awareness	based on rumours of misinformation that can easily be found online!
Goal achieved! PhD is not the ultimate goal Experience changes PhD goals Ripple effect The accidental researcher by experience Turned inside out: the accidental researcher with ‘experience’ Mother/daughter dynamics The mother connection Experience is ‘the mother’ of wisdom Means everything to me	I’m so glad, that no matter what the outcome of this research, this PhD, it sounds like it’s helping raise awareness, helping share people’s experiences, and starting new conversations both at home and further. Ripple effect? Yes! And just to top it all off, I thought it was really lovely, and it made me think of my own relationship with my daughter of all the chats that we have, as Mavis now from watching the animation will, ‘feel more open to talk to my daughter about em, getting checked or talking to me if she’s got any worries em and hopefully having that open conversation that she can then tell me if she’s got any worries as well and we can go from there then, I can help her. This just means everything to me.
Anne	

Me as a mother The mother connection Experience is 'the mother' of wisdom The mother bond The mother connection Experience is 'the mother' of wisdom	I was keen to make sure to check that this was really a suitable time, that I did not mind rescheduling explaining that as a mother myself, this would be entirely understandable, but I also did not mind having a very happy little one there in the background. No, no issues at all. 'Well, you're in charge. Just know you can stop or pause at any point that you want'.
BCA is personal to me! Breast cancer awareness is personal Making things personal may cause ~~offense~~ sense. Making breast cancer awareness personal, to personally make breast cancer awareness	However, as Anne agrees it is important to communicate the message that if you are not happy with something to get it checked out, and therefore 'nipping it in the bud'. This was really an important issue for me to have experienced within the design of this animation, of being able to go and seek help and catch breast cancer early. I know how important that is from my own experience. It makes all the difference. It makes all the difference to those that I love.
Lilly	
The importance of planning Working with researcher imposter syndrome The accidental researcher by experience	Although, I do have my checklist printed out, and my script! I read out exactly what needs to be said for consent. I literally have things highlighted in different colours if I really need to remember them such as 'Press Record!' and then 'Make sure to press STOP and not Pause!', 'ask participant

Turned inside out: The accidental researcher with 'experience' In control Working with researcher imposter syndrome The accidental researcher by experience Turned inside out: The accidental researcher with 'experience'	to pick a pseudonym', and 'start new recording for interview'. After every interview I send each participant a 'thank you' and a debrief sheet. I feel much calmer knowing I have my checklist and consent script. I wonder are researchers with lots of experience just able to rock in and not be awkward and just go for it? If they do, I wonder how long it takes to get to that stage? I'm more relaxed now. Still nervous, but it's not getting in the way.
Highlighting my position of privilege in the medical world My position as outsider My inside-out position Turned inside out: The accidental researcher with 'experience'	From Lilly's interview, it seems that she has had to do quite a bit of travelling to get appointments for different things. She doesn't mind travelling, but it really highlights the potential barriers that some with NF1 face to get seen to for various concerns. It's a common issue over here, particularly like Lily, if you live in a rural area. I know for some of my appointments I had to be in for 7.30am to get a full blood work done before treatment. I could crawl out of bed at 6am, drop my kids up for 6.30 at a friend's house for breakfast and school run, and then head into hospital. No stress there apart from the usual morning traffic.

	There were people coming from all over Ireland to sit for a few hours to get chemo. Some got on a bus after for a journey back home that could take up to 3 hours. The hospital I attended was a 'hi-tech' hospital and was often only one of two or three hospitals in the republic that had the drugs required to treat certain cancers. I was often quite unwell after chemo sessions, often found on a couch with my head slanted to the side as I developed a strange side effect of vertigo. However, it was only a short journey home for me where I was able to be on the couch, wig off, and duvet on…again, I recognise how lucky I was. I am. Lilly does not have that luxury with where she lives, and this is despite the pain and depression she experiences due to her scoliosis she has because of having NF1.
My position as mother The mother connection Experience is 'the mother' of wisdom	Her daughter came up a good few times in the interview, and I really heard not only evidence to demonstrate that the animation helped her with confidence in checking, but also with going to seek help; that feeling of being empowered, to take control and take action. For Lilly, the animation could also provide the perfect opportunity for young girls to also learn and take it upon themselves to be breast cancer aware. There was that lovely reflexive pronoun again, which was great to

	hear, ‘even the children without NF1, it’s great for learning, for girls to check themselves’.
Lucy	
My self-doubt and belief in myself Working with researcher imposter syndrome The accidental researcher by experience Turned inside out: The accidental researcher with ‘experience’	I think this has been the shortest interview that I have conducted so far in this research. I worried that short interviews would not bring much. How ridiculous. Lucy, within the short interview, shared valuable contributions.
Comfort is important Working with researcher imposter syndrome The accidental researcher by experience Turned inside out: The accidental researcher with ‘experience’	This is great to hear as I wanted to make the experience of watching the animation as comfortable and as engaging as possible. Of course, the animators did the most stellar job on that front. Nobody should be subjected to my 2-D stick person drawing limit.
The self-doubt Working with researcher imposter syndrome The accidental researcher by experience Turned inside out: The accidental researcher with ‘experience’	Is there a number you are supposed to hit because it’s a PhD and I don’t know, bigger is better or something stupid like that? Am I supposed to like, razzle dazzle, ‘oh look I interviewed lots and lots of people. ‘Look how great I am!’ But, if it’s not adding anything new..., and I don’t want that to sound like anything to do with data saturation because it’s not, I think there will

The love of hearing experiences Working with researcher imposter syndrome The accidental researcher by experience Turned inside out: The accidental researcher with 'experience'	always be something found in conversations with others, but I think what I'm getting and hearing and exploring is tightly mapped onto the information power framework. I just don't know. Again, the doubt and the expectation that there is some sort of other hoop I'm supposed to jump through to get this research across the line just so somebody can tick a box, despite it not bringing anything helpful to it. I'm happy to keep going on the few others that I have, that will hopefully speak with me this week. I look forward to interviews. It's not like I want them to end really, but that is just me being greedy I think as I enjoy the process. I'll go and talk to my supervisors at the start of next week, and give them an update and see if they can help me with this quandary/moment of self-doubt!
Anya	
'mom guilt' The mother connection Experience is 'the mother of wisdom'	This was another case of being diagnosed at a later stage, in Anya's case, the diagnosis came about after having her first child. They both received it together. This is something that I can only try to imagine what is like. How do you get your head around the fact that your child is diagnosed

	with a rare genetic disease that you now must try to start making sense of, put plans in place, start a new path of appointments, and specialists, and wonder what is going to happen as NF1 varies not only from individual to individual, but also varies in issues throughout a single person's lifetime? But now, what do you do when you then find out that you also have the condition, that you then passed it genetically to your child? Do you wonder what's going on in your body? Do you start to join the dots of how certain things such as pains, lumps, perhaps struggles in school academically, all start to make a bit more sense? Are you angry? Are you relieved? Do you swing from one to the other?
The curious researcher My safety of medical care Hearing the gaps from experience The accidental researcher by experience Turned inside out: The accidental researcher with 'experience'	There is a pull to delve deeper into the experiences of a late diagnosis of NF with these individuals. I want to know more. There seems to be a deep chasm, a void once you turn 18. That's it. The care and the appointments just disappear. I find this hard. All of us, as we age become susceptible to the wear and tear of life, those little telomeres getting shorter and shorter. We can say 'hello' to our doctor more frequently as the aches and pains, and the other concerns that can come with ageing start to surface more and more. But what do you do when you are, not only an

	adult that has NF1, but one that has only received a diagnosis as an adult? How do you traverse a new landscape, that from what I have heard within previous interviews, lacks accessible information, and lacks healthcare professionals that have an adequate level of knowledge of the condition?
Drawn in Breast cancer awareness is personal Making things personal may cause ~~offense~~ sense. Making breast cancer awareness personal, to personally make breast cancer awareness	I notice that I am now even using battle language. That feeling of 'fight' is so strong within many of the interviews.
Flash backs remind me of 'why' Breast cancer awareness is personal Making things personal may cause ~~offense~~ sense. Making breast cancer awareness personal, to personally make breast cancer awareness	I do agree with what she said next, '...and with things like breast cancer, you shouldn't feel hesitant to want to contact your healthcare provider if you're concerned'. This sentiment echoed with me and I did feel that little twist in the stomach. She's right, we shouldn't feel concerned about contacting a doctor if there is something that we are concerned about, but I know it's not that easy. I certainly was not beating down the door into my GP's room. I poked and I prodded that little lump that I found. I don't know

Hypocrite but take action Breast cancer awareness is personal Making things personal may cause ~~offense~~ sense.	why I kept doing that. Maybe I could break it and get rid of it, and then everything would be okay. It wasn’t a good time to ‘get sick’. Corinne was only a few weeks from making her first communion, and we were going to have our hair done together, we were going to get all dressed up and have the day I thought about for so long, and that she was super excited about as she’d get to dress up like a princess for the day. I spent that day smiling outwardly, but the little lump and a sore boob from the amount of poking and prodding kept me worrying all day. I went to the doctor the Tuesday after for reassurance that it was nothing. Instead, I got referred to a triple assessment clinic. I still feel awkward going to the GP and can feel that sometimes my needs are not met. I recognise that I may then appear a bit of a hypocrite, but the point is I will go if I have any concerns, and as much as I hate doing it, I will make sure that I am somewhat satisfied with the outcome of the appointment or next steps.

Making breast cancer awareness personal, to personally make breast cancer awareness	
Willow	
Researcher of knowledge of NF1 barriers Personal opinion of importance of check ups Hearing the gaps from experience The accidental researcher by experience Turned inside out: The accidental researcher with 'experience'	There really does seem to be a sense of having to go your own way once you are legally an adult. I really do find this odd, and quite irresponsible to be honest. Surely, an annual appointment to check in would be far better? I suppose it doesn't help with the fact that the condition is not that well known about, and with looking at the fact that there are only two main hospitals that I hear about in the interviews in London and Manchester, perhaps all they can do or have the capacity to do is put all their energy and resources into paediatric care and hope that somehow this will help with equipping individuals with NF1 better with navigating adulthood with the condition.
Noticing gaps clearly as a 'survivor' Hearing the gaps from experience The accidental researcher by experience Turned inside out: The accidental researcher with 'experience'	I'd never actually thought about it, and I do think that this is an area that should be researched more. Are women with NF1 perhaps increasing their risk on top of the already increased risk of developing breast cancer by taking certain contraceptives, due to the lack of information and knowledge among healthcare professionals out there? Are there any resources out there about this and about fertility for

	women with NF1? I have not seen any that are readily available.
Women's NF1 health gaps Hearing the gaps from experience The accidental researcher by experience Turned inside out: The accidental researcher with 'experience' Experience brings more 'power' than questionnaire Hearing the gaps from experience	If there is no continuation of regular services and checks past 18 years, why are these young women not being provided with important information like this? I know how important this is. I, myself, while having gone through triple negative breast cancer, am not advised to take any hormones whether it's certain contraceptives or HRT. These can only be given, when other options are not feasible, if the case is so bad that it affects quality of life such as debilitating menopausal symptoms, or in low doses for a short period of time with monitoring. This can hugely impact on women's lives. There are other options out there, different contraceptives with different hormones and doses that are more suitable for women with NF1, however, if they don't know, and their healthcare professional doesn't know information that is pertinent to this condition, well, there's quite a problem there. There are so many gaps! I feel that this intervention can only make a slight dent in things, if at all. I knew it was going to be complex, but these interviews are throwing up a lot more issues that can get in the way here. You get absolutely

The accidental researcher by experience Turned inside out: The accidental researcher with ‘experience’	nothing about these from the questionnaire part!
Dual positionality Breast cancer awareness is personal Making things personal may cause ~~offense~~ sense. Making breast cancer awareness personal, to personally make breast cancer awareness	The animation, while Willow was breast aware before, she feels has made her more aware of what other things to be aware of like checking a greater area such as the armpits, and has made her feel that she will be a bit more thorough. This is great to hear, and it’s something I remember looking at when researching the warning signs that I even went, ‘oh, I never check there, really!’, and you would think that I would be Queen of awareness, but no, there’s always room to learn something more.
Getting a conversation going Getting people talking about the facts Making things personal may cause ~~offense~~ sense. Making breast cancer awareness personal, to personally make breast cancer awareness	[...] not having, ‘...that kind of (.) ongoing conversations about NF1...’. I think this is key here, really and I really like the way Willow has explained this. That’s what is needed for everyone here, to really learn and reinforce that learning. Ongoing conversations with accessible and evidence-based resources to start the conversation. Willow mentioned worry and fear. I think that’s very common. It’s not great that we do experience this, but I do think that having conversations more about this will help with reducing this worry and fear so much.

Facing my fear Breast cancer awareness is personal Getting people talking about the facts Making things personal may cause ~~offense~~ sense. Making breast cancer awareness personal, to personally make breast cancer awareness	As I've discussed in the research, when people hear the word 'cancer' people can very quickly jump to conclusions and automatically connect it to 'death'. Easy to do. We all know people who have died or are dying of cancer. I know it too well. Fear and worry nips at me still at times too.
The goal Breast cancer awareness is personal Making things personal may cause ~~offense~~ sense. Making breast cancer awareness personal, to personally make breast cancer awareness	I love asking the participants how taking part in the research made them feel. I don't know, it's a bit of an odd question on the surface, and a bit of a 'why are you asking!'. I really hoped that anyone who took part in this research felt heard, felt connected, and felt part of something. Yes, I know, it maps on very nicely to relatedness in SDT, but I just really wanted for people to feel good! That it was a positive experience. So far, it's been lovely to hear the answers, and when I get to see their faces, it's great. There's that, 'oh!'.
Empowering others Understanding my limits Understanding their power	I really do hope that people will walk away from this, and go, 'yep, I helped make a difference'. I might be writing a heavy (in more ways than one) book that appears to be munching on the steroids, but those that speak with me, are the ones that are

BCA is bigger than my PhD The accidental researcher by experience Turned inside out: The accidental researcher with ‘experience’	the bigger more pertinent part. They are the ones with experiences. And for many, this is far heavier than what I am expected to do or write.
Teagan	
Considerations through my experience Hearing the gaps from experience The accidental researcher by experience Turned inside out: The accidental researcher with ‘experience’	Scoliosis appears to be quite frequent as a way that NF1 manifests physiologically. It makes me consider how this in itself may be a barrier to screening. I thought about this as only a week or so ago I was in for my own yearly scans and how it is very much like an act of contortion with mammograms, how you have to be positioned in a certain way, and to stay very still in what is always an awkward position. Nobody has discussed this in the interviews but then again none of the women with NF1 that I have interviewed have started attending for yearly breast screening, yet.
Feeling personal annoyance Understanding pressure of HPs’ work Hearing the gaps from experience The accidental researcher by experience	I can see how this can happen more easily when the people that you are supposed to rely on, to trust, those healthcare professionals, do not understand the condition, can dismiss you, and therefore are part of the misinformation problem themselves then. This does annoy me when I hear this as frequently as I am hearing it. I know they are busy, I know that healthcare

Turned inside out: The accidental researcher with 'experience'	professionals are under pressure, but they need to take a little bit of time to make sure that they do know important information such as screening eligibility and the increased risk of breast cancer.
Rose	
Reality of research Self-doubt Barriers Working with researcher imposter syndrome Hearing the gaps from experience The accidental researcher by experience Turned inside out: The accidental researcher with 'experience'	It was a bit of a bumpy start with recruiting, with a person cancelling an hour before, and another then rescheduling during the week. I was beginning to think that nobody was going to talk with me! The relief when Rose picked up the phone. The interview went okay, after what felt like a never-ending process of the consent part. Not great really, when you are trying to build rapport.
Dr Google's a bad memory Remembering Breast cancer awareness is personal Making things personal may cause ~~offense~~ sense.	...it made me think about how we always go to 'Dr Google', how I went to Dr Google when I got diagnosed with a type of breast cancer that I had never heard of. My stomach did a bit of flip, as Rose said this, and I remembered my own bad experiences.

Making breast cancer awareness personal, to personally make breast cancer awareness	
Importance of early diagnosis Breast cancer awareness is personal Making things personal may cause ~~offense~~ sense. Making breast cancer awareness personal, to personally make breast cancer awareness	How important it is to get diagnosed early, and to put supports in place from the get-go.
Trying to beat Dr Google Breast cancer awareness is personal Making things personal may cause ~~offense~~ sense. Making breast cancer awareness personal, to personally make breast cancer awareness	She explained that she always tries to do her research before saying anything, and that she's very knowledgeable about the condition. I was delighted to hear this, and I'm not surprised as Rose (as have I!) know how dangerous Google can be.
Taking it personally Owning power Breast cancer awareness is personal Making things personal may cause ~~offense~~ sense.	That meant a lot. Not just, yes I learnt a few things, but it was the fact that Rose had said 'for myself'. That lovely reflexive pronoun, that refers back to the subject. Not just taking in the learning but bringing it back within the self. The taking ownership to be breast cancer aware. Owning this power. Wonderful.

Making breast cancer awareness personal, to personally make breast cancer awareness	
Outsider My position as outsider My inside-out position Turned inside out: The accidental researcher with 'experience'	It's easy enough for me. I don't have NF1. I can literally go by all those warning signs on the infographic and that's it really. And many women with NF1 can also do the same.
Previous research a friend The researcher My inside-out position Turned inside out: The accidental researcher with 'experience'	Welcome back my old friend from the MSc research.... negative experiences of attending healthcare professionals.
Taking it personally Breast cancer awareness is personal Making things personal may cause ~~offense~~ sense. Making breast cancer awareness personal, to personally make breast cancer awareness	'I'm still stuck in the same position I was in before'. That did make me feel annoyed. I at times found it like pure hell during the pandemic trying to organise scans and procedures. The wait, them prioritising who was more important, the phone calls that I took over lockdowns, particularly in the early days when we didn't know what we were dealing with, within my volunteer role to support those newly diagnosed with breast cancer and them howling down the

I am privileged Critical of a true multidisciplinary approach My position as outsider My inside-out position Turned inside out: The accidental researcher with 'experience'	phone, choaking on tears and angry and frightened guttural sobs of how it took so long to get seen to, how they had to go to appointments on their own, had their cancer spread? What to tell their kids? What to tell themselves? Now it's back to ringing my consultant's secretary for my review scans, having a light and friendly chat and having an appointment in the post for the next month. No, this is not reality. This is privilege. This is my privilege of being a private patient, of having private health insurance. My participant today does not have this and is not in 'the system' under a team of oncology specialists. You have to be in the right 'system'. Rose has an NF system. They are singular. Aren't multidisciplinary teams a shared system? Perhaps not. Perhaps some are just a shared space of voices during a singular meeting.
I'm too scared too Breast cancer awareness is personal Taking things personally make cause ~~offense~~ sense.	Well, Rose feels that it 'has encouraged' her, that she could potentially call the doctor and say, 'I've come into some knowledge that I'm allowed to have one [screening] earlier due to the condition that I've got'. That sounds quite powerful! However, when I asked Rose 'do you feel that it could increase that empowerment,

Making breast cancer awareness personal, to personally make breast cancer awareness Bigger picture Breast cancer awareness is personal Making things personal may cause ~~offense~~ sense. Making breast cancer awareness personal, to personally make breast cancer awareness	or no?' The perfect and ideal picture was broken by our reality of the times we live in....'I'd hope so, but obviously I work for the ****** and I understand the strain that the ****** is under...and I think sometimes, it makes me a bit scared to call and say, 'this is what I know. This is what I want done.'. Huh. And then I realised that I can feel like this too. Are others feeling like this, too? There's no doubt our healthcare professionals are overworked, and overwhelmed. Plenty of pictures, and interviews, of nurses absolutely worn out, and underpaid. Yes, they most certainly need to be treated better, but are we considering the negative and potentially dangerous effect of how we don't want to feel we are making more problems, more work for them? Are people holding back from picking up the phone if they feel that something is wrong? Are their emotions being taken advantage of and their health suffering? Care too much? Die too quick.
I know my position I know my 'why'	Go Rose! Be brave. Thank you for sharing your experience of what it's like to have NF1, and your struggles too. I can't fight your fight, but I'll do my best to support

My inside-out position Turned inside out: The accidental researcher with ‘experience’	you. I hope you know that Bea has got your back too.
Jessica	
My preference as a researcher My inside-out position Turned inside out: The accidental researcher with ‘experience’	I love how 2 minutes 40 seconds can bring about such wonderful interviews. How can people just use questionnaires?!
Honesty is the best policy Breast cancer awareness is personal Making things personal may cause ~~offense~~ sense. Making breast cancer awareness personal, to personally make breast cancer awareness	I get a sense that a lot of this could be of course the pressure that healthcare professionals are under, but also a ‘fall on sword’ issue. Wanting to save face?! I have a lot more respect for someone who is honest but that shows me that they are concerned, they do care, and they are going to go and investigate further.
Laura	
The nervous researcher Working with researcher imposter syndrome The accidental researcher by experience Turned inside out: The accidental researcher with ‘experience’	I really do enjoy this stage of research. Of course, I’m always nervous, but I love how you can get so much out of an interview.

Cancer can just happen I get that Breast cancer awareness is personal Making things personal may cause ~~offense~~ sense. Making breast cancer awareness personal, to personally make breast cancer awareness Cancer makes you nervous Breast cancer awareness is personal Making things personal may cause ~~offense~~ sense.	Breast cancer is already in Laura’s family. This is nothing to do with her birth dad having NF1, as she says, ‘...it’s just the family is unlucky to get them ((laughs)), to get the cancer’. She doesn’t think there’s a BRCA gene or anything like that. It just happens. I get that. They scratched their heads, did the genetic test, sent my blood over to Manchester to see if I was carrying a BRCA gene. Isn’t it strange how I’ve somewhat followed my vials of blood over to Manchester a few years later? A part of me was already there in Manchester waiting. However, finding out that you are not a BRCA1/2 carrier does not always give a cause for celebration. You’re still left with the, but why then? How then? I picked up on those nerves that seem to have rooted themselves within Laura’s family, as they drill it into her,’...so I’m always told to like, ‘check’, ‘do this’, ‘do that’ ((laughs)).

Making breast cancer awareness personal, to personally make breast cancer awareness	
The potential downside to be ‘aware’ Breast cancer awareness is personal Making things personal may cause ~~offense~~ sense. Making breast cancer awareness personal, to personally make breast cancer awareness	. As Laura said, ‘Yeah, I’m always checking ((laughs)). I have, like really bad anxiety so I’m always checking, always going to the doctor even if there’s a slight difference’. Laura’s not on her own here, and neither is her family that may have added in instilling this fear of breast cancer within her. It’s not uncommon for either family members who have seen someone close to them go through breast cancer, or indeed for the women that have gone through it and fear recurrence to begin checking their breasts too frequently. I remember at one of my appointments after I had been told that the outcome from chemotherapy and surgery was NED, my oncologist at that time warned me not to become too overzealous with checking. He advised me that not to worry at this stage, that everything was okay, and to leave the checking to the team for the time being. This makes sense when looking back. I was in every 3 months at the time for checks, bloods, pokes, and prods....it would have been so easy to start becoming obsessive, particularly after being let loose out in the wild again, after so many months of being in what became my second home and wrapped up in not

	only cannulas, tubing, and wires from monitors, but also in constant support and immediate medical attention. Laura's family were fearful of breast cancer, and now with a young family member with NF1 increasing this risk, it was palpable that fear that most probably came from a place of love.
Sticking up for my children My position as mother The influence of the mother position The mother connection Experience is 'the mother' of wisdom	'I've got much better ((laughs)) for sticking up for myself in from of doctors, because of, because of this, so...' I'm not hearing much about patient-centred or person-centred care. All the research says how important it is, but what's really getting in the way here? I've spoken to some lovely doctors within my own appointments and when with my kids for theirs, who have really put me and them smack bang in the middle. They've truly listened, and they've asked what I would like, however, we've also experienced the not so lovely individuals. I think the worst was the doctor that said in front of my daughter only 9 years old at the time, 'she won't be able to do certain jobs when she's older'. Disgusting. Corinne has a visual impairment. It does not have her. She sees the world differently, two of everything. Two of me. Two of dad. Two of Gavin. And so, four dogs. 'Sometimes the picture shakes'. She's had a number of surgeries. It

Not giving up	has not helped, but she has many coping mechanisms to get from A to B, to function in school. You would not know anything was different from the way she looks, or the way she acts. She's 16 this summer. She sometimes trips if there's a drop in pavement or it's hard to make out a change in path. She gets embarrassed. She's a teenager. She doesn't want to be seen or thought of as 'different'. She wants to learn to drive next year. We remember back to that consultant when she was 9 years old. Corinne remembers that appointment. Corinne remembers back to things she used to do when she was a toddler. She'd hang you, 'no, but you said...' Memory of an elephant. We're not giving up. She hasn't and she won't, so why would we?
The kids' opinion The mother connection Experience is 'the mother' of wisdom (	The animation for Laura helps with, 'not getting too scared of everything, it's best to reassure the young people'. So, maybe this could also be good for girls with NF1 and their associates from puberty, 12 years up perhaps? My kids like it although they are two teenagers that are used to hearing about breast cancer. They're a bit like me and have become a bit sterile in reaction to certain aspects.
Sarah	
Learning struggles	I know I considered learning difficulties as carefully as I could when I was developing

Pulling at my heart strings My mother, her learning struggles The mother connection Experience is ‘the mother’ of wisdom The mother connection Experience is ‘the mother’ of wisdom Supporting mum by supporting participants Educational barriers	this intervention, however, I did not expect it to be as prevalent as I am experiencing. For that vast majority of those that I have interviewed so far, they explained how they struggled at school, with many not getting a diagnosis of NF1 until a later age, and therefore just thought as Sarah described herself as, ‘not so bright’, and ‘thick’. That really broke my heart. Learning difficulties are prevalent on mum’s side, and all my cousins have received really good support in their education. Two run their own businesses and are doing really well in their trades. Mum didn’t receive the support, often shouted at and punished by the nuns in her school, made to stand up and subjected to mockery. She left school at 15 and did very well as a hairdresser, running her own business for a while. Mum struggles with reading but she is tenacious and will stick at a book no matter how long it takes. She’s also a fabulous golfer, and don’t bother playing cards with her particularly if it involves money. You’ll go home with empty pockets. They all want to be partnered with her if there is a bridge tournament on. There is one important thing that I have learnt with mum. She is not ‘stupid’ as she would refer herself to be. She is in fact very smart and has a wonderful eye for detail. Mum just learns in

	a different way and is definitely more visual. Animations are a visual glory.
The accidental researcher by experience Turned inside out: The accidental researcher with 'experience' Frustrating Research limitations I really want to help Exhausting Uncomfortable feeling A need for battle? Hope of the intervention	'So, I'm like, 'where the-, heck do I go next?' So, I was just like, fed up with being passed from pillar to post so I put the phone down, got in touch with the NF nurse, and she was like, 'right, leave it with me. D'know, I'm going to contact where I need to contact and again, not through my doctors, through the NF nurse she actually sorted it all out and I got an email from her saying, 'I will get my appointment through soon, and I'll be seen hopefully soon'. I find it frustrating hearing this all back. You really want to help. You really want these women to be able to be confident in not only spotting changes early, but also be able to seek the medical help that they need and are entitled to without such as struggle, and such a fight. It's exhausting listening to it, at times. You do your best, you are meticulous in your research, in how you are going to approach it and design it, but then you come up against a brick wall. I practically feel the power dimensions that these women experience. It's uncomfortable. Do I need to go into battle too to get this message communicated to all those that need it? I certainly hope not.
Information walls make me sad	What was important to hear was Sarah's reason for taking part in this research. It

The mother connection Experience is ‘the mother’ of wisdom	wasn’t just for her, it was for her daughter who also has NF1 that, ‘she doesn’t have the same (.) walls that I’ve had’. I found this both powerful, and also quite sad to be quite honest. Nobody should have walls when it comes to something that could potentially save your life.
Bernie (A)	
Discomfort for good The mother connection Experience is ‘the mother’ of wisdom Mother to mother	However, as Bernie watched the animation it was the first time that she learnt that young women with NF1 have an up to five-fold increased risk of developing breast cancer at a younger age. I thought about how it was her, a mum’s first time learning that her daughter has this increased risk. It made me feel a bit uncomfortable and then very quickly it flipped to a feeling of, ‘well good. I’d want to know so as to better protect my daughter’. And it was clear from speaking to Bernie, and being able to see her body language and facial expressions due to our conversation taking place via Teams that she felt this way too. She wanted to know, and appreciated learning about this increased risk.
No communication is just as bad as misinformation My preference for earlier screening Experience within the research findings	It made me think how there’s quite a bit of research, particularly recently, that does share the information about the earlier breast screening eligibility for NF1. Great for me as a researcher, however, this important information is not being

The accidental researcher by experience Turned inside out: The accidental researcher with 'experience'	communicated out there to those that do also need this. I think this is nearly as bad as communicating mis or disinformation, as it just give voids that can be filled by everything or anything. Why aren't they sharing this!? I've read recently about recommendations to change the breast screening age to 30 years for the UK. That of course will mean Ireland too as we align together in this aspect. I would welcome seeing this, and I think if it's brought in earlier there's less of a gap between when much of the appointments end at 18, and then screening at the original 40.
My researcher identity My inside-out position Turned inside out: The accidental researcher with 'experience'	It's very specific information that is not readily available out there unless you're like me and you have at this stage spent a few years trawling through research papers. I see that as my job. Others don't have the time or the access to such materials.
Self-doubt Working with researcher imposter syndrome The accidental researcher by experience Turned inside out: The accidental researcher with 'experience'	[...] it makes it much easier to have a discussion about it, because it is in that format'. This is similar to feedback from other interviewees. This really bolsters the argument about animation potentially creating that protective distance when delving into topics that can be perceived as a bit embarrassing or taboo. This is great as there was a part of me that did worry that it could all go terribly wrong in that people

	may have been like, ‘what is this? I’m not 3!’.
Draining Emotionally hard	She was eager to know when she could share the animation, which was really lovely to hear someone who was passionate about breast cancer awareness too. I do find this research emotionally hard at times, it can be quite draining, and to be quite honest I’ll be relieved when it’s over as I put everything I have into it, but it’s these moments of meeting someone else with a desire to spread awareness that gives me another bit for the tank to keep pushing forward.
Saffie	
Pushing through Nerves My inside-out position The accidental researcher by experience Turned inside out: The accidental researcher with ‘experience’ Comfort	I could see that Saffie was nervous. Yes, I could hear, I’m sure my voice has a slight tremor too. I wonder do the participants know that I’m nervous? I wonder do they push through the nerves when they know that something is bigger than those nerves, too? I made sure to give a little bit of extra time for just a general chit chat before, until I could see and hear that Saffie was more comfortable. Until I was more comfortable, too. Vanessa let me know that some are too scared to be interviewed. They have anxiety, and being interviewed would be too much. I talk so much about power, empowerment, and power dimensions in my research. I have

Recognising my ‘power’ The listener I am ‘me’ Ethics as a barrier My inside-out position The accidental researcher by experience	experience of being the patient. I’ve been both empowered and overpowered by healthcare professionals. My heart sank, and my stomach churned. They may be thinking I am a cold monster, one of those ‘others’. Oh no, no, no. That’s not what I wanted. That’s not what I want. Academia does a lot of talking about inclusivity. Ethics talks a lot about inclusivity. Many of my participants have learning difficulties. They experience anxiety. They’ve had bad experiences with healthcare professionals that do not listen, that fob them off. Are they seeing me as just as a PhD researcher in psychology, as another person that will not listen? I will listen. I am listening. I am Caitriona, I am Cat. I am mum. I’m more likely to come out with something random, talk way too much, put my foot in it because I get nervous, and regret it for a decade rather than the stereotypical person in academia that is so level and calm, and ponders insightful stuff. I’m the one that asks questions at 2am in the morning like, ‘I wonder what dinosaurs really sounded like?’ See! Not insightful. A bit odd, but there you have it. Do we really have to bombard participants with so much *stuff* to quite frankly cover our tooshies? Yes, it’s for the benefit of our participants, it’s to fully inform them. But, really, it’s also

Turned inside out: The accidental researcher with ‘experience’	in case somebody wants to complain, to sue. How cynical of me, but cynicism comes from having worked in HR and in management roles over the years.
Self-doubt My inside-out position Working with researcher imposter syndrome The accidental researcher by experience Turned inside out: The accidental researcher with ‘experience’	As Taylor Swift sings it, ‘It's me, hi, I'm the problem, it's me..’ That song has such good lyrics. So true. I still doubt my abilities. I still think that I won’t, that I can’t get through this PhD. Am I going to get to the viva and be told, ‘eh, no. You’re not good enough. Your research is not ‘smart’ enough’? Yes. Power dimensions. I didn’t agree with what I had to do to get my ethics over the line. But I didn’t fight it. I made myself small and agreed to get approval, as I believed I am only a student. I went off mumbling about it. I didn’t speak up. I said it at home, ‘this is going to put people off. This is hardcore. How is this inclusive?! This would either completely scare me off or bore me off’.
Fighting Dr Google Breast cancer awareness is personal Making things personal may cause ~~offense~~ sense. Making breast cancer awareness personal, to personally make breast cancer awareness	.... yep, Dr Google strikes again, which Saffie admits ‘is not the best thing to do, ‘cos it, Google tells everybody that they’re dying...((laughs))’. Ah, yes, this always triggers a wincing within me. Dr Google had me dead too when I looked up triple negative breast cancer. Lovely. At least I had a nurse I could call to tell her about my findings from online ‘research’. It’s taken going back to uni as a mature student, and a proverbial beating by Dr Google’s

	stethoscope to know that I don't trust Dr Nick Riviera ('Hi everybody!'), The Simpson's phony doctor types.
Sharing the lumps confusion Breast cancer awareness is personal Making things personal may cause ~~offense~~ sense. Making breast cancer awareness personal, to personally make breast cancer awareness	Of course, when it comes to confidence in checking breasts and spotting something, Saffie 'sort of' feels confident now, however, it's when you spot something, it's the confusion of is it? Isn't it? It could of course as she correctly said, 'hormones'. I know I've had that moment of 'is that a lump?' And after a scan them saying, 'your breast tissue is very dense, and you have fibrous tissue. No cancer there but yes, it's quite lumpy'. Ugh. More confusion. I get you Saffie on the hormone front. Many of us women do.
Privileged position My inside-out position Turned inside out: The accidental researcher with 'experience'	Also, a reflection of the current times we are living in, that difficulty in trying to get a GP appointment in the first place, that actually suits a busy lifestyle of a young woman. Saffie says that she would just go private if she had to if she felt that there was a serious concern, and would hope that by doing this, it would put her into the system. Again, I really recognised my privileged position of being a private patient. I'm very grateful, but I'm sure so is the hospital's bank balance.
Difficult to hear Beas is a fighter	I'm hearing there's that sense of fight again. Always having to fight, to come back with evidence that they will listen to. I find

GP love/hate My own anxiety Breast cancer awareness is personal Making things personal may cause ~~offense~~ sense. Making breast cancer awareness personal, to personally make breast cancer awareness	it hard to hear this. I wonder will they take Bea either in video form or the information leaflet to their GP? ‘Look! See! Now give me my screening! Take me seriously!’ I’m just awaiting an email from a GP someday...I wonder will they be angry or grateful? I hope that this intervention may in fact help healthcare professionals, it’s not great when you hear a participant tell you that they look at her like she’s ‘neurotic, and you know, fussy...’ Been there.
The BCA goal! Breast cancer awareness is personal Making things personal may cause ~~offense~~ sense. Making breast cancer awareness personal, to personally make breast cancer awareness	For Saffie the animation has also made her realise that she should take her health more seriously. I do feel happy about this. it’s all about catching breast cancer early. For me, it’s the listening out for the taking ownership, the real power. And I found it within Saffie’s last sentence,’...I need to stop brushing everything -, it might be normal, it could just be nothing, but it’s not a waste of time to find out it’s nothing...’ 🙌
Alice (A)	
Ripple effect delight All about raising awareness Breast cancer awareness is personal	This animation appears to have had a ripple effect, not just with raising awareness of NF1 and breast cancer awareness, but also about creating a personal breast cancer awareness in everyone and anyone, no matter the genetic status. For Alice she has

Making things personal may cause ~~offense~~ sense. Making breast cancer awareness personal, to personally make breast cancer awareness	taken on board important information that can help her too, of checking her breasts once a month but also about the idea of setting a reminder. I have to admit that when I hear this, it really makes me feel positive and motivated. I like helping raise breast cancer awareness due to my own experience, and I thought with this research, it would be a lot more focused on women with NF1, but I really am delighted that I can continue to raise breast cancer awareness for anyone who watches the animation.
Amy (A)	
Glad to be challenged Breast cancer awareness is personal Making things personal may cause ~~offense~~ sense. Making breast cancer awareness personal, to personally make breast cancer awareness	This was an interesting one, in the sense that Amy was keen to know more about why I was conducting this research, not just a simple why of the answer being raising breast cancer awareness components specific to NF1, but more of a 'why you?', 'what's your connection?'. I did get a sense it was a real enquiry into finding out whether she really should go ahead and do the interview with me. I think that's absolutely fair. Am I just doing it because I need to do this research to pass something at university? Do I really know anything about NF1? Do I even care about breast cancer awareness? I'm actually glad that somebody did challenge my motives for this research. This person obviously does care

The power of my story	about the subject, and rightly so, does care about her time. Both precious. I took the time to explain the story. How I don't have NF1, how I did have breast cancer at a young age. How I came to learn about NF1, how it matches well with my desire and own personal motivation to create more focus within research on younger women and breast cancer, including those with an increased risk. I could see Amy was not so on the defence as I openly explained.
The 'experienced' researcher Hearing the gaps from experience The accidental researcher by experience Turned inside out: The accidental researcher with 'experience' Hiding researcher Perspective shifting Motives	I accidently found a recent paper with the lead author being a woman who I reached out to when considering doing a PhD. She's here in Ireland, and she was undertaking her PhD in Health Psychology. I chatted with her about the process, really to not only learn about undertaking a PhD, but to see if I was capable of doing it, if it wasn't going to be too advanced for me. She had lost her mum to breast cancer. Her mum hadn't realised that she had a BRCA gene mutation. This woman who I spoke to about doing a PhD, let's call her Mary, also was a carrier and at increased risk. She was happy to speak with me as she recognised my face from some of the awareness campaigns that I had been involved in within the Irish media. She knew that I had gone through breast cancer and was interested to hear about the proposed research that I was trying to decide whether

Growth reflection My inside-out position Turned inside out: The accidental researcher with ‘experience’	to do a PhD on or not. It was lovely to find that she had successfully completed her PhD, and that I was now reading one of her papers, and she had conducted reflexive thematic analysis. What distracted me from just looking for her participant numbers, was the fact that she also reported on the experiences of individuals with the BRCA gene mutation that they feel that they are a burden to healthcare professionals. So, this is not just limited to women with NF1. Of course, individuals within both our research, like Amy, may be more on the defence, mistrusting of us as they may perceive us as ‘them’. Mary had been open, in that all her participants knew that she also carried a BRCA gene mutation. I wonder should I have been more open and honest about having gone through breast cancer as a young woman? There is always a shift when participants ask me and find out that I’ve gone through it all. I’ve always considered it potentially unprofessional, but I think we are shifting our perspectives when it comes to conducting research. That we recognise that no matter what method we use, it’s not possible to remove ourselves completely from research. Our interests and motivation are always there, even if it is just a small interest or one of personal experience. I think if I were to do it all again, I would

	approach the research, the advertising, the recruitment, and the data collection differently. I'm honest about it within the method of reflexive thematic analysis, for goodness sake I'm pouring it all out here in a reflexive log! But it's still all quite 'hush hush', a behind the scenes. Will anyone really read these logs?!
Christina (A)	
Personal preference within the evidence for earlier screening My inside-out position Turned inside out: The accidental researcher with 'experience'	Don't get me wrong, I welcome these earlier screening recommendations. I think it would be beneficial to have screening start at a younger age, particularly as results form a systematic review and meta-analysis has found that breast cancer with NF1 predominantly occurs from 34. It's hard not commenting on this during interviews, but I just purse the lips together and go mm-mm.
This research is personal Catching cancer early My own continued fallout from chemo Motivation for awareness and being alive drives me Breast cancer awareness is personal	Christina really cares about her niece. I think I would be thinking and wanting the same if I was in her shoes. Her argument makes sense in that 'prevention is cheaper' but the intervention and early screening will not stop these women getting breast cancer. It will hopefully allow them to catch it earlier if they do find themselves with a diagnosis. Still though, earlier diagnosis is also cheaper for both the health system and the patient. And also you can't put a price on quality of life. More treatments for

Making things personal may cause ~~offense~~ sense. Making breast cancer awareness personal, to personally make breast cancer awareness	an advanced diagnosis does affect quality of life. I'm still experiencing the fallout of side effects years on from intense chemo, but that's all it was. Intense for a short period of time in the greater scheme of things. I can get on with being alive.
An important piece of work Goal already achieved PhD to prove? Working with researcher imposter syndrome The accidental researcher by experience Turned inside out: The accidental researcher with 'experience'	It's clear that people are eager to get this out there. To share and raise awareness. I explained the process of the research, and what's happening and what is hopefully going to happen. Her reply, 'Right! An important piece of work'. And, yes it is. I'm sure everyone that embarks on a PhD believes that their work is important, but I do think that the animation design in itself is the important bit. I'm not saying that the PhD is not important. My exhaustion, often sleepless nights, and constant thinking about it coupled with long hours working on it would also reflect that I too think my PhD is important, but for me I already feel that the most important bit has been done, in a way. I just hope that the PhD offers more credibility to it, and for me and my imposter syndrome and self-doubt, I suppose to me too.
Brenda (A)	
Enjoying the process	[...] I am grateful that I spoke with a few more as I am quite new to this process. The

Keeping in check Letting go Questioning the after My inside-out position Turned inside out: The accidental researcher with ‘experience’	questions asked are very specific in that they are based on what has already come before, however, I have enjoyed hearing individual experiences and communicated effects that have arisen from taking part in the research overall, to specifically watching the animation. I also keep forgetting that this research is about exploring the feasibility of the intervention, nothing more and nothing less. In a nutshell...can it be done? Why bother? And from the learnings of this research, what needs to happen next? I have grappled with just ‘letting go’. I don’t know. Perhaps there is a selfish part of me that does not want this part to end. Will I get to do research again after all this? What’s going to happen after all this?
Keeping the researcher happy? My inside-out position Turned inside out: The accidental researcher with ‘experience’	Thinking back, there has not been a negative comment in relation to the animation. I wonder is it because it’s that good, or because they don’t want to hurt my feelings, or not put themselves in a position of upsetting the ‘researcher’? Is it power dimensions, or is it that they do, wholeheartedly, like it? Something to always bear in mind.
Stereotyping health and disease	This whole research has highlighted to me how we really do approach aspects of health often in a ‘one size fits all’ or in a stereotyped way. I’ve made numerous

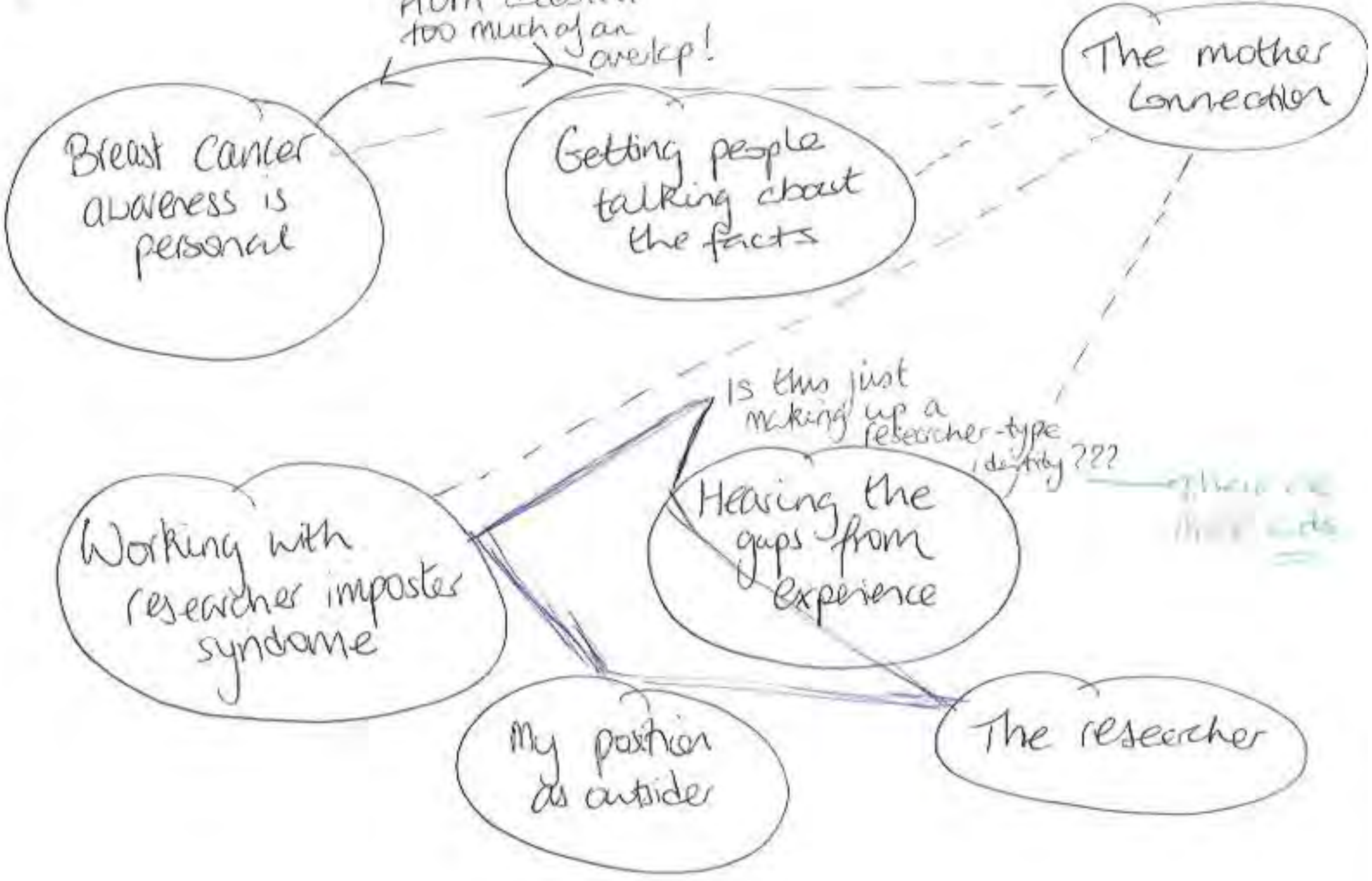
Cancer images drive me nuts My inside-out position Turned inside out: The accidental researcher with ‘experience’ We need to do better Not taken seriously Update needed	remarks by emails and within feedback meetings of how the charity that I volunteer for heavily relies on and uses older women in their stock images, that have the typical sick person, headscarf, about to ‘kick the bucket’ look. It drives me nuts. It’s not a truly accurate portrayal of what cancer ‘looks like’ these days. It was a fashion show experience for the weekly chemo sessions for me, with a wash and blow-dry of the wig the night before! It’s the whole shock appeal, I suppose, but it doesn’t do any favours to educate the public. Information for breast cancer arguably could be more inclusive. Breast cancer is currently not that rare in young women. About 20% of breast cancers are diagnosed in women under 50 years. That’s 1 in 5. We need to do better for younger women who if they get diagnosed with breast cancer, they have a poorer prognosis as they are often diagnosed with more aggressive subtypes that are often found at a later stage due to no screening and healthcare professional and personal attitudes of ‘you’re too young’, and ‘I’m too young’. It’s the same for women with NF1. I know only too well how difficult in can be for young women in the general population to be taken seriously, to take their own health concerns seriously when it comes to

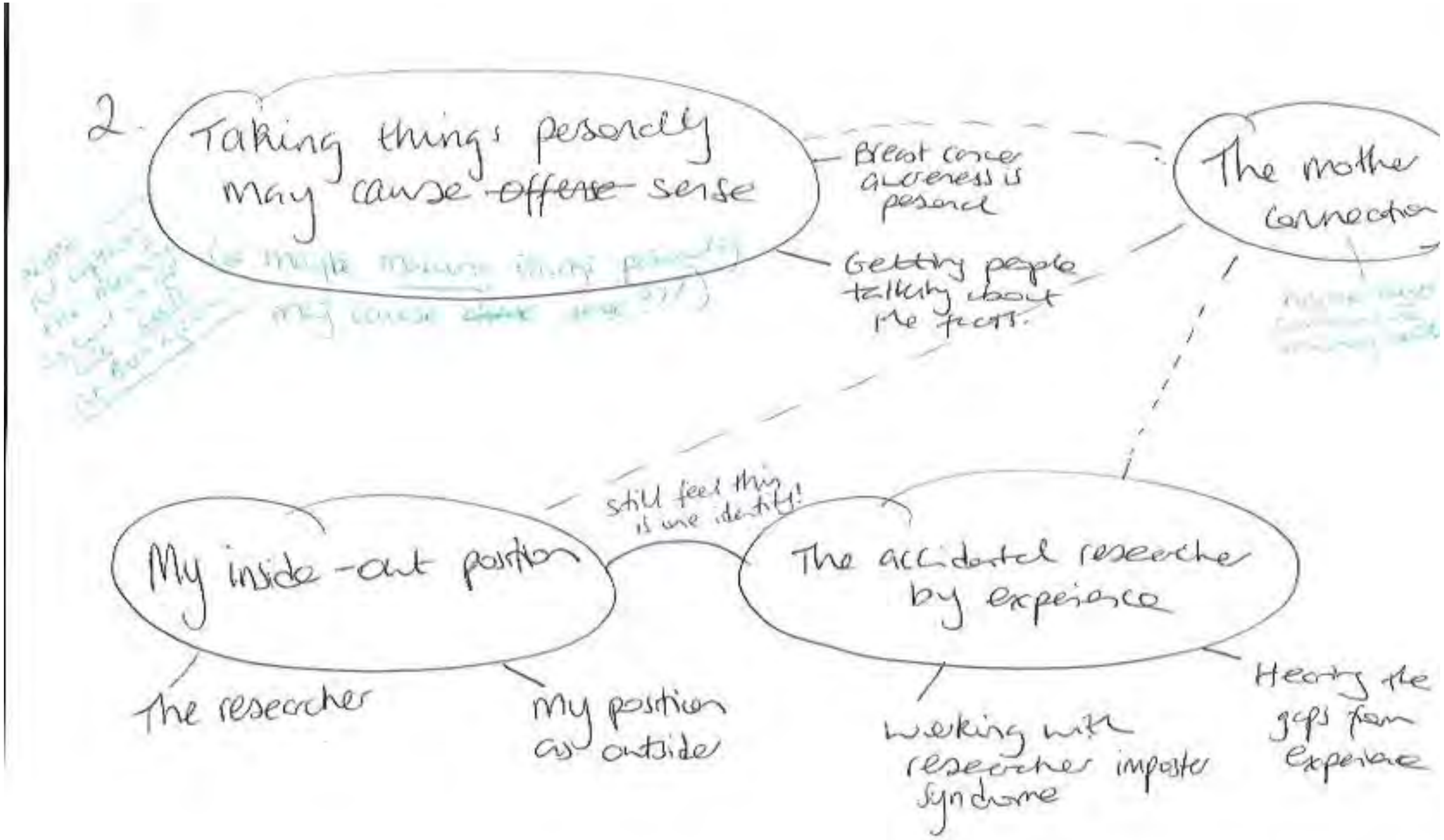
Info for all	breast health. But, add on the fact that you are increased risk of breast cancer at a younger age like those with BRCA mutations and also NF1...well, we need to do better. We need to put the image of the old woman in the headscarf on her death bed in the bin for a start. And we need to also update and add to the information available to *all* online. Highlight BRCA, highlight NF1, highlight the effect of dense breasts on risk. Stop putting barriers in place of screening.
Sasha (A)	
Likert's concealing the truth My inside-out position Turned inside out: The accidental researcher with 'experience' Plot twists	So, asking a question on level of confidence to attend a healthcare professional on a Likert scale type which on the surface looks like it offers a fairly reasonable number of options, can actually in fact, still be concealing a lot of the truth. From speaking to the participants, gaining confidence and self-efficacy is not as straight forward as watching an animation...but who am I kidding! I knew that there would have to be a plot twist or two within this research. You can learn something, you can go, 'oh yes I know what to be aware of now when it comes to breast cancer awareness and NF1!', however, the barrier is not within the confidence and self-efficacy of learning, it is within the lack of confidence in the healthcare professional. The questionnaire

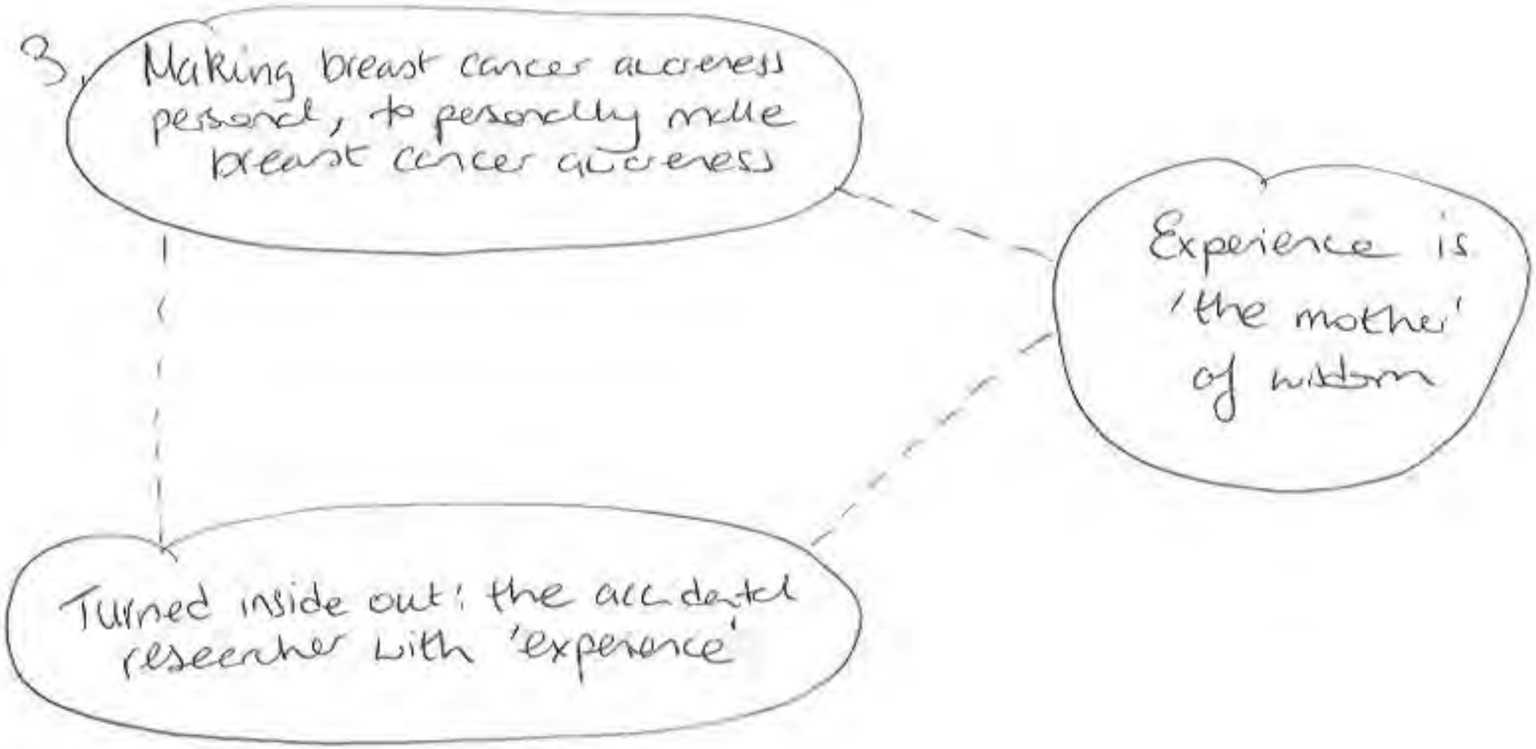
Surrender to the voices Different eye	items neither before or after can really pick that up and convey it. Can they? I’m afraid I may have to wave my white flag of surrender on that one. And, of course, with the overwhelming message and portrayal, of healthcare professionals as barriers to breast cancer awareness throughout the interview process, I’ll really have to look at the statistical outcomes with a different eye.
Mother/daughter bonds The mother connection Experience is ‘the mother’ of wisdom	However, with the mothers I have spoken to whether they are young women with NF1, or associates, it is also a connectedness and a responsibility to share with the other young women in their lives, namely their daughters. For Sasha she now feels that she will ensure her daughter has breast cancer awareness with her condition, and that she checks herself on a regular basis now that she has watched the animation.
Motherly protection The mother connection Experience is ‘the mother’ of wisdom Sharing awareness Breast cancer awareness is personal	This has made me reflect on my own relationship with my daughter, of wanting to help, guide, and protect her as much as I can when it comes to breast cancer awareness through my own experience with cancer. But, of how, I too, wanted the world to know that young women can get breast cancer too and wanted to share that information with everyone. There’s always that innate driving force present.

Making things personal may cause ~~offense~~ sense. Making breast cancer awareness personal, to personally make breast cancer awareness	
Hope The supporter Support through research My inside-out position Turned inside out: The accidental researcher with ‘experience’	Many have sounded exasperated, and quite frankly, exhausted. There is that hope that a short little cartoon has brought some reprieve and some light into their lives, knowing that there are some out there that want better for all of them, too.

1.


From codes....
too much of an
overlap!
Breast Cancer awareness is personal
Getting people talking about the facts
The mother connection
Is this just making up a researcher-type identity ???
Working with researcher imposter syndome
Hearing the gaps from experience
My position as outsider
The researcher


2.
Taking things personally may cause ~~offense~~ sense
(or maybe making things personally
may cause sense ???)
Breast cancer awareness is personal
Getting people talking about the facts.
The mother connection
still feel this is one identity!
My inside-out position
The researcher
My position as outsider
The accidental researcher by experience
Working with researcher imposter syndrome
Hearing the gaps from experience


3, Making breast cancer awareness personal, to personally make breast cancer awareness
Experience is 'the mother' of wisdom
Turned inside out: the accidental researcher with 'experience'

Appendix Z

Transcription Notation Key (Guidance from Braun and Clarke, 2013)

Laughing, coughing:	((laughs)), ((coughs))
Significant pause or silence of a few seconds or more:	((pause))
Short pause or silence:	(.)
Overlapping speech:	((in overlap))
Inaudible speech:	((inaudible))
Non-verbal utterances:	Mm, mm-hm
Cut-off speech:	e.g. Wha- for what
Reported speech:	Within ‘----’ single quotation marks
Vernacular usage:	‘Cos’ instead of because
Not entirely sure if Accurate hearing:	(and then I went) transcriber believes it to be this but not entirely sure on accuracy

Appendix AA

Example of Dual Familiarisation and Reflexivity Logging

This was interview number 15. I've been sensing a fulfilment of information power from about the 11th interview. That's not to say I've reached anything like 'data saturation'. I don't think that is possible. There will always be something to find, something new to hear. However, when looking at the specificity of the research question, the 15 interviews have offered plenty of information that is heavily relevant to the study. There are the common meanings, but the differences in these are also evident whether it is during an interview with a young women with NF1, or an associate. The similar final outcomes, but the different paths, experiences, reflections, and attitudes that lead them to these. I'm not entirely surprised that information power was ascertained at about interview 11, however, I am grateful that I spoke with a few more as I am quite new to this process. The questions asked are very specific in that they are based on what has already come before, however, I have enjoyed hearing individual experiences and communicated effects that have arisen from taking part in the research overall, to specifically watching the animation. I also keep forgetting that this research is about exploring the feasibility of the intervention, nothing more and nothing less. In a nutshell...can it be done? Why bother? And from the learnings of this research, what needs to happen next? I have grappled with just 'letting go'. I don't know. Perhaps there is a selfish part of me that does not want this part to end. Will I get to do research again after all this? What's going to happen after all this?

So, to Brenda. Interviewee number 15, an associate. Despite Brenda giving a very good answer to what she knew about NF1, although quite what you would see as information on the usual 'blurb' boxes on websites and leaflets, she felt that her knowledge of breast cancer specific to NF1 including the increased risk had changed, 'hugely'. For her, previous to watching the animation, she was not aware that there was such an increased risk of developing breast cancer at a younger age in women with NF1. She seemed quite shocked. I find this interesting, the sense of the reaction with this particularly with associates. I can hear, or indeed perhaps merely perceive not just shock but nearly like a sense of guilt, of awareness of the difference between them that do not have NF1 and those women that they know have this risk. There is nearly that 'shook' sense, that taken aback. I feel that from the interviews, this statistical risk shocks them more than the women with NF1. Is this because they can afford to feel more shocked and stay in this state, rather than having to move on and integrate this as part of your life if you are a woman with NF1? That outsider versus insider perspective, perhaps?

Again, when I asked Brenda the question about how her feelings have changed with encouraging a woman with NF1 to contact their doctor if they had a breast concern, there was a similarity with other associates that I have spoken to, in that there is a recognition that it's important for 'any woman'. There is an ingroup here, as women, as a reference. However, I observed how there was also then the separation, the difference or out-group of women with NF1, that, 'it might actually be a really hard thing for them to do'. I was really drawn to this...why does Brenda feel this? Her answer covered reasons, those potential barriers in fact to seek help, and to be breast aware. Embarrassment, assuming that a lump is just NF1. For Brenda as she was thinking about these barriers, it was nearly as if she was again just having that realisation of those difficulties for women with NF1, stopped in her own tracks of thought, ', I suppose if you've got NF, you're kind of used to little lumps possibly appearing, but to be aware that actually you've got such a big increase of a risk of breast cancer that I think you should be more-, definitely more aware if you found something near your breast or your armpit or- (.) yeah it's huge really. It's massive'.

Again, from the animation there were new learnings for Brenda from the intervention in that she was not aware that women with NF1 could attend for breast cancer screening from the age of 40 years. She again, seemed genuinely shocked, nearly a bit despairing perhaps, with herself, realising the importance of it all, I had no idea and that's-, and that's the really important thing to do, isn't it? I mean that's a whole 10 years earlier-...'. However, this may not have been an annoyance for her, as it may be as she believes that there isn't the awareness of this information among the women with NF1 either, '-which I don't think-, I can't imagine many women with NF are aware of that to be honest'. I wanted to explore and to get a better understanding of the points from Brenda and the sense of some sort of despair but also a sense of responsibility now as an associate from watching this animation, and how shocked she seemed from what she had learnt, so I probed a little bit further, 'yeah, and not being aware em, what could prevent that awareness among women with

NF1, but also associates so their friends, their families, their partners?’ I felt that she now believed that she was part of this awareness movement, with me included now, as there were times throughout that Brenda would directly address me, like we would align with our thoughts, our beliefs, and a mission to raise awareness, ‘ yes, I mean that’s- that’s huge as well, isn’t it? Because if you know someone with NF1 then you can prompt them if they’re approaching 40 to sort of go and make sure that they are being screened...’. I was curious to explore this desire to help with awareness so I asked what then could help raise awareness amongst everyone? There were hesitations, short pauses, a long pause....best communicated within the response of, ‘Hmm (.) I don’t know (.) em ((pause)) I suppose em, it’s difficult, isn’t it?’ It is difficult, but it’s certainly made easier when more are involved with learning about NF1 and breast cancer awareness! As demonstrated by Brenda who was not aware of quite a bit of information before watching the animation. She pondered to herself, wondering aloud, nearly hoping I would answer which was difficult not to as she tried to convince herself, ‘ I don’t know if GPs (.) have-, because I know that the breast, they have-, there’s a breast screening programme, isn’t there? Where women are written to as they approach 50, so surely women with NF1 should be on a programme via the GP so they’re automatically sent out letters to offer screening when they are 40? Should they not be?’...Yes, Brenda, they should be but if only it was that straight forward. My mind drifted to the women with NF1 in particular that I have spoken to, to their struggles, their frustrations, their feelings of not being taken seriously as they tried to have breast concerns dealt with. How GPS and healthcare professionals were not fully aware about the condition and the associated risks. I think Brenda quickly copped that I wasn’t going to offer anything on this, I was enjoying hearing her train of thought as she continued, ‘Well, I think they should be! I guess it’s a very tricky area. I know, I worked in a GP’s surgery. I suppose it’s all down to coding where the patients with NF1 are coded in-, I don’t know. I guess it’s a tricky area’. The dichotomous thoughts of Brenda pretty much some up a big part of the research...yes, it should be easier for young women with NF1 to attend for breast cancer screening, to be more aware, to have the confidence to attend if they have a breast concern, but again, yes Brenda...it is ‘a tricky area’. I wasn’t aware of the coding system that they use in GPs. Is this coding system a shared system? Could this be used better so as to ‘code’ a person with NF1 and then perhaps have information files activated and sent to their central files to share with medical professionals to aid them, so it comes up with all appointments. Let’s say a woman attends a new GP. He types in their name, date of birth, and some other identification that then automatically shows the person's health records. It shows that the woman has NF1. The GP can click on this, and immediately get information that is pertinent to the condition, and as the biological sex is 'female' so for those that do not identify as woman, or are trans for example, it will offer information about the associated breast cancer risk at a younger age including screening eligibility. This could then subsequently activate screening within the NHS at 40 years within their system? Just thinking.....and thinking....and thinking... how to help all concerned?

Brenda also mentioned that learning difficulties could also be a barrier to awareness, and that, 'it could be that there are vulnerable women that really aren't aware'. This is important too, and again it made me think back to those who I have spoken with who spoke about their learning difficulties and how they found the animation easy to understand. Thinking back, there has not been a negative comment in relation to the animation. I wonder is it because it's that good, or because they don't want to hurt my feelings, or not put themselves in a position of upsetting the 'researcher'? Is it power dimensions, or is it that they do, wholeheartedly, like it? Something to always bear in mind.

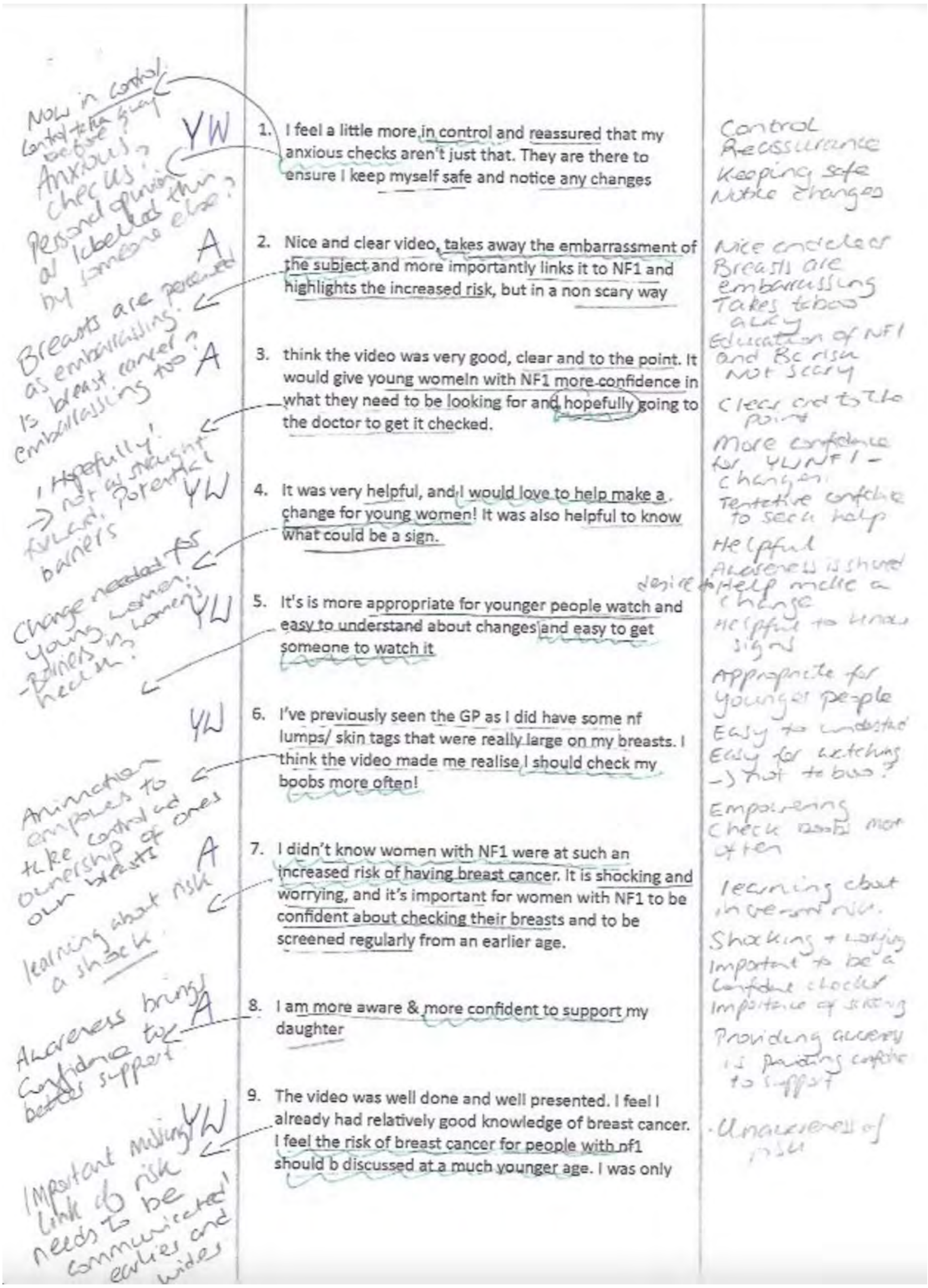
From Brenda's perspective, who has worked in a GPs, she thinks it would be nice to see, particularly about the increased risk in leaflets about breast cancer in doctors' surgeries. I agree, and it is something that other interviewees have also expressed. Why not have this increased risk of developing breast cancer at a younger age if you have NF1 on breast cancer information whether it is online, in school presentations, and in leaflets? That need to share, to highlight, to make NF1 more visible to everyone. Everyone reads the leaflets, so everyone can then see NF1...perhaps some may be curious, 'what's NF1? Let me 'google' it?' Yes, why not? A small paragraph could have a big impact. This whole research has highlighted to me how we really do approach aspects of health often in a 'one size fits all' or in a stereotyped way. I've made numerous remarks by emails and within feedback meetings of how the charity that I volunteer for heavily relies on and uses older women in their stock images, that have the typical sick person, headscarf, about to 'kick the bucket' look. It drives me nuts. It's not a truly accurate portrayal of what cancer 'looks like' these days. It was a fashion show experience for the weekly chemo sessions for me, with a wash and blow-dry of the wig the night before! It's the whole shock appeal, I suppose, but it doesn't do any favours to educate the public. Information for breast cancer arguably could be more inclusive. Breast cancer is currently not that rare in young women. About 20% of breast cancers are diagnosed in women under 50 years. That's 1 in 5. We need to do better for younger women who if they get diagnosed with breast cancer, they have a poorer prognosis as they are often diagnosed with more aggressive subtypes that are often found at a later stage due to no screening and healthcare professional and personal attitudes of 'you're too young', and 'I'm too young'. It's the same for women with NF1. I know only too well how difficult in can be for young women in the general population to be taken seriously, to take their own health concerns seriously when it comes to breast health. But, add on the fact that you are increased risk of breast cancer at a younger age like those with BRCA mutations and also NF1...well, we need to do better. We need to put the image of the old woman in the headscarf on her death bed in the bin for a start. And we need to also update and add to the information available to *all* online. Highlight BRCA, highlight NF1, highlight the effect of dense breasts on risk. Stop putting barriers in place of screening. Choose appropriate screening based on age, on density of breast tissue, on health condition and radiosensitivity status.

Brenda felt that the animation, '...just made it easier to talk about as well', that, 'it was clear but there was not a huge fuss, it was just easy to take in, easy to watch'. I nodded as those I have spoken to previously have also mentioned these factors too. That shared experience, that shared meaning. When asking more specifically about the format of animation on helping with learning, Brenda felt that 'it sort of stuck in your mind. It was much better than just reading something or, you might feel a bit uncomfortable actually watching a real woman maybe, I don't know. I just thought-, no I just thought it was really good'. That idea of being more comfortable to watch breasts in animated form. It's so interesting and again something that has been previously communicated. Yes, we can make breasts perfectly formed but created into animated form and we can watch and learn, but that uncomfortableness, that perhaps we are doing something wrong if we watch a woman's breasts in real life.... Oh, societal norms and the sexualisation of the woman's body...look at the damage you have done. Look how you now have women getting in the way of their own health and wellbeing. Thank goodness for animation, I suppose. But still...

For Brenda, the big takeaway message from taking part in the research has been learning about the increased risk. That was such a shock for her. But will she do anything differently from watching the animation? Interestingly, as has been shared by other associates, it has highlighted breast cancer awareness from them too, despite not having NF1. Brenda has become more cognisant of her breast health. It has made her reflect on losing close female relatives to breast cancer, how important it is to catch things early and not leave things, and 'just to get checked out', 'to encourage women to check themselves as well regularly', but for Brenda the intervention has also reminded her that when it comes to checking regularly she admits, 'I don't do to be honest, which I should do'. Great Brenda, I hope you will set a monthly reminder in your phone too, like Bea.

Appendix AB

Entire Iterative Coding Process of Interview Data with Example Provided of Initial Coding and Note Taking



Now in control; Control taken away before? Anxious checks? Personal opinion or labelled this by someone else?	YW	1. I feel a little more in control and reassured that my anxious checks aren't just that. They are there to ensure I keep myself safe and notice any changes	Control Reassurance Keeping safe Notice changes
Breasts are perceived as embarrassing. Is breast cancer embarrassing too?	A	2. Nice and clear video, takes away the embarrassment of the subject and more importantly links it to NF1 and highlights the increased risk, but in a non scary way	Nice and clear Breasts are embarrassing Takes taboo away Education of NF1 and BC risk Not scary
Hopefully! → not as straight forward. Potential barriers	A	3. think the video was very good, clear and to the point. It would give young womeln with NF1 more confidence in what they need to be looking for and hopefully going to the doctor to get it checked.	Clear and to the point More confidence for YW NF1 - changes Tentative confidence to seek help
Change needed for young women; barriers in women's health?	YW	4. It was very helpful, and I would love to help make a change for young women! It was also helpful to know what could be a sign.	Helpful Awareness is shared desire to Help make a change Helpful to know signs
	YW	5. It's is more appropriate for younger people watch and easy to understand about changes and easy to get someone to watch it	Appropriate for younger people Easy to understand Easy for watching → not taboo?
Animation empowers to take control and ownership of ones own breasts	YW	6. I've previously seen the GP as I did have some nf lumps/ skin tags that were really large on my breasts. I think the video made me realise I should check my boobs more often!	Empowering Check boobs more often
learning about risk a shock	A	7. I didn't know women with NF1 were at such an increased risk of having breast cancer. It is shocking and worrying, and it's important for women with NF1 to be confident about checking their breasts and to be screened regularly from an earlier age.	learning about increased risk. Shocking + worrying Important to be a confident checker Importance of screening
Awareness brings confidence to better support	A	8. I am more aware & more confident to support my daughter	Providing awareness is providing confidence to support
Important missing link of risk needs to be communicated earlier and wider	YW	9. The video was well done and well presented. I feel I already had relatively good knowledge of breast cancer. I feel the risk of breast cancer for people with nf1 should b discussed at a much younger age. I was only	Unawareness of risk

Risk only relatively new learning. 'Pot-luck' of getting info.	made aware of it about 3 years ago when I went to get a pill check at a new clinic..	
new learning of risk. YW	10. I didn't know that having nf1 increase my risk of breast cancer fivefold	Unawareness of risk
YW accessed on mobile? phone; subtitles available for other participants.	11. It was easy to explain and somewhat accessible. It might have been better if there were subtitles for those hard of hearing or with audio processing issues which can be a common thing in those with NF. It hasn't really changed how i feel as my family already has a history of breast cancer	Subtitles Family history of breast cancer
YW	12. Animation was very informative.	Informative
YW Doctor holds the power for screening.	13. I turned 40 last June and knew I was able to get breast screening because I have regular NF appointments with my 3 year old little girl and got told at these appointments that I should ask for screening. I don't believe we should have to ask for this we should just get offered it. I asked my Dr to refer me over 1 year ago now and I am still waiting!!	Screening went Powerful system Powerful doctor
A	14. Amazing	Amazing
A -reduction of power dimensions?	15. It was a brilliant video - really easy to watch, really informative and not at all patronising.	Really easy watching Really informative Not patronising
YW Power dynamics -> A battle where HPs win. Old teaching of performing breast exam	16. Doctors still need to be educated and be made more aware of what NF1 is and the associated risks of having it. Its can be a loosing battle trying to push for things NF causes and puts you at risk, you aren't always listened to because of your age and doctors not understanding what nf is and the increased risk of other heath issues. I think it would be useful for the video to explain how to check your breasts as your always advised to check them but never been told the right way to do to it	lack of NF1 knowledge of HPs loosing battle Not being heard Barriers: age Barriers: lack of HP knowledge Right way to do it?

learning of increased risk A low personal breast cancer awareness? other concerns → breasts not considered a priority?	17. I did not previously know about the increased risk of breast cancer for women with NF1, so I have definitely learnt something by watching the intervention video. I was not previously aware that women with NF1 should check their breasts once a month, so I was surprised at this frequency, and feel sad at the thought that women with NF1 would have to think about this risk so much/often. I understand why women with NF1 would feel nervous or reluctant to check, given that they often have other health concerns to think about too.	learning about increased risk Surprise of monthly checking lack of own BCA Burden of other health concerns Reluctance with concerns
A learning of warning signs	18. It listed a few more things to look out for than I was aware of.	increasing about warning signs
A	19. yes a little bit very informative	Informative
A Breast cancer awareness is important for all Do we need to look at how we are communicating our BCA information in general? Lots out there, BUT this does not mean that it's been 'taken in' ??? Animation - a potential missing link to create a deeper level of self awareness to set intentions?	20. I think it was a very clear animation that would encourage people with NF1 and those without to check their breasts regularly. Being the age I am and having had mammograms and finding cysts in my breasts I had pretty good idea of what to look out for before but a lot of younger people who haven't reached the age to have mammograms may not know as much information. I personally do not check my breasts as much as I should. This animation has made me think to look at them once a month either by having the same date eg 1st of the month or setting a reminder on the phone which was an idea I picked up from the animation.	Clear Encouraging for all Providing self-awareness setting behaviour intentions set a reminder Picked up from animation

Coding process

Step 1: Collation of codes

Rose (YW)

Late diagnosis	Eh, I had a late diagnosis, and I was diagnosed at 18
HPs – lack of knowledge HPs – rare knowledge of rare disease Nothing to worry about (unmet needs) Broken links in the system Broken knowledge breaks links in the system	When I hit puberty, I started growing fibromas. I'd been to the doctors multiple times and they'd informed me that all children and young women have different lumps, and bumps, and marks, and it was nothing to worry about.
HPs – growing knowledge of rare diseases HPs – growing knowledge of rare diseases Meeting needs Strong links create a chain reaction Forging chain reactions from strong links	[...]I managed to get an appointment with a newly qualified locum and basically just asked if she could refer me to have the lump removed just not knowing obviously what it was. She informed me she wasn't happy for me to just have it removed, she wanted me to go see a geneticist because she believed that I had this condition [...]
Googling for answers Googling for answers	[...] I was like, I 'googled' even though she told me not to google it, I googled it.
An obvious diagnosis for an obvious sign An obvious diagnosis for an obvious sign	[...] when I got the appointment with the geneticist I walked through the door and she basically said, 'I don't even need to blood test you, I can tell by looking at you that you have this condition, and that's how I got diagnosed!

Unmet needs (late diagnosis) Unmet needs create struggles Broken links in the system Struggle (childhood -learning) Unmet needs create struggles Broken links in the system Broken knowledge breaks links in the system	Em, so obviously before I was diagnosed, I just thought that I struggled in school, I know that em, they say that a lot of NF1 patients struggle to keep friends and make friends. That was definitely something that I struggled with, but I think more it was school, so I really struggled at school, learning wise.
Awareness is a shared experience – social media (TikTok) Awareness is a shared experience Rare knowledge of rare diseases General rare knowledge of rare disease Broken knowledge breaks links in the system	I (.) I do have, I'm quite big on TikTok, and I use my TikTok platform to spread awareness for NF1 because it is a condition that a lot of condition that a lot of people don't know about...
Patient having to be expert/teacher Patient having to be expert/teacher	So, I always try and do my research to talk, when I do a question and answers about the condition that I'm very knowledgeable on what the questions I've been asked [...]
Animation increases BCA Animation provides the ins and outs Animation provides the 'ins and outs' beyond the lump 'Ins and outs' through animation Knowledge as empowerment ('myself' = ownership) Knowledge empowers	[...] but until I watched the video, I didn't really know much about the breast awareness. I knew that NF patients were more likely to have breast cancer at a younger age, but I didn't really know the 'ins and outs' of it, so, I it was very knowledgeable for myself.

Continuing confusion – breast fibroma or breast cancer? NF1 complexity - fibroma or cancer?	So, I'm, I've got a lot of fibromas on my breast area, I would never say that I was comfortable in noticing the changes because, to me I don't know how I would know a change from a fibroma to potentially a cancerous lump.
Barriers to seek medical help goes beyond BCA Barriers to seeking help goes beyond BCA Unmet needs (breast concerns/screening) Unmet needs A disconnected system. A disconnected system Stuck Power play barriers Stuck within barriers of a disconnected system	So, I've, (.) I've always, ((pause)) eh, I'd say for the last 2 years I've spoken to my GP about em, having a breast screening because I'm always concerned because the fibromas grow, and sometimes they can be painful, sometimes they can't be. My doctors have never ever helped me with getting that done. The majority of them have said I need to contact my, em, NF clinic in *** but they are sometimes quite hard to get hold of, so I'm still like, I'm still stuck in the same position I was in before.
Screening knowledge – not much change Knowledge is power Knowledge is potential power Tentatively planting the seeds of potential power	Eh, it has, I wouldn't say it's changed a lot, but it has encouraged me that I could potentially call my doctor and say that I've come into some knowledge that I'm allowed to have one earlier due to the condition that I've got.
A strained system in power A disconnected system Broken links in the system A strained system strains patient power/empowerment Broken knowledge breaks links in the system	**Interviewer:** Yeah, yeah absolutely. Do you feel that it could increase that empowerment, or no? **Rose:** I'd hope so, but obviously I work for the NHS, and I understand the strain that the NHS is under...

Stuck within barriers of a disconnected system	
A strained system strains patient power/empowerment Stuck within barriers of a disconnected system	...and I think sometimes, it makes me a bit scared to call and say, 'this is what I know. This is what I want done'.
HPs – lack of knowledge (HPs qualified years ago) HPs – growing knowledge of rare diseases (newly qualified HPs) Patient having to be expert/teacher Broken knowledge breaks links in the system Strong links create a chain reaction Forging chain reactions from strong links Patient having to be expert/teacher	I think that older doctors may need a bit more knowledge on the condition. I know of family members, who are like, just qualified to becoming doctors that em, newly qualified doctors are made very (.), they're made aware about the condition a lot more, than maybe a doctor that qualified, say 15 years ago, but I do think that they (.), it's almost like they need the knowledge of the condition because a lot of them have never heard of the condition really, and I still, like, when I go to the doctors I'm sort of telling them about the condition, more than them helping me with the knowledge that they are aware of.
How has taking part in research made you feel? Empowerment through animation Knowledge empowers	Em, it's made me feel quite good about myself, and I feel like I can use hopefully when everythi-, like the research has been completed that I could help relay what the research has said to help other people who

Tentatively planting the seeds of potential power Awareness is a shared experience Awareness is a shared experience	might not necessarily know anything about it, who have the condition, if that makes sense?
Do or feel differently? Check breasts more within struggle to figure out differences Self-efficacy confusion NF1 complexity - fibroma or cancer?	I probably would check my breasts a lot more, although obviously I still will struggle to figure what is what, because it's (.) I wouldn't know, obviously like I said, I think I said previously, I wouldn't know the difference in the feel of a fibroma and a lump, because, yeah, I don't know how you'd know the difference in that feel.
Confidence to seek medical help Empowerment through animation Tentatively planting the seeds of potential power Knowledge empowers Tentatively planting the seeds of powerful actions and empowering thinking	I mean, 'cos obviously I have, I have been before, but the video has definitely made me realise that I can go, and I can't be pushed away as I have been before.

Sarah (YW)

HPs – lack of knowledge	I was diagnosed with NF1 when I was roughly
	about 26, (.), em, I knew that I had the CALs
Unmet needs (pain)	when I was younger, but obviously I did go to
	doctors about these and it was just,' yeah,
Broken knowledge breaks links in the system	you've got birthmarks, em I did have the-,
	and I never know what it's called, one of the
HPs – growing knowledge of rare diseases (optometrist)	little-, on my ankle and it was quite big so I
	went to the doctors about that and I said,
	'hey, it's just like a birthmark it just comes
Strong links create a chain reaction	right out', rather than being like, the café sort
	of mark,' so I was like, 'okay', I didn't think
Forging chain reactions from strong links	anything of it. I used to have a lot of back
	pain as well and just thought, cos I used to be
	a gymnast and a dancer, and just thought it
Googling for answers	was due to that. So, I never really got
	anything done about it, and then when I was
Googling for answers	in my middle twenties, I went to my regular
Patient having to be expert/teacher	eye checkup that I have, and the doctor
Patient having to be expert/teacher	picked up that I had Lisch nodules, em in my
In the power of 'lost' healthcare professionals	eyes so he, will not the doctor, the op-, the
	eye people ((laughs)) and they referred me to
	the doc-, the hospital. I went to the hospital
Patient having to be researcher	and while I was there they said, 'yes, you
	have got Lisch nodules', and then googled
Patient having to be expert/teacher	Lisch nodules which made me feel really
	uneasy, em thinking, 'why are they googling
Broken knowledge breaks links in the system	Lisch nodules?', and they said, 'yeah, no
	problem, you're fine, they're just like
	birthmarks in your eyes', so okay. Me being

	me, when I researched Lisch nodules, and I know you shouldn’t google, they tell you not to but I went and I googled, and as soon as I put in ‘Lisch nodules’, neurofibro-tosis, I can never pronounce that properly ((laughs)) came up, and I started reading the, d’know, what the main things are, and it was like the CALS, the freckling in your armpits, your like lumps and bumps. I was just like, ‘god, I’ve got too many of these. And then I looked a bit further in and it scared me to death because obviously it’s so wide open, isn’t it? Em, and I went to my doctors, and I said, ‘look, I think I’ve got this’. And they’re like, ‘why?’. And I sort of told them, and they was a bit lost and said they didn’t know, they didn’t know what to do with me, and if I didn’t have any problems, it’s not a problem. So, I was like, ‘well that’s not right, really’. Em, I started researching more myself, finding Neuro-, it was Neuro Foundation, it’s changed its name now ((pause)), em- ((pause))
Awareness is a shared experience (The importance of charities) Awareness is a shared experience HPs – An obvious diagnosis for an obvious sign An obvious diagnosis for an obvious sign	They chang-, when I first found it, it was the Neuro Foundation, obviously it’s the Nerve Tumours UK now and I found that and I ended up speaking to one of the nurses on the helplines and the referred me to **** which it was at the point, and doctor, was it, *** (.) I think. He’s retired now. And I went to see them at *** hospital, em and they

	confirmed there by looking at obviously my body and said, ‘yes, you have got it’.
HPs – lack of knowledge Unmet needs - abandoned	[...] it went obviously back to my doctors that I’ve got here, and they said, ‘cos you’ve got to the age you are (.)- you haven’t had a problem so, any changes to your body, any major headaches, anything come back to us’.
HPs – lack of knowledge (NF1 and women’s health) Broken knowledge breaks links in the system	All I got told when I was pregnant was, ‘if you have an epidural, it might not work if you’ve got a growth in your spine’. That was literally, all I got told through my pregnancy.
Unmet needs – abandoned Lack of resources and support for rare diseases/NF1 Persistence needed to have needs met Broken knowledge breaks links in the system The power of knowledgeable HPs Strong links create a chain reaction Forging chain reactions from strong links Awareness is a shared experience - Importance of charities	Em, and then I sort of started focusing on my daughter, rather than me ((laughs)), d’know, I sort of forgot about me again. I then, I tried to get in touch with *** again, because I thought the support of the NF nurse, d’know, the NF nurse, she’d retired or moved on, the doctor I’d saw had moved on, and I was like, ‘where do I go? What do I do?’. I was e-mailing. I was getting nowhere so I went back to the Nerve Tumours-, people, and they said they haven’t got anyone for sort of my area yet, an NF nurse, but they are looking at getting one. So, anyway, I kept messaging, d’know d’know, ‘have you got anyone yet? have you got anyone yet?’, and then eventually they came back and went, yes, they have, and it's *** isn’t it? And she’s been absolutely amazing. Em, as soon as I got in touch with her, she was like, ‘right, I’m

Awareness is a shared experience Forging chain reactions from strong links	your nurse and I'm your daughter's nurse now. Don't be alone, d'know'. And then she told me about the breast screening, and what I should go looking for. As well as she sorted out all the appointments and things for my daughter as well, cos obviously we've also got hydrocephalus appointments as well from someone else. So, but if it wasn't for the Nerve Tumour Trust, I probably wouldn't be here now, d'know, talking to you cos I'd be still be thinking, 'yeah, we're alright' ((laughs)).
Unmet needs (by being undiagnosed as a child) Struggle (childhood – learning) Unmet needs – the negative effect on the perception of the childhood self Broken knowledge breaks links in the system	Em, well I was at school, I em, struggled with maths and English, em, and back then you was like, you are either bright, or your (.) not so bright ((laughs)), I don't want to say 'thick', but basically that was it was when I was at school, and it was like, 'well, em, you're not making a problem in class, you're a well behaved child. Just get on with it'. And I went through school which I haven't really told many people, copying my work to get where I needed to get. It was going in but because I had the problem with the literacy and things, it (.) d'know I struggled, and then when it came to my exams, I never finished any of my exams because I had to read things, two, three times for it to go in before I could answer it, and then by the time I got to say question 10 if there was 15, the time was up. So, it sort of affected me in that way. But

	then I always knew what I wanted to do. I was like, 'right when I leave school, I'm going to do this', and I did it. My mum helped me through all my assignments and things, and I've now got the job that I wanted to do. Em, but that's not through help of anyone else. It's me and determination and my mum helping me. But yeah, I did struggle through school, and now thinking about it, it wasn't just, 'I'm thick'. I obviously have problems, d'know, and it's probably linked to the NF as well.
Increased BCA – wider knowledge of warning signs Animation provides the ins and outs Animation provides the 'ins and outs' beyond the lump	[...] it was interesting to know what to look out for, for the breast cancer and what is just, like what you said just the NF because I didn't really know the difference if I'm honest, d'know. You get told how to check with your palm of your hand and things, but other than that it's like, yeah it's just a lump but what do I look for. It made me aware of what the changes could be, and what to look for. Cos all I really knew was, you check it with your palm obviously if you've got any discharge coming out of them, and I knew that, but I didn't really know any of the other things to look out for.
Unmet needs – the push for a doctor's appointment The power of knowledgeable HPs (charity support)	Em, I don't know if I would be confident or not to be fair. Em (.) it's hard-, because I think when we go to the doctors, it's difficult cos I'm very, if I want to go to the doctors I'll go and they're going to see me and I will push

HPs – lack of knowledge a barrier to confidence in seeking medical help Patient having to be expert/teacher HPs – lack of knowledge a barrier to seeking medical help Broken knowledge breaks links in the system Strong links create a chain reaction Forging chain reactions from strong links Stuck within barriers of a disconnected system Patient having to be expert/teacher	for that appointment because it's so difficult to get my appointment now. It was like I want an appointment about some lumps that I've got, em, and I sent a message in cos you don't really ring these days, do ya? And they said, 'oh we'll get back in touch with you within 4 weeks'. 8 weeks later, I'm still waiting, and the NF nurse said that I should be seen within 2, if it's to do with anything like that. Of course, then I chased them, and then it was like, 'no, no we can't, we can't remove any of your lumps ((laughs)), d'know and it's like, 'we need the ((inaudible))', and it's like, 'well, no I've got NF, you don't'. And the lack of knowledge from the doctors just makes me think, 'why bother going?', 'why don't I just get in touch with the NF nurse and see what she says?'. But you still gotta go through your doctor, cos they've go to-, d'know, and so sometimes, ((laughs)) to answer your question (.), going to the doctor, I might put off longer than I should. I'm confident going, it's not a problem there, but I might put it off a bit longer because they're like, 'oh, I don't know'- 'well, you need to know!' ((laughs)). D'know, and they sort of-, because they don't know lots about it, they're like, 'well I don't know where to refer you'. And I'm like, 'well I don't', d'know. And that's why now I go and speak to the NF nurse, because I'm like, 'tell me what they

	need to do, and I'll go tell them'. And actually, this week, she's rang them for me, and told them what they need to do, but to me it's like, there's no knowledge that much with the doctors, and that's maybe why I stand back and not go when I should go and wait a bit longer. If that answers your question ((laughs)).
HPs – the desire to learn about rare diseases Patient as specimen Strong links create a chain reaction Forging chain reactions from strong links The need for respectful curiosity in learning	((in overlap)) when I went the last time, there was some students in, and there was like, 'oh, we've got some students in and they've just done about this. Can they all have a look at you and have a feel of this- ((laughs))', and I'm like, 'well yeah but then what are you going to do for me?'.
HP – lack of knowledge HPs – lack of knowledge a barrier to seeking medical help Broken knowledge breaks links in the system Stuck within barriers of a disconnected system	And the doctors do try, I'm not saying they don't try, but they just don't' seem to know what to do with me when I go about an NF problem. And that's why, maybe, not I'm scared to go, or I haven't got the confidence to go, it's just, 'what's the point?' More than-, if that makes sense.
Empowerment through animation Confidence to seek help through learning	Em (.), I think because it's not an NF problem as such, it could be like breast cancer, I think I would go to my GP more now, now since I've

Tentatively planting the seeds of potential power Knowledge empowers Tentatively planting the seeds of powerful actions and empowering thinking	seen obviously that file that I've watched. I think I'd be like, 'well no, it's not my NF. It could be breast cancer. I'm going'. So, I think that I would go for that reason. But if it was to do an NF reason, I think I'd stand back.
HP – the power of knowledgeable HPs (charity NF nurse) Strong links create a chain reaction Forging chain reactions from strong links	, and they said, 'well, the one thing you need to know is, from 40 you're entitled to breast screening'. So, I was like, 'Oh right, okay. Fair enough', d'know.
Patient having to be expert/teacher HPs Lack of knowledge a barrier to accessing screening Patient having to be expert/teacher Broken knowledge breaks links in the system Stuck within barriers of a disconnected system	. And then as I was coming up to my 40th birthday, I was like, 'right', I think it was about 6 months before, I was like, 'then I will go to see him. Then it will be in place for when I am 40'. You can probably see where this is going. Em, so I went to my doctors, and they went, 'but you're not of an age for that yet.', and I'm like, 'no', and then I had to explain to my doctor, 'but I've got NF1, and d'know I can get them from 40'. 'Oh right, okay, well we'll refer you then'. Anyway, referred me. I got a letter saying I was on the waiting list. Em, my 40th came and went and then only a couple of weeks ago, I was like, 'right, I need to chase this, cos I'm like getting towards 41 now. Em, I'm going to chase this'.

	I chased it. I rang the number that it said on the sheet that said I'm on the waiting list.
A disconnected system Passed from pillar to post HPs – the power of knowledgeable HPs (charity NF nurse) Broken knowledge breaks links in the system Stuck within barriers of a disconnected system Strong links create a chain reaction Forging chain reactions from strong links	[...] you are on our list, but we don't do breast screening'. So, I'm like, 'where the-, heck do I go next?' So, I was just like, fed up with being passed from pillar to post so I put the phone down, got in touch with the NF nurse, and she was like, 'right, leave it with me. D'know, I'm going to contact where I need to contact and again, not through my doctors, through the NF nurse she actually sorted it all out and I got an email from her saying, 'I will get my appointment through soon, and I'll be seen hopefully soon'.
HPs – lack of knowledge Broken knowledge breaks links in the system Stuck within barriers of a disconnected system	[...] it's just again, like you say, this is what I'm entitled to. This is what I should be having. And nobody knows.
Barriers to BCA HPs – lack of knowledge Patient having to be expert/teacher Power struggle	**:** Em, I think it's-, for me it's just mainly the lack of knowledge of professionals out there really, you know, if it's not an NF specialist they don't seem to know or link-, to obviously cos with my daughter having hydrocephalus they'd know about it as well, but if you just speak to a normal GP or a walk in centre or

Broken knowledge breaks links in the system Stuck within barriers of a disconnected system Patient having to be expert/teacher	anything, I think that's what will put them off because you go and it's like, 'well you've got NF1, you know, that lumps that, or that marks that', and I think that would put a lot off, but I'm quite confident in myself to go and say, 'no, look it's this, it's this, it's this, it's this', and then they're like, 'well, we've got to look into it', and it's like, 'well, just take my word for it!' ((laughs)), d'know, and then, they get back to you, god knows how long later, and so I think that's the main thing I think that would put women off, the lack of again knowledge of the local GPs.
HPs – growing knowledge of rare diseases Strong links create a chain reaction Forging chain reactions from strong links	But, when I was last with my GP, I was impressed that the students there were doing a, like a unit on it. And I was like, 'oh that's a good start' ((laughs)).
HPs – growing knowledge of rare disease HPs – the desire to learn about rare diseases Rare disease reality – difficulty of getting diagnosed Strong links create a chain reaction Forging chain reactions from strong links	So, and then they said, 'we've literally done a unit on it but not seen anybody'. So, I was like a shiny penny to 'em, you know ((laughs)). 'So, let's look at you!', so that gave me a little bit of hope, but then they've got to come through, it's the doctors now that don't have the knowledge. And I know everyone says, 'oh but it's rare. But it's more common than you think, I think. And if I didn't have my eyes checked, I still wouldn't know, d'know, you'd just think, you've got birth marks, d'know.

Broken knowledge breaks links in the system	And I think that's the scary thing about it, as well.
HP – lack of knowledge HP lack of knowledge – a barrier to seeking medical help Patient having to be expert/teacher Broken knowledge breaks links in the system Stuck within barriers of a disconnected system Patient having to be expert/teacher	But, now I'm like, no. I've got my right to be seen by a doctor. I've paid into the system and what not, and but when I have to more or less tell them what I've got it's a bit (.) worrying, and a bit off putting, really.
HP lack of knowledge – a barrier to seeking medical help Power struggle Broken knowledge breaks links in the system Stuck within barriers of a disconnected system	And I think that's the main thing because I'm quite confident in that now. And I think, 'no, I'm gonna go, and I'm gonna tell 'em', but the people aren't confident, and are d'know, less-, 'oh I don't want to bother them'. They might not go, because what's the point. They'll just say, 'no, you can't have it, or you've got no symptoms of it'. And I think it would put less-, nervous people off.
Increased BCA – warning signs Animation provides the ins and outs	I think it was like very good, cos like I said I didn't know what to look out for. All I thought, and knew was, honestly if you feel a lump-, but it's not just about the feeling the lump.

Animation provides the ins and outs beyond the lump Beyond the lump	
Beyond the lump Breast cancer is a taboo subject Animation provides the ins and outs beyond the lump Breasts are taboo	[...] I just thought, 'oh yeah if you've got a lump, d'know if you're feeling then that's-, you go get it checked out'. But I didn't really know all the other signs as well. What to look out for. Cos it's about breast cancer, it's not something people talk about, is it?
The assumption of 50 years for all Confusion in age for increased risk – issue with Breast-CAM-NF1 items Increased BCA – warning signs Increased BCA – breast checking Animation provides the ins and outs beyond the lump	And especially if you've got NF, it's like, 'oh yeah, well you're not 50 yet, like everyone thinks. But I know with NF it's more important isn't it between 40 and 50, or is it 40 and 60, or whatever they are, I'm not-, see I don't 100% know what age ((laughs). I know, I have known that from 40, but I wouldn't have known what to look out before I watched that, but now I do. And I probably wouldn't have checked as often.
Behaviour change – Checking once a month Setting a reminder Tentatively planting the seeds of powerful actions and empowering thinking	Well, I said to myself, payday ,that's my reminder ((laughs)).

Payday is breast day Tentatively planting the seeds of powerful actions and empowering thinking	Because it's like the end of the month I get paid so then it's like bills, it's when you sort everything out. So, it's a bit like, I'll sort that out at the time, as well. That was my thinking.
A visual learner Animation for inclusive learning Seeing human breasts is taboo Seeing human breasts is stressful Animated breasts are not so taboo Breasts are taboo Animation has the safety of a children's programme Animation is a protective shield from taboo breasts and scary facts	I mean, for me, to be fair, I probably learn better through animation. Because I'm a bit more of a 'seeing learner', rather than a 'reading learner'. Em, and if I watch an animation, it's like, 'oh, yeah I'll remember that'. Em, and I think for me that it sinks in better because I think if you saw, like, a real woman on the screen, like feeding or showing, or whatever, because it's a bit of a taboo subject you feel a bit, 'oh', tense as you're watching it. And it's like, I don't know, do you know like, that's a woman, that's her breasts, that's-, and it shouldn't be a taboo subject, but I think it automatically puts people off a little bit. Where if you see an animation, it's not anybody, it's no one's face. It's just like watching a programme, d'know, a children's programme, so for me because I'm a thinker and a learner of watching, I think it was better in animation, than an actual person stood there. Because, then it's not so taboo.
Taking part in the research Protection of anonymity when raising awareness	But now, I'm still cautious who I tell because I suppose I'm a bit like, I don't want them to think that I passed it onto my daughter. I don't want them to think I'm selfish, em, and

Awareness is a shared experience Awareness is a shared experience	I know you'd say I'm not, but depending who I tell, is depending how I feel about them. So, I do sort of shy away. So, helping on research, because I don't have to give my name and because it's all anonymous, I'm like, 'right, we need to get it out there. We need to get people knowing about NF'. So, I will help all I can. If I had to put my name to it, I don't know if I'd be as helpful, but I just want to help as much as I can and get it known out there. Getting the doctors to know, getting women to know.
The desire to reduce unmet needs of others Strong links create a chain reaction Forging chain reactions from strong links Awareness is a shared experience – Reducing unmet needs for daughter Awareness is a shared experience Animation to empower others (daughter) Tentatively planting the seeds of powerful actions and empowering thinking Knowledge is power	I just feel happy that I can help put towards the research because obviously I struggled getting anyone to point me in the right direction or give me answers that I needed that I haven't got because nobody knows. So, yeah, I'll help all I can. It's-, I'm a little bit proud of myself that I can do that now because before I wouldn't have been able to, and I think it's more for when my daughter grows up as now as well. D'know that she doesn't have the same (.) walls that I've had.
Child as motivation to be breast cancer aware	I think that's made me see it all differently. Cos, I said it earlier on that I don't matter now, but I know I do because I've got to have

Strong links create a chain reaction Forging chain reactions from strong links Tentatively planting the seeds of powerful actions and empowering thinking	these checks because I've got to be here for her, but I think she's made me focus, 'yeah, we're going to do this. Yeah, we're going to get it out there'.
Increased BCA – checking and warning signs Awareness is a shared experience (partner) Animation provides the ins and outs beyond the lump Awareness is a shared experience Strong links create a chain reaction Forging chain reactions from strong links	Em, I feel like I need to check once a month ((laughs)), it's not just the lumps you've got to feel, it's all the other things that you need to look out for. And, I think, I know, it's probably daft cos I-, I think I'm gonna tell my partner what we need to look out for as well, and sort of have him to have a look and check cos obviously looking underneath and things is a bit more tricky.
Increased BCA – Confidence Increased BCA – self-efficacy Tentatively planting the seeds of powerful actions and empowering thinking	I think I'll feel more confident in looking now, as well.
Awareness is a shared experience HPs lack of knowledge Rare disease reality – difficulty of getting diagnosed	I just-, I wish you luck in this research and I just want it to get out there more. Because you mention NF and some doctors even look puzzled, d'know, or the longer word ((laughs)), d'know, and I just want people to be more aware of it. People out there that

Forging chain reactions from strong links	don't know that they've got it. Even to have that sort of knowledge on it, d'know although everyone says it's a rare disease but there's more out there than you know.
Awareness is a shared experience Forging chain reactions from strong links Lack of knowledge of rare disease makes it taboo Forging chain reactions from strong links Tentatively planting the seeds of powerful actions and empowering thinking	But and I just think for me, it's that important that you're doing this research, and that's why I've offered to help that, more people to know, d'know. I don't know how to do that, that's obviously what your research and things is for, but just to get to get out there, and it not to be, 'don't tell anyone', like, feel like I can't tell anybody, d'knew, it's nothing to be ashamed of. It's just like, if a child has down syndrome, if a child has dyslexia or on the other side of it, it's nothing to be ashamed of, it's just (.) life, d'know. So, I just want- in answer to that question, I just want it to get out there, and people to understand about it.

Saffie (YW)

Late and recent diagnosis Shock of diagnosis Only diagnosed through son's diagnosis Broken knowledge breaks links in the system	Okay, so I was actually only diagnosed last year, em (.) because my son was being tested and they decided to do my blood test as well and they said that it was to see about who carried it, and yeah that I had it, so yeah it was quite a shock, didn't know I had it...
30 years of not knowing Broken knowledge breaks links in the system	Em, so yeah, I've been like (.) 30 years not knowing ((laughs))

Only diagnosed through son's diagnosis Personal suspicion of NF1 Broken knowledge breaks links in the system	So, em, so it's quite recent really. I mean (.), my son was being, he was being tested over a period of 3 years and there were times that I sort of suspected that I had it because I had some signs, but not like my son, I was like, 'oh no, I don't have any of that', that it turns out that I do have it.
NF1 clues Unmet needs (late diagnosis) Struggle (childhood – learning) Broken knowledge breaks links in the system	Em, I'm quite small and em, so my son has a lot of problem, he's like, with his growth, he has a lot of pain, em and some of the like, the markings, like I only have like 3, and I always thought they were just birthmarks, and so right, I do have them, em and have quite, and my son has some minor learning difficulties and when I was in school I struggled a lot, em (.) so it was sort of like that, oh, you know, I've gone through quite a long time, with all these problems, thinking I was just stupid, or slow, when actually there was probably a reason.
HPs – an obvious diagnosis for an obvious sign HPs – growing knowledge of rare diseases An obvious diagnosis for an obvious sign	Em, so, I think it was during a check-up when he was at the paediatrician because he wasn't growing, em, and he had a lot of other issues and they were like, 'we want to do a genetics test', em, because I think they suspected things like dwarfism with him, em and then they were like, 'actually there's this other thing', because then they sort of, you know, took all his clothes off, and they were like, 'oh he has got quite a lot of markings, we do need to test him for NF1'. But yeah, didn't even know what it was before then.

Unmet needs (adult diagnosis) A disconnected system Broken knowledge breaks links in the system Stuck within barriers of a disconnected system	Yeah, and I think 'cos it's, I'm not, I'm not under anyone, I'm not, like I've never been checked, em, so yeah, it's a bit worrying, I was like, 'cos still now I'm still not under anyone clinically, I'm you know, no one, I'm not even sure if my GP is aware that I have it, have they been passing information? But I don't think that they are aware.
Increased BCA (Risk) – learning through son's genetic consultant Googling to fill in the blanks Forging chain reactions from strong links Googling for answers Patient having to be expert/teacher	((in overlap)) em well I found out, I found out obviously that the risk was em slightly like higher when my son went to see his genetic consultant, and she...his consultant was quite concerned, you know, you've gone a long time with no checks and no awareness of this, em, so I really had to do a lot of my own information from Google, which ((laughs)) is not the best thing to do, 'cos it, Google tells everybody that they're dying and ((laughs))...
Learning through NF charities Learning from others on social platforms Awareness is a shared experience HPs – Lack of knowledge Forging chain reactions from strong links Broken knowledge breaks links in the system	em, that yeah there's, however the Childhood Tumour Trust, they've been quite good. There's lots of information with them, and you know, being able to speak to other parents is great, em, but I would say that there's little for anyone else. Like, I mean, (.) I work in the NHS and most of them are not even aware of NF1, they're like, 'what's that?' You know, they're clinicians, they're not aware. There's such a small percentage of them that are like, 'oh I do know what it is, but I'm not quite sure on the (specific)'.

Previous BCA knowledge Knowledge is empowerment to check BCA can lack diversity (breast sizes) Animation provides the ins and outs beyond the lump	Em, I mean I think I already had quite a good understanding on, you know, the signs and that, and checking. It is something that I do, do. However, I will say that on most, you know, there is a lot of information on how to check, but it's (.), it's often based on women with (.) average, I don't know if you say average sized breasts, not you know, it's not based on women who are flat chested which is, you know, for me, I'm fla-, if I do develop breast cancer I'm not going to get those obvious symptoms because I don't have breasts. I'm very flat chested, so I think there's little information on that of how to check, em, but the video, it was-, it was good because it lists-, you know, most people would just think lumps, which is not definite, you know, it's not always the case...(.)
Confidence to check if all is okay Is it cancer or something else? Tentatively planting the seeds of powerful actions and empowering thinking NF1 complexity - fibroma or cancer? NF1 complexity – fibroma, cancer, or hormones?	I do feel, I sort of feel confident checking, em, I just think, you know, yeah there's not much confidence if you suspect something, that's when I think my confidence probably goes.
The general confusions of BCA	yeah, yeah, and is it just like hormones?

NF1 complexity – fibroma, cancer, or hormones?	
Confidence is undermined by lack of HPs knowledge HPs – lack of knowledge HPs – potentially dangerous assumptions comes with lack of knowledge The fight to get an appointment Unfairly treated because of being a young woman – lack of HPs knowledge Broken knowledge breaks links in the system Stuck within barriers of a disconnected system	Em (.) I would be nervous; I still would not be as confident. I don't think that there's a good understanding of NF1 with GPs. I don't think that they have the expert knowledge as they should, and I've come from other things in the past and I've always been told, 'oh you're too young', you know, 'you're too young, it's just, it's just hormones. Come back in a couple of weeks if it's still there' And you're like, you know, I know that, yes, I am young, cancer in my age group is not as common, but it's not unheard of, it does happen, but it's the whole, 'you're too young', you know, and I don't think that they are aware that I should be screened at a certain age, and even, and if I do have signs I should be screened. And I think it's also trying to get an appointment now, just (.) I mean, I feel guil-, I feel that if I was say in my 60s and said that I had, like a lump, I would get an appointment straight away. If I was to say now, I have a lump, it wouldn't be considered an urgent appointment. And it would probably be like 3 weeks before I got to see a GP, so I probably would put it off because I would just-, eh yeah, I think it is yeah like trying to fight to get an appointment and it's just time consuming and, I'm just, like even just to try and get a regular GP appointment now is just (.), really hard ((laughs)).

Previous BCA (screening) Knowledge does not always mean power Power dimensions – GP has power to screening access Difficult in gaining screening access Going private to get screened to get into the system Knowledge is empowerment Broken knowledge breaks links in the system Stuck within barriers of a disconnected system Tentatively planting the seeds of powerful actions and empowering thinking	So, I think I did come across something before saying that I was to, that I could be screened younger than the average person, em so that's definitely saying, so that's something that I definitely want to happen, em but the access to getting it may be difficult, with the lack of ((in audible)), because you know, it's usually the GPs that arrange it. However, I think, if I was having a lot of issues, I would just go private. I think I can get that arranged. Em, (.) and I'd hope that I'd only have to do that one time because then they would understand that actually yes, this is something that you should be screened anyway, we'll put you back to your GP, to make that they regularly do it, em, so yeah, I think, I mean yeah, the screening is something that I would definitely would take on when it's available, em, I think, you know, I have a few more years yet so I'm entitled to do that, but yeah, I think I would just bring all the information sheets to the GP, and say, 'look you're supposed to do it' ((laughs)), and just go... ((laughs))
Perceived power and opinions of HPs Awareness is a shared experience The importance of HPs having NF1 knowledge	Em, I probably still wouldn't feel as confident 'cos I think sometimes they...(.) I mean I've gone about things in the past, I think sometimes they look at me like I'm a bit, like, neurotic, and (.) you know, fussy, em ((pause)), I do think it would help though, you

The importance of empowering HPs with NF1 knowledge The need for HPs to meet unmet needs of HP patients Broken knowledge breaks links in the system Stuck within barriers of a disconnected system	know, with GPs, you know, if there is patients in their care that have got things like NF1... ...it should automatically be, you know, they should be given information for their patients on how to care and make plans for, and I don't currently think that they are, like, given that information. I think that would help-, it would probably, I would probably feel more confident if I knew that there was something that, you know, that the NHS itself did, automatically did.
Barriers to BCA Busy life *Breaking barriers to BCA* Make screening accessible – pop up clinics Cut out the middle GP Take back power Stuck within barriers of a disconnected system	I think as well, so as they recommend imaging from 40, you know, most, most women at that age are busy, are working, they've got kids, it's not convenient to make a GP appointment because most of the time it's nine to five, I work nine to five, I can't, I don't want to take the day off to go to an appointment, em, I think screening, more screening clinics, like these pop up clinics that they sometimes, I remember seeing they used to do like temporary breast screening units, I don't know if they got rid of, em, but things like that, em easier access to getting screened without the need for a referral from your GP, because I think the whole having to go to your GP first then waiting, it's time consuming. It surely must be costing the NHS a lot of money, em yeah, I think that if you're entitled to

	screening, you should be just able to arrange an appointment to be screened rather than having to wait for your GP to do it.
GPs as obstructing screening Take back power Stuck within barriers of a disconnected system	yeah, because if they have access to you, then yes, because I'm sure the ones that do the breast cancer screening, they're aware that there are a certain amount of people that do need screening much earlier. So, they're already aware of it. It's just getting the GP to get it in ((laughs)). So, if you could by-pass the GP it would be so much easier.
Disconnected system Stuck within barriers of a disconnected system	I think, if we were on their books, you know, instead of just having all that..., that would help, so I think that anyone that has NF1, females that have NF1 they should also be aware so that we just get a letter to go to our screening, rather than having to ask the GP to put you on that system. You should already be on it.
The animation gets you more No skimming More attractive to watch videos Animation for inclusive learning A Goldilocks animation for inclusive and engaging learning	Em, it was good to watch, I think, lots of people when it's just words skim, it wasn't something that you could skim so it was just good to watch, and I think a lot of the time it's (.), when you know, words, it's telling you without even looking, so I think sometimes visual, like pictures, is better 'cos it gets you more, like I'll be honest I skim a lot of stuff when it's just a long ((laughs)) yeah, so it's more attractive to watch videos, and yeah, really.

Animated versus real body – no difference as a personal opinion	Yeah, I think animation form is fine, I think, yeah it could be in life-like form, but I think in anim-, I don't think there's a difference to be fair.
People are more comfortable watching animation Watching animation offers more privacy to the topic Animation is a protective shield from taboo breasts and scary facts	Em, I think, I mean I'm comfortable watching anything, I think with animation, I think people are more comfortable watching animation form, then you know, non, because it depends obviously where you are watching it, and if someone looks past you, 'what are you watching?!" ((laughs))
Taking part in research BCA – not just something that can be ignored I think I need to be more aware Stop ignoring everything Embracing the truth and actions of being BC aware with NF1 Tentatively planting the seeds of powerful actions and empowering thinking	I can't say it's massively changed how I feel, but it's definitely know, you know, that it is something that I have to take serious, it's not (.), it's not just something that I can ignore. You know, I don't want to get ill. I don't want to get ill, young. Em ((pause)), so yeah, I think it, I think I need to be more aware, so it has it made stop ignoring everything. Not everything-, okay sometimes it is a hormone, it's just hormones, it might not be, and having, you know, I do work in NHS, you see lots of people who are sick, I don't want to be like that, and I know if I can prevent that, then great. Rather than, ignoring it. So, I think, yeah, I will take on that I am at more risk, and I just need to be checking as regular as I can, so I can be screened if I need to be screened.
Do or feel differently	Yeah, I think it is just more aware, I mean, I still sort of think like, 'this not really a convenient

BCA – can be an inconvenience BCA – not being taken seriously BCA is the power to potentially stop a bad outcome BCA and NF1 – power to potentially stop a bad outcome as a young woman Tentatively planting the seeds of powerful actions and empowering thinking	time', I think again, I think a lot of people who are like, 'oh I'm too busy', and like, 'I'm not going to take it as serious, oh it's probably nothing'. I think now though, I'm like, 'no'. It's not like, it's not just like a cold, it's possibly nothing, but I think if I ever do have symptoms, like, it's not something that, if it is cancer that it's not something that I can just ignore, like it will get worse, and I don't want that. Not at this young.
Take health more seriously BCA – added complexity with NF1 BCA and NF1 – It's for a good reason Shift in attitude – knowledge is power Tentatively planting the seeds of powerful actions and empowering thinking	[...] I think I'll take that one and take my health more seriously, and although I'm under hospital for different things, I don't, it's another thing that I'm like, 'ugh, more things that we have to do', but I think, you know, it's for a good enough reason, it's not something minor, it's something that could potentially be serious, so yeah, it's good, it's good information to know. Because, if I think if I was this young, and I did get any changes, I probably would have thought, 'oh that's hormones, or it's just where my clothes are uncomfy', without knowing any of that information, I probably would totally ignore it, like, 'oh I'm too young for that'.
The ability to face reality Empowerment through animation	Yeah, I think yeah. Now I know it's, it's probably just hormonal, probably, but there is a chance because of the NF1, and yeah, I need to stop brushing everything-, it might not be

Self-efficacy Confidence – not a waste of time to check Tentatively planting the seeds of powerful actions and empowering thinking	normal, it could just be nothing, but it's not a waste of time to find out it's nothing.

Laura (YW)

Early diagnosis	Eh when I was 7 years old.
HPs – knowledge allows for early testing NF1 family history Forging chain reactions from strong links	My birth dad has it, and there was a doctor that really pushed to get me diagnosed when I was younger.
BCA knowledge – not really changed History of BC in family Power of family with BCA Forging chain reactions from strong links	I don't really think it's changed because my family already has, em, a history of breast cancer so that adds on to my risk of it, so I'm always told to like, 'check', 'do this', 'do that' ((laughs))
Previous knowledge of screening Forging chain reactions from strong links	Eh, I was told from quite a young age that I'd be eligible for earlier screening.
Anxiety with BCA Always checking Anxiety	Yeah, I'm always checking ((laughs)). I have, like really bad anxiety so I'm always checking, always going to the doctor even if there's a slight difference.

Always going to the doctor NF1 complexity – fibroma, cancer, or hormones?	
Surprised by advice of 'once a month' checking Animation provides the ins and outs beyond the lump	I was quite surprised with that one.
Over checking Tentatively planting the seeds of powerful actions and empowering thinking	Well, I've always checked it, you know, every time I've had a shower... which is quite a few times a week.
Effect of animation – reduce frequency of breast checking Misinformation (family) Tentatively planting the seeds of powerful actions and empowering thinking	Yeah, I mean I think for my own personal-, that I'd reduce it down to doing it once a week (.). Em, but yeah, I thought it was a lot more, because I was always told, 'every time you shower, check!'
Always in contact with HPs, but HPs have a lack of knowledge HPs – lack of knowledge Memory from childhood remains HPs – online search for information Broken knowledge breaks links in the system	No, I mean I contacted them recently myself to go, about to go to them about the NF for a general check-up, so I'm always in contact with them. But then comes the issue of them having not a 'scooby do' about what the condition is. There was one time when I was younger, and my mum took me and we walked into the room and he had the information page up on the screen, which we both thought was quite unprofessional.

Googling for answers	
Lack of confidence in HPs' knowledge continues Lack of confidence in HPs' desire to know Broken knowledge breaks links in the system	I'm hoping the doctor I'm seeing today knows what it is or has at least researched it a bit.
HPs – lack of knowledge ('older' doctors) HPs – growing knowledge of rare diseases (junior doctors) Qualified doctors not given a chance to learn about NF Broken knowledge breaks links in the system	Just a bit annoyed, that there's not a lot of teaching going on, especially-, I mean, I know junior doctors now are taught about it because I've been to A and E, I was a student nurse. I've left the course now, em and the junior doctors knew about it, but the older doctors didn't, so, the older doctors aren't given the chance to learn about it, which is a bit disappointing.
Patient having to be expert/teacher Fight against the power of HPs Knowledge is power Stuck within barriers of a disconnected system Broken knowledge breaks links in the system Patient having to be expert/teacher	I tend to just give them, you know, a quick run-down of what it is and what normally is done, so for example, today I'm going for headaches that I've had recently, but that combined with some other symptoms I've had like dizziness, and such, warrants an MRI. And if they sort of say, 'well, no you don't need one', I would just kind of say to them, you know, I already have the tumours, there could be one on the brain, it could be something else. It could be this. It could be that.

Fight against the power of HPs Sticking up for yourself Patient having to be expert/teacher Stuck within barriers of a disconnected system Patient having to be expert/teacher	I've got much better ((laughs)) for sticking up for myself in front of doctors because of, because of this, so...
Barriers to being BCA Fear of the increased risk of breast cancer Facts in video might scare them Avoidance of BC reality Breasts are taboo	Eh, I think like general fear of it. Because obviously-, they already know that em, you know, well hopefully they already know through the doctor that they are at increased risk, so they wouldn't want to watch the video because it might scare them more, or they might just not want to think about it right now.
Cartoon format Helped Not scary No orders so no power taking Animated interventions are eye catching Seeing real people is boring	**:** Em, personally I think it helped. It was quite easy to understand. It wasn't, you know, using terms that would scare someone into, being like, 'oh no, I've got to do this now!' ((laughs)) Well, I prefer animated awareness videos anyway myself because it's more eye catching, where if it's people you're like,' oh no, this is boring'.

Animation is a protective shield from taboo breasts and scary facts A Goldilocks animation for inclusive and engaging learning	
Animation makes you think of childhood Animation is a protective shield from taboo breasts and scary facts	It's animation that makes you think of your childhood ((laughs)).
Animation is best to reassure young people Animation is a protective shield from taboo breasts and scary facts	The animation does help with, in you know, not getting too em, I can't think of the word (.), em, not getting too scared of everything, it's best to reassure the young people.
Screening eligibility Previous knowledge from family member going earlier Forging chain reactions from strong links	Yeah, because I remember my em, (.), my nan on birth dad's side going to screenings when she was 40...
Animation encouraging BCA HPs – lack of knowledge Animation to fight against HPs' lack of knowledge Forging chain reactions from strong links Animation provides a chance of empowerment and of giving power	Em, I think like particularly for people with NF, you know we're- (.), there's not enough specialists out there, so you know, some doctors be like, 'oh no, you're not eligible for this screening', then you can go, 'look this is, you know a proven fact', and show them the animation', and they can be like, 'oh okay'. So, it can boost in that aspect.

Tentatively planting the seeds of powerful actions and empowering thinking	
Increasing HP knowledge The need for basic training to be prepared to care for a patient with NF A compromise to accepting that it's not possible to know about every condition The need to fight against HPs' lack of knowledge as medical negligence The need for respectful curiosity in learning Patient having to be expert/teacher Broken knowledge breaks links in the system Stuck within barriers of a disconnected system	I think it's just, you know, basic training in it, em (.), doctors can't learn about every single condition out there. It's impossible, there's hundreds of thousands, but if a doctor's surgery in particular has someone with NF, em on their patient roster, because it's probably very rare there's going to be a doctor's surgery, you know, that has two or more people with NF, em, but if they do have a patient with the condition, they should do training on it so they are more prepared, you know, so for example, if I were to go into my doctor's surgery and be like, 'look this lump is hard. It's, you know, it's bumpy, like hard bumpy. It's hard, it's painful, you know, that is a sign that it's turned cancerous'. And if they don't do anything about it, and they don't listen because they haven't had the training it's medical negligence (.)
The perception that HPs don't care about NF patients as much as those with other conditions Misinformation about the statistical prevalence of other conditions (DS occurs in 1/1000 births). Broken knowledge breaks links in the system	Because you know if it was something like down syndrome, you know, they had a young kid in their surgery that has down syndrome they'd do the training on it, they'd probably already have the training, and if I remember right, NF is more common than things like down syndrome and cerebral palsy, yet nobody knows about.

Stuck within barriers of a disconnected system	
Knowledge barrier of HPs to learn about NF at university Broken knowledge breaks links in the system	I mean there's definitely loads of help for animations about the condition out there, em but even at university they can't learn about everything about NF...
The desire for patient centred care HPs need to place patients at the centre to help them learn about the individual's experience of NF Creating the individual benchmark for future consultations A learning culture of respectful curiosity and patient-centred benchmarks	but obviously the basic training would be, what it is em, how it affects someone, and meeting with that patient, you know, having you know a meeting, like an appointment with the patient, being like, 'how does this affect you?', 'what's normal for you?', so that they know that if I go in with something that is different, they know the next step.
A lucky dip of care for the patient Disconnected system A learning culture of respectful curiosity and patient-centred benchmarks Stuck within barriers of a disconnected system	And I'm sure there are some doctor's surgeries out there that do that, but mine don't ((laughs))
Taking part in research Helping	(.) Like I'm helping ((laughs)), you know, cos I saw it on the Facebook page and not many people had seen it by the looks of it, and that

The effect of lack of knowledge of NF on research and subsequently BCA Forging chain reactions from strong links	just yeah, lack of knowledge, probably about, you know, the charity and what they do, and about the condition, you know.
Do/feel differently Changes in checking – no longer continuously checking Feeling a lot more calmer Tentatively planting the seeds of powerful actions and empowering thinking	Em, I feel a little bit more versed now that I've seen that they recommend that they do it once a month instead of, you know, continuously checking. Em, that's made me feel a lot more calmer in that aspect.

Lilly (YW)

Diagnoses in childhood Diagnoses genetically recently	I was screened at the age of 12 and then I was genetically tested almost 2 years ago to have NF1.
Learning difficulties Scoliosis Depression Broken knowledge breaks links in the system	I have scoliosis with it, and I have learning difficulties, dyslexia (.), and it actually made my depr-, I actually have-, because I've had no ((inaudible)), I also have depression with it.
Animation suitable for young people Easy to understand	It's a really clear imag-, imagery and it's easy to understand for young people as well... (.)

A Goldilocks animation for inclusive and engaging learning	
Awareness is a shared experience – sharing with child Forging chain reactions from strong links	...because I'm also a parent with a child with NF1 so it's easier to understand.
Awareness is a shared experience – animation for everyone, including children without NF1 to learn Animation provides empowerment (check themselves) Tentatively planting the seeds of powerful actions and empowering thinking Forging chain reactions from strong links A Goldilocks animation for inclusive and engaging learning	Even with children without NF1, it's great for learning, for girls to check themselves. It's a great learning curve.
Animation paints a thousand words A Goldilocks animation for inclusive and engaging learning	It was more, what actually to look out for, what it looks like. The *** is not very good at show-, it's words and not many pictures (.)...
Animation keeps the eye on it A Goldilocks animation for inclusive and engaging learning	((in overlap))...the video was so clear and so understanding, it kept your eye on it and you could understand it.
Animation format Animation as providing protective distance	Sometime-, for me it's- (.), if you see an actual person you would feel a bit embarrassed seeing that but, like that form, in an animation

Actual person's breasts embarrassing to watch Breasts are taboo Animation is a protective shield from taboo breasts and scary facts	format, you know it's been designed so as not to embarrass somebody.
Diversity of characters – not only one race with NF1 A Goldilocks animation for inclusive and engaging learning	It shows you that, like, other people, is not just one like- I'm not trying to be racist here, it's not one set of, it's not one em (.), not one race that has NF1, it's lots of different races. I couldn't get the words out there.
Previous scare of breast concern Breast cancer is scary Breasts are taboo	I had a scare a couple of years ago...
Animation instils confidence to know what to be aware of when checking breasts Creating confidence through creating animation Animation 'shows' you what to do Animation provides the ins and outs beyond the lump	You know what you're looking for. You know what you're looking for now, because when you are on other pages it just says-, what exactly am I looking for, or when doctors say to you, it's like, 'what am I looking for', it's not easy to-, like it's that far up your armpit and round and it's like, but the video actually shows you what to do.

Animation instils confidence to seek help for a breast concern Power to go and seek help Empowerment to instruct HP Knowledge is power Tentatively planting the seeds of powerful actions and empowering thinking	((in overlap)) yeah that helps as well, so if I find a lump or anything, I can go to my GP and say, 'quick, I need to get seen'.
Previous knowledge of screening eligibility Forging chain reactions from strong links	**:** I knew it was round about the age of 40 before with NF1 and you had to start being checked. I knew that for a long time.
Knowledge does not always mean power Difficulty accessing screening Broken knowledge breaks links in the system	I don't if people with NF1 get it, get screened. I don't know many people that actually take-(.) cos I've got family members over the age of 40 and have NF1, and I don't think that they've been screened.
HPs knowledge of rare disease empowers patients with NF1 Awareness is a shared experience	((in overlap)) It was a genetic, it was a genetic clinic
HPs knowledge provides power to patients with NF Forging chain reactions from strong links	**...**It was that long ago, but that's one thing I'll always remember. Any genetics appointments after that, I was always told to remember what to look out for, even with no screening 'til 40, just to still keep looking.

Disconnected system Fallout felt by the patient Disconnected system effects BCA Broken knowledge breaks links in the system Stuck within barriers of a disconnected system	It's changing at the moment because the genetics nurses went back to *** ((inaudible)), so we're trying to figure out who it is. But I know that my team is based in Glasgow.
Awareness is a shared experience – for daughter Knowledge is power Empowering daughter with BCA knowledge Tentatively planting the seeds of powerful actions and empowering thinking Forging chain reactions from strong links	Because she's hit puberty I have to ((inaudible)) I now have to this for her, you know, she's only young. I want her to know what to look out for.
Awareness is a shared experience – for all ages Awareness is a shared experience – animation should be available to all Forging chain reactions from strong links	**:** Even it's for people over the age of 40 as well. Even if-, put it on as well, the animation, on one of the NF1 pages on Facebook, it would be amazing.
Barrier to being BCA Lack of internet access	Sometimes people not having internet access, or low income (.).

Low income Broken knowledge breaks links in the system	
Importance of information available in different formats to reach everyone HPs (genetics) – desire of patients to be kept more up to date Broken knowledge breaks links in the system	Sometimes stuff like that can't get through, but if like, if their clinic can speak to them about it, or if they send leaflets out. That's the one thing with genetics, I think, they don't keep enough up to date with their NF1 patients.
NF patients – forgotten HPs – perceived as dismissive Stuck within barriers of a disconnected system	I've had to phone genetics half a dozen times. They forget to respond back. They forget the NF1 patients are there sometimes.
HPs – barrier to getting appointments HPs – hold the power Stuck within barriers of a disconnected system	[...] it took me about 2 months to try and get an appointment sorted, and it was over email...(.)
The desire for extra support A waiting game to be seen Stuck within barriers of a disconnected system	I know everyone is having that problem but I think sometimes people with conditions should get that wee bit extra support, and a wee bit extra, 'somethings not right, we need-', especially with NF1 patients. I have had a few things, and I've had to wait months [...]
HPs – dismissive to patients	I was a wee bit fobbed off.

Stuck within barriers of a powerful yet disconnected system	
A dichotomous experience with NF1 Stuck within barriers of a powerful yet disconnected system	I just feel sometimes, like you're looked at having NF1 and you're just, 'oh right, oh you're definite to have a look', and then just fobbed off.
HPs – lack of knowledge Postcode lottery for care Lack of learning resources for HPs Lack of information provided to HPs and trainee HPs Broken knowledge breaks links in the system	Cos I think it's because I now live in a rural area. It's quite rural, and they don't know-, there's not enough information given out in books, especially books training a junior doctor, and it's one small paragraph in that eh, in teaching books.
NF1 patient as a guinea pig Power dimensions – HP over patient One size does not fit all with NF1 Unmet needs A learning culture of respectful curiosity and patient-centred benchmarks Patient having to be expert/teacher	sometimes I feel like a human guinea pig ((laughs)) when you're at the hospital. Like you're doing research yourself, you're doing research on NF1 as a whole. Because my little girl's last school they'd tried, they had a different child who had NF1 at the school, to go the same way but every child that has NF1, everybody who's got NF1 is different.

Broken knowledge breaks links in the system	
Student doctors – more curiosity rather than knowledge Different attitudes to rare disease research A learning culture of respectful curiosity and patient-centred benchmarks	More curiosity. There's not enough in the textbooks.
HPs – learning on the floor NF1 potentially being misdiagnosed Importance of genetic testing Broken knowledge breaks links in the system	I know that where you learn the most is on the floor in hospitals, it's where they learn the most. But it's a wee bit unfair. They don't know much about NF1 cos it's-, it can be misdiagnosed as I've just-, I've been told it can be misdiagnosed, but I would-, but not enough people are being genetically tested.
HPs – lack of knowledge Lack of information about NF1 in textbooks Barrier for the shared experience of BCA Broken knowledge breaks links in the system	So it's-, I feel like there's not enough em information in text books about people with NF1 for anything. Especially breast can-, breast screening.
Taking part in research Voice is being heard Diversity in the voices of NF1 Forging chain reactions from strong links	It feels good that I got my opinion across, as a young female, and as a parent of a female as well. It means my voice is being heard, not just-, not just this sounds bad, not just in England but it's being heard from Scotland...

Tentatively planting the seeds of powerful actions and empowering thinking	
NF1 affects different people, and different places Tentatively planting the seeds of powerful actions and empowering thinking Forging chain reactions from strong links Goldilocks animation	...it's a different voice. It's not just UK. Sometimes people say, 'oh just England', but no, it's-, you've got to remember it's Scotland as well, it's Ireland as well, It's Wales. Everybody gets it.
Do or feel differently Increased BCA – checking properly Increased BCA – what to look out for Empowerment – for myself Awareness is a shared experience – for child Providing power – for mother and daughter Tentatively planting the seeds of powerful actions and empowering thinking Animation provides the ins and outs beyond the lump	Now I know how to check myself properly. That's it there. And I know what to look out for, for myself, for my child. If anything's different. That's always one thing I've always said is, if you notice something that changed, go see your GP, and for the breast screening, because I'm not at that age, I'm just about not-, I'm 28, so I need to start ((inaudible)) more for myself. Things like that.
Awareness as a shared experience – for all	I would say the age of primary 7 because she's already hit puberty. She hit it at 8. She was early. I had to see a specialist about it, but it

Animation as a powerful learning tool for all children NF1 and precocious puberty Forging chain reactions from strong links Tentatively planting the seeds of powerful actions and empowering thinking Goldilocks animation	can be because NF1 can make you hit puberty early. So primary 7, first year, I think girls should see this in school.
Animation to raise awareness that some need to be screened early Forging chain reactions from strong links	and just say that certain people can em-, have to be screened early ((inaudible).
Awareness as a shared experience – desire to see animation everywhere Forging chain reactions from strong links Tentatively planting the seeds of powerful actions and empowering thinking	I would love to see the animation actually published. Even on tele, even if they changed it, to just get themselves checked with breast cancer. People say, 'oh but the time, the water-, the time of day', but you could get it for older-, after 5 o'clock. Like 6 o'clock. It would be great cos it means you hitting the right ages-, age range.
Awareness as a shared experience – partner watched animation with woman Forging chain reactions from strong links	mm-hmm cos my partner watched it with me.

Anne (YW)

Early diagnosis Proactive parent HPs – an obvious diagnosis for an obvious sign HPs – knowledge is power 'leading expert' Forging chain reactions from strong links An obvious diagnosis for an obvious sign	Yeah, so I was about 4 or 5, em and my mum was always, kind of a bit of a worrier, I would say. Em, and she noticed, what we now know obviously is café-au-lait marks so she mentioned it to the school nurse, I think it was, em and she wasn't sure, and you know, I think it could be, you know, something like a skin condition, so, eventually, and I'm not too sure because I was quite young at this stage, we get referred to, em, *** (name of hospital) so it was *** at the time, em and we saw Dr -, he was obviously a leading expert at the time, and he diagnosed me with NF at that stage. Now, interestingly, em they thought it was inherited because (that's what they often believed at the time), and my dad had a fatty lump it was, em but he didn't really have anything else. Em, but it turns out, I think, 10 years later maybe to find out ((inaudible)) I had scoliosis so em, that was from the age of 5. I would count myself as being quite lucky cos I think I have quite a mild case, em, like obviously it has got worse in time since having (child's name). I got more growths when I was pregnant which was to be expected, em but yeah that's kinda my diagnosis story really.
From the animation Increased BCA – checking more frequently	Em, I think it's made me aware to check more regularly cos I mean-, I did, I think just before I was pregnant maybe, em with (child's

Booster to be more vigilant Increased BCA – wider warning signs to be aware of Tentatively planting the seeds of powerful actions and empowering thinking Animation provides the ins and outs beyond the lump	name), I did notice that I had some extra growths kind of round-, em my nipple area basically, so I thought, 'well because I know I'm at increased risk and I presume it's NF, and kind of like an extra growth, em I'll just go and get it checked out. It was obviously NF related and nothing sinister, it was just another em kind of like a large skin tag really. So, I feel because I already knew em that I am at higher risk, and I do obviously take my health seriously, em I do but I think now from watching the video, it's probably given me that boost to say actually, 'well, no I am right to be extra vigilant', and actually I need to check more under the skin, and not just surface things. If that makes sense?
Previous knowledge of increased risk Proactive mother Mother as expert/teacher HPs knowledge provides patient empowerment Awareness is a shared experience Having the right connections increases BCA Forging chain reactions from strong links	Em, I think it was probably a combination, so, em, a worried mum ((laughs)), my mum used to get very anxious at how often ((inaudible)), we were at that stage at that point where we could get in touch with (name) hospital as when we needed, and she did that, because she read something about NF, so she did obviously worry, so as I'm sure I would with (child's name). Em, and I think just from having the counselling sessions and seeing people and em (.) I think maybe when we went for genetic counselling when we were doing the PGT to have (child's name), so I think again that kind of came up in conversation, within the general health one.

Animation as motivation to be breast cancer aware Tentatively planting the seeds of powerful actions and empowering thinking	((in overlap)) yeah. And I think seeing that animation has made me more aware, and telling me, 'yes, you know you definitely have to do it'.
Increased BCA (animation) – checking once a month Tentatively planting the seeds of powerful actions and empowering thinking	Em, I think previously em I would probably check once in a blue moon, so if I noticed any changes, it would be a bit 'ad hoc', em but I think having read-, kind of watched the video and stuff, then yes, I would be more inclined to check once a month.
Increased BCA – detecting any breast changes Increased BCA – seeking medical help if concerned about breast changes Increased BCA comes with practice Tentatively planting the seeds of powerful actions and empowering thinking	Em, I think it kind of comes with practice really. So, you know, even though ((inaudible)), at the same time I think I would be more inclined to go and get things checked out if I wasn't certain now.
Animation instils empowerment and self-confidence to seek medical help Animation provides power to the watcher Tentatively planting the seeds of powerful actions and empowering thinking	I think I would feel more confident em that it is the right thing to do, rather than feeling there's a worry, or paranoid, or just nothing and it's actually-, you know that if there's something this month, don't worry but if it continues, I think I would be more confident in going. You'd say, 'look I've noticed this, it's new'. Em, I mean that even if it's a case of, 'oh right well let's keep an eye on it', but at

	least I've made that initial contact and got that reassurance.
Previous knowledge of screening eligibility Forging chain reactions from strong links	I think I always knew that it was kind of 40 from looking on websites and probably just being vigilant, em so I already knew it was 40.
Barriers to being BCA Women with NF1 – lack of knowledge Personal misdiagnosis Assumption 'it's just NF1' Broken knowledge breaks links in the system	I think, kind of self-misdiagnosing almost, so you know, I had those extra growths on both my breasts and I just got-, well, I know now, I know that it is NF, but I think a lot of people could go, 'oh it's NF', or, 'oh, it's just one of my growths, it's nothing, it's just new development', rather than it being anything else so I think maybe that really and I don't know how best to put it. Em, but just that, I don't know, that blasé attitude, but just that, 'oh it's nothing'.
Barriers to being BCA Confusion knowing difference between fibroma and malignant mass NF1 complexity – fibroma, cancer, or hormones?	I think maybe, and I honestly don't know if it's possible, but understanding what the differences are. So, what would a fibroma feel like, compared to a tumour, or what would be the warning signs that you need to look at?
If in doubt just go Nipping something potentially sinister in the bud Tentatively planting the seeds of powerful actions and empowering thinking	yeah, and I think that's something that I've learnt, is you know, if you are at all concerned just go. Em, I think, and I know it's publicised but, you know, I think people would rather you go and see them with something that is nothing than come months much later when it's something more serious,

	you know, and you need to do different further interventions, rather than just nipping it in the bud.
Animation emphasises vigilance Animation bridges gap of an unmet need Animation as a BCA reminder Tentatively planting the seeds of powerful actions and empowering thinking Animation provides the ins and outs beyond the lump Broken knowledge breaks links in the system Stuck within barriers of a powerful yet disconnected system Forging chain reactions from strong links	you do just need to be that little bit more vigilant. The last time I saw someone specifically for my NF, was probably when I was about 18, and obviously there's a lot of time between 18 and 40, em and that was the last time really that they reviewed my NF properly, other than that obviously when I was going to have (child's name) but (.) yeah, I think it's just a nice reminder.
Animation format Perception of more informal Easier to digest a serious message Allows for a different mindset A Goldilocks animation for inclusive and engaging learning	I think when we look at kind of animated, I think it makes it more informal, so rather than being some of-, because I do a lot of training with work with stuff, but it's good I would say to have (a format that's) a little bit more informal, and not any less more serious but actually I think it's easy to digest when it's a little bit more animated, because it's easy, you can watch it. There might even be a slightly different mindset, but for that kind of

Animation is a protective shield from taboo breasts and scary facts	information, I think it's more appealing to be in animation.
Real people means a really heavy message Animation is more friendly to watch Animation keeps you 'switched on' Animation is a protective shield from taboo breasts and scary facts A Goldilocks animation for inclusive and engaging learning	Just, em, I think, when you put a video on with like live actors, I think it might switch people off cos they go, 'oh, this is going to be really heavy, and I haven't got the time', you know, whereas with animation, it's like, 'oh actually, yes, it is more kind of easier to follow, and a bit more friendly to watch'.
Taking part in research Awareness is a shared experience Research allows for sharing of experiences within a condition of many variables Helping raise awareness Tentatively planting the seeds of powerful actions and empowering thinking Forging chain reactions from strong links Goldilocks animation (inclusivity)	Em, it's always something that I kind of meant to do, em and actually where I can kind of share my experiences cos we know that NF1 is so varied, em you know, (on a scale of 1 to a thousand), there's so many different variations, it's good to kind of get my views across and my kind of share my experiences, and if it can help, it can only be a good thing.
Do/feel differently Feel reassured	I think it's reassured me, more than anything that actually, yes, it is the right thing to do and get checked out if there are any changes.

Promoted self-efficacy and confidence to get checked out Tentatively planting the seeds of powerful actions and empowering thinking	Em, even if I notice it once, em, you know, and not be leaving it a couple of months without getting checked. So, I think it's just that reassurance, when I am not sure.

Lucy (YW)

Early diagnosis	Eh, I was diagnosed from birth.
NF1 in the family Forging chain reactions from strong links	Eh, my mum also has NF1, and my two older brothers do as well.
Increased BCA – accurate information on risk Animation provides the ins and outs beyond the lump	I knew that we were more at risk of having breast cancer but I didn't realise the risk was that much higher.
Not much change with detecting changes Animation made it clearer on identifying what changes are Animation provides the ins and outs beyond the lump	Probably not that much. I was already aware of most of them. The changes, but it gave a more identifying of it, if that makes sense?
General confusion with breast changes NF1 complexity – fibroma, cancer, or hormones?	obviously like, yeah, with the natural cycle your breasts can change. It's just knowing if it's because of that or something else.
Quicker contact with HP from watching animation	I'd probably contact them a lot bit sooner than I originally have though, from it being a

Tentatively planting the seeds of powerful actions and empowering thinking	month before I watched it, and then now it would probably be 2 weeks, 3 weeks after seeing it.
Previous knowledge of screening eligibility Forging chain reactions from strong links	I was already aware that it is 40.
HPs – knowledge of NF1 helps create patient empowerment Forging chain reactions from strong links	I think it might have been through the paediatrician, or geneticist (.) once upon a time ((laughs)).
Animation encouraging BCA Encourages watcher to be more aware of NF1 information Tentatively planting the seeds of powerful actions and empowering thinking	((pause)) em, I think it encourages that (.), you need to be more aware of it because of the increased risk, because of the NF.
Animated format Easier to digest in animated format Easier to understand Webpage of information is difficult to read Animation allows for clearer communication instead of using 'actual humans' (protective distance) Animation is a protective shield from taboo breasts and scary facts	Having the video does help because, just having like a webpage of information, 'oh, this is like a lot to read and a lot to digest'. It's an easier form to understand the information. And when it's animated, you can like (.) depict things a lot easier, I think than just like having, you know, actual humans. If that makes sense?

A Goldilocks animation for inclusive and engaging learning	
Taking part in research Happy research is being done Feeling seen and heard Research can increase knowledge among HPs HPs – lack of knowledge Forging chain reactions from strong links Broken knowledge breaks links in the system	Em (.) happy that there's research being done so doctors do understand that there is like an increased risk because quite often when you turn up to the GP, and you're like, 'oh, I have NF1', they just come out and look at you blankly, and they're like, 'what is this?'
Perception of HP disregarding NF1 patient HPs lack of knowledge potentially dangerous Danger of power of GPs with a lack of knowledge HPs – lack of knowledge means a lack of access of breast screening Broken knowledge breaks links in the system	and it's almost like they disregard it and they just look at your age and they're like, 'nah, it can't be it'.
Do/feel differently Check breasts more often	Em, I'll probably check my breasts more often than I do.

Tentatively planting the seeds of powerful actions and empowering thinking	

Bernie (A)

Associate – mother	Em, she’s my daughter.
HPs – lack of knowledge as a barrier to being diagnosed Diagnosis in childhood Broken knowledge breaks links in the system	Em, so my daughter was diagnosed when she was em, 5 years old, and it took us an awful long time to get a diagnosis because no one in the hospital in the area where we live, no one had ever heard of NF1 before.
HPs – knowledge is power An obvious diagnosis for an obvious sign Lack of information HPs – lack of knowledge An obvious diagnosis for an obvious sign Patient having to be expert/teacher Broken knowledge breaks links in the system Googling for answers	and we literally walked in the door, and the lady said, ‘I know what that is – NF1’. Straight away, we got a diagnosis and then after that, it was trying to find out information. Again, not much information available. I mean, we’re talking 13 years ago, em so yes, not much information. The paediatrician, my daughter was under the care of never heard of it before, em, so again lots of learning I think on everyone’s part.
An obvious diagnosis for an obvious sign An obvious diagnosis for an obvious sign	yeah, it was literally ‘take her top off. Can I have a look at her?’. As soon as she saw all the café-au-lait spots, she went, ‘yeah, that’s

	what it is', and we were like, 'oh! Okay' ((laughs))
Increased BCA – risk Personal experience of breast cancer – family friend Motivation to be BCA – death of family friend to BC Animation provides the ins and outs beyond the lump	Yeah, I mean to be honest I didn't know that there was that increased risk, em with someone who has NF1 so it was really helpful cos it-, you know, it highlighted something I didn't know. Em, I mean obviously I know someone, a family friend that passed away from breast cancer so I have an awareness of it separately-
Awareness is a shared experience – providing information to daughter Animation bridges a knowledge gap to be shared Animation provides the ins and outs beyond the lump Forging chain reactions from strong links Forging chain reaction from stronger links	so even from an early age I've talked to my daughter about the importance of, you know, checking your breasts every month and, she's like, 'well, why do I need to do this?', 'well, you know, these are the reasons', 'why', but I didn't realise that there was an increased risk with NF1.
Animation reinforces importance of seeking medical help for a breast concern Animation highlights importance of BCA within an NF1 context	I think what it's reinforced in my mind it's absolutely critical, as soon as possible because there is that increased risk. I mean that anyone that finds something wrong should contact their doctor straight away but obviously there's an increased risk as well,

Tentatively planting the seeds of powerful actions and empowering thinking	you know, check more regularly, more thoroughly.
Increased BCA – in general for associate Increased BCA – provision motivation for associate to be more BC aware Animation creates ripples to think about your own breast nipples!	Well it has, cos to be honest, I've just turned another age milestone and I was wondering, 'oh, when will I start going for, you know, breast screening as well?' so it was, 'oh let's go on the NHS and have a look' and look at it in general about what age, you know, you start getting screening, and how often that happens, so again it's sort of there in the back of your mind, but then it's like, 'oh, I really should go and check that'.
Increased BCA – screening eligibility Perception of increased risk, screening should be earlier than 40 years Animation provides the ins and outs beyond the lump Stuck within barriers of a powerful yet disconnected system	I was a bit surprised to be honest that given that there is that higher risk, I thought the age would have been lower with someone with NF1. I thought it would have been much lower, but you know, if there is that increased risk why are they waiting until someone is 40 years old to do that regular screening?
Increased BCA – monthly checking for daughter with NF1 Setting a reminder good for those who like a routine Tentatively planting the seeds of powerful actions and empowering thinking	I suppose it-, you know, I mean my daughter for example, she loves routine so she likes doing things at set times at that, so for her that would be perfect. It's like, choose a day of the month and do it, so I think, yeah, it's really good, and you know if you've got, you know, cos I've got everything in my calendar ((laughs)) to remind me to do things, put it in your calendar and it will pop up and remind

	you to do it, so I think it is a good idea to have that regular slot to that.
Barrier to being BCA HPs – lack of knowledge Animation has provided the BCA information needed Hearing it all for the first time Broken knowledge breaks links in the system Animation provides the ins and outs beyond the lump	I guess it's probably lack of knowledge, I mean, if I'm honest, I go with my daughter to all her medical appointments and-, I don't think anyone's mentioned, as I just said, you know, when I watched the video it was the first time that I was aware that there was that increased risk, no one's ever said to her at any point, 'you need to be checking your breasts on a regular basis'-
The complexity of NF1 So much information to be communicated BCA never discussed Broken knowledge breaks links in the system	I know there's a lot, you know, that they need to tell you, and a lot for you to take in but I-, no one's ever mentioned it.
HPs – lack of knowledge Patient having to be expert/teacher Specialists not communicating BCA information The search for answers	I mean, em the paediatrician, I mean I know, I don't want to be dismissive because he's fully qualified, he's such a generalist and he's got to know about so many conditions. I mean, as I said, he'd never heard of NF1, em and so that the questions, you know, we've obviously been online, and we've been researching things and looking at things. And we've been asking questions and he's been

Potential assumption of knowledge on patient/associate part Broken knowledge breaks links in the system Googling for answers Patient having to be expert/teacher	like, ‘well, I don’t know about that’, and it’s like, ‘okay, but can we speak to someone that does know about that?’. So, so I-, I guess from that perspective, when you are seeing someone that is a generalist they’re not gonna know everything,- we can’t expect them to. But I would of thought that when you’re going to see this specialist that are specialising in that condition (.) they would say something. Or they assume that we already know?
Animation appropriate for younger ages Animation makes a serious message more fun Animation is a protective shield from taboo breasts and scary facts A Goldilocks animation for inclusive and engaging learning	I think it does, I think it’s targeted-, I mean I’m obviously a lot older than the age group that it’s targeting but cos it’s targeting towards a younger audience, I think it’s quite good, you know, it’s not too serious, it’s a bit fun and it’s, you know. I showed it to my daughter, and she said, ‘oh. That’s really good. I like that!’
Animation format Body as taboo Animated character provides a protective distance Animated helps break taboos	yeah, I think some people can get very embarrassed talking about, you know, bodies and things, so I think because it’s like a cartoonish character, it’s not so embarrassing and so you can look at things and then it’s not like, you know, if it’s a younger child they’d be all giggly and things, but I think it makes it much easier to have a discussion about it, because it is in that format.

Animation helps open channels of communication Animation is a protective shield from taboo breasts and scary facts	
Taking part in research Helping ‘spread the word’ Awareness is a shared experience	I mean, I’m really happy to take part, em and obviously we heard about it through the Childhood Tumour Trust em which is a charity that we’ve been involved in for a couple of years so they publicise lots of things and lots of opportunities, em and I’ve said to my daughter, ‘we take part in as much as we can, if we can help to spread the word, or we can help people that are trying, you know, to improve awareness, or anything like that’ [...]
Awareness is a shared experience – the importance of being part of a charity Sharing stories has the potential to share accurate breast cancer awareness information Forging chain reactions from stronger links	[...] and so she’s made loads of friends, you know, she knows people that has the same condition as her, so it’s so much easier, and they talk about things and share stories, and so it’s great to take part in anything that helps in, you know, in increasing awareness.
Do/feel differently Help raise awareness of NF1 and BCA Awareness is a shared experience – for all The power of social networks	So, at the moment, we-, me and my daughter do post quite a bit on social networks about the condition. She never used to before but as she’s got older she’s got more comfortable with sharing, you know that she has the condition, so I think we’ll think about more putting thing on there about breast cancer in

Forging chain reactions from stronger links	general, not just if you've got NF1, but trying to raise awareness- **Interviewer:** ((in overlap)) yeah **Bernie:** because it is so important that women check.
Relatedness – researcher and participant Forging chain reactions from stronger links	I mean, it's just lovely to speak to someone, you know, to talk about the condition, and talk about raising awareness, yeah it's brilliant, it's really good.
Desire to raise awareness Eagerness – importance of raising and sharing awareness Forging chain reactions from stronger links	That would be great and if we can-, are we able, are we allowed to share it at the moment?
Awareness is a shared experience Forging chain reactions from stronger links	yeah, no that would be fantastic, and then we can all share it and encourage people to watch it.

Mavis (A)

Associate – mother	She's my daughter
Precocious puberty	[...] so (.) learning difficulties can be associated, em precocious puberty and also em a lot of tumours can grow, em so optic pathway gliomas as well, and also an increased risk of developing cancers, em (.) yeah!

Animation increases confidence to speak with daughter about BCA Animation opens channels of communication Simple and clear Awareness is a shared experience – watch together Forging chain reactions from stronger links Tentatively planting the seeds of powerful actions and empowering thinking A Goldilocks animation for inclusive and engaging learning Animation is a protective shield from taboo breasts and scary facts	It's helped me feel more confident in speaking to my daughter about checking, em and also knowing what we should be looking for, em (.) so and it, I think that the animation is quite simple to understand em and quite clear and something that we could watch together.
Previous knowledge of BCA (warning signs-general) Power of BCA information available in public Personal experience of cancer in family (BCA motivation) Forging chain reactions from stronger links	yeah so I've seen quite a lot of it, it's definitely more aware now, em some in the doctors' surgery that I attend, em posters on the wall, some em public toilets as well, I've seen inside public toilets which is great, em yeah and just other people have known in my family have had it, I kind of understand what to look out for as well.
Previous knowledge of increased risk	yeah, I knew of the increased risk, but before the animation I didn't know that em it was

Increased BCA – screening eligibility Animation provides the ins and outs beyond the lump	from the age of 40, is it that they can have the (.) **Interviewer:** the breast screening? **Mavis:** yes. I didn't know that before, before the animation.
Would encourage anyone to go for a breast concern Positive mindset – proactive Importance of spotting something early Tentatively planting the seeds of powerful actions and empowering thinking	Em, I'd definitely encourage em anyone to go if they have any concerns of any breast lumps or pain or swelling or discolour-, just anything. Em, yeah it's -, it can get missed very easily em, and also you know it's important because if you don't go, it could be-, it could mean a lot more treatment or, you know, worse case scenarios, but if you go, the worst thing that could happen he goes, 'oh yeah, you're fine. There's nothing to be worried about'.
Barrier to being BCA Woman with NF1 – lack of knowledge Assumption a lump is NF1 Importance of a shared awareness Importance of open channels of communication HPs – lack of knowledge	Em, I suppose it could be harder because if they got fibromas anyway, they'll just go and think, 'oh that's just a fibroma. I'm just gonna ignore that', and you know just carry on. I suppose it depends on how open they are with the family, and how much they've already discussed things like this. Em, so I think could definitely affect someone with NF1 just kind of passing it off as something else, or maybe not even wanting to go to the doctor if the doctor doesn't know much about NF1 they could be put off thinking, 'well that doctor doesn't know anything

HPs lack of knowledge a barrier to seeking help Broken knowledge breaks links in the system Stuck within barriers of a powerful yet disconnected system Forging chain reactions from stronger links	about this. I'm not even gonna waste my time'. Em, so there's a lot of things really that could put someone off going.
Encouraging BCA Easy to understand Easy to watch Awareness is a shared experience – Easy to discuss with either family or professional Animation opens channels of communication Animation reduces fear Animation empowers women with NF1 to go to the doctor Animation is a protective shield from taboo breasts and scary facts A Goldilocks animation for inclusive and engaging learning	Em, so I definitely think that it did help, em encouraging breast cancer awareness em (.) it was very easy to understand, easy to watch and I think it would be easy to discuss with either family or a professional. Em, and it would make someone a lot less maybe fearful. It's encouraging people to go to the doctor, to share and reassuring that it's not-, no one's gonna laugh at you. You're gonna go and you're gonna be checked and it's gonna be fine, it's great and if not then the next steps will be taken.

Tentatively planting the seeds of powerful actions and empowering thinking Animation as reassuring to seek help	
Animation format Helps with learning Helps with understanding Format helps open channel of communication Format encourages help seeking Tentatively planting the seeds of powerful actions and empowering thinking A Goldilocks animation for inclusive and engaging learning Forging chain reactions from stronger links	yeah so I think that if someone didn't know about being at increased risk with NF1, and breast cancer em then they would certainly get it from watching the video, watching the animation, em and I think that they would (.), I think it would help with understanding so if there was somebody with NF1 they could say, 'oh, you know, is everything is okay?', and ask them about it and then hopefully it would open up a new, a new em chat with someone, and they could maybe tell somebody else about their fears, you know, just a friend or, it could open up a lot of things and maybe encourage them to go to see someone if anything is worrying them.
Taking part in research Research allows for rare disease lived experiences to be shared Awareness is a shared experience Tentatively planting the seeds of powerful actions and empowering thinking	Em, I love taking part in research because if it means that someone can go and get help when they need it, or you know, just a bit more knowledge of how it affects families and em people living with NF1, as well, em I just like to try and get as much word out there as possible ((laughs))

Forging chain reactions from stronger links	
Do/feel differently Animation opens channels of communication Awareness is a shared experience A two-way experience Animation has the potential to support young women with NF1 Forging chain reactions from stronger links Tentatively planting the seeds of powerful actions and empowering thinking	I feel more open to talk to my daughter about em, getting checked or talking to me if she's got any worries em and hopefully having that open conversation that she can then tell me if she's got any worries as well and we can go from there then, I can help her.

Willow (YW)

Diagnosed as a child HPs – knowledge of rare diseases Knowledge means meeting needs of the patient Discharged of care at 18 – left to deal with NF on own	Yeah, so I was diagnosed very young. I think I was about 6 months old, maybe? Em, and my parents noticed a lot of freckling around my armpits and groin area which is a classic kind of sign of it, and I think they went to the doctors and the doctors at that point said, 'this is NF1', and that was kind of it, really. I had regular check-ups from then on with my eyes and my ears and the paediatricians. I was, em, very late to learn to walk as well,

Forging chain reactions from stronger links Broken knowledge breaks links in the system An obvious diagnosis for an obvious sign	apparently, which is probably not connected to the NF1, more me just being lazy, em ((laughs)), but they were interested in me because of that, and then obviously the NF1 and things as well, and then I don't talk so it was like, okay but NF continued until I was about 16, 17, 18 maybe and then ((pause)) I was kind of left to deal with it myself after that, which I think is (.) from me I had very few symptoms or anything, it's just the freckling and the, I call them blodges, but the café-au-lait spots, em so I had, yeah, very few anything. I've got a few lumps, eh, which I noticed in later life, the last few years, em but, yeah apart from that, kind of (.) that was it really.
BCA awareness – probably increased a bit Previous knowledge of BCA Googling information fill in gaps Animation as inclusive Forging chain reactions from stronger links Googling for answers Patient having to be expert/teacher	I think probably it's increased a little bit, em I didn't-, breast cancer awareness in general em, I'm probably okay with em for NF1 specific I only really knew that it was a risk about myself, probably about 4 years ago, em, so then from that I obviously, you know, go home and google things straight away because I'm a classic case of googling everything, em but I think, I thought the animation was good. It was very, I think inclusive and I thought it worked really well.

A Goldilocks animation for inclusive and engaging learning	
HP – lack of knowledge HP – lack of knowledge but desire to learn and research Contraception as an increased risk of developing BC in general Missed opportunity for empowerment – Increased risk of BC with NF1 not communicated previously Gap of knowledge acquisition and sharing in adulthood Isolating – Having to manage the condition yourself Disconnected system – assumption medical records on a shared system Disconnected system – disconnects the ability of a shared experience for knowledge and care Forging chain reactions from stronger links Broken knowledge breaks links in the system	yeah, so I went to the GUM clinic to get eh, to speak to the doctors or nurses, whoever it was em about changing eh from the pill to some other form of contraception that might be slightly more reliable to somebody who forgets to take that pill every single day, em and they were probably just asking general questions, medical history blah de blah em, and I said about NF1 and I think she probably went away and googled it because nobody's ever heard of it, em and came back and said, 'oh I've just had a little look and there's an increased risk of breast cancer so I wouldn't suggest that you continued with the pill anyway because the pill obviously carries the increased risk of breast cancer'. And I was like, 'oh! Okay! Well it's a good thing I've come in, you know, the past how many years I've been on the pill for. No one's bothered to mention that to me'. So, em, yes swiftly swapped it away from that to eh something a bit better and I don't have to remember anything these days, so, even better really. Em, so yeah that was (.) interesting. I think probably because at the time when, I guess when I started on the pill would have been when they were transitioning me out of children's services and it was then at the point where you're not really anybody's that-,

Stuck within barriers of a powerful yet disconnected system Patient having to be expert/teacher	you're not high risk or anything, you're pretty stable with everything that is happening, em so you-, they left me to manage NF on my own, em so I's probably because it was left to me and (.) I don't know the questions to ask necessarily ((laughs)) so it wouldn't have been something that I'd ever really thought of or, I just assumed that it's on my medical records so they can see that I've got NF1 and wouldn't then prescribe me something that would increase the already increased risk that the pill can give, but em, now I work in the *** a little bit, I kind of understand more now that is not the case ((laughs)).
Increased confidence to contact a HP with a breast concern Strained health system – difficulty to get an appointment Disconnected system – information not being shared with other HPs Struggle to communicate with a GP GP holds power to access other services HPs – lack of knowledge	Em, I think now since watching the video, I probably would be more likely to contact them em (.) but it's-, I guess it's getting the appointment, I think that's where I'd struggle. I-, I recently, well I say recently, I've lived where I live now for a year em and I've never actually met my doctor, spoken to him on the phone to him a couple of times. He's, em (.) still not referred me. I was registered at *** in *** em when I had some concerns, not concerns, but just wanted to make sure that all the lumps that I had which I felt were new lumps were, not breast related, just general on my body were all okay, em and so then I was eventually put in touch with *** and registered there and I've been trying to move

HPs – lack of knowledge a barrier to access services Tentatively planting the seeds of powerful actions and empowering thinking Stuck within barriers of a powerful yet disconnected system Broken knowledge breaks links in the system	to another-, now I don't live down south, eh to the clinic in *** and I'm struggling to eh, relay that to my doctor, but I just need to get on it more and keep trying. So, I think for me, it would be the, being able to feel like I can get an appointment and that they would take my concerns seriously because I think it is something that people haven't heard of, even in the medical industry.
Improved BCA – detecting changes and warning signs in a more extensive area Improved BCA – the need to be more thorough Animation provides the ins and outs beyond the lump	I think probably better, I think I'd be more, more kind of aware of what to do look for and things and I guess you kind of-, when you're told, 'you need to check your breasts', and things, you don't really think about the armpits and things, as being part of that whole area really. Em, so I think having that, like has definitely, you know, made me more aware that I need to be a bit more thorough, I guess?
Previous awareness of screening eligibility (GUM clinic) HP – desire to learn and research if unsure HPs sharing of knowledge empowers the patient	I think probably about the same because I think when I had that appointment, at the GUM clinic, I think she said that at that point, the doctor or the nurse, I'm sorry I probably should know what they were but I don't remember, em said that I would be eligible for earlier screenings and definitely when I had an appointment a few years ago in ** the

Animation provides the ins and outs beyond the lump Forging chain reactions from stronger links	doctor actually said that I can get earlier screenings. So, I think from that side it's kind of-, I've been aware of it since, I guess the last four years.
Barrier to BCA Women with NF1 – lack of knowledge Lack of ongoing conversations about the condition and associated risks after healthcare ends after childhood Worry and fear Lack of doctor availability for an appointment Broken knowledge breaks links in the system Stuck within barriers of a powerful yet disconnected system	Em, I would say like of knowledge, if they have been in similar situations to me where they leave children's services and because their symptoms are so (.) like doesn't affect their day to day life that much, em, they're not having that kind of (.) ongoing conversations about NF1 and it's almost kind of just, 'oh I know I've got this thing but I don't need to worry about it for the moment, hopefully'. Em, so I would say lack of knowledge, not knowing about it and if they do have the knowledge then it would be worry and fear and lack of doctors' availability.
How to reduce these barriers? Access to information where people look Forging chain reactions from stronger links	. I should know, on their website, on both of their websites, em so people can go and have that information and maybe across the NHS obviously where people go naturally to go and look for information, so maybe having the video on there, kind of, as you know, if you're a woman just you might want to be made aware of this, and know what you are

	eligible for really, as well with having the checks at 40 plus.
Awareness is a shared experience (information availability on social media) Importance of accessibility on various platforms that is wide reaching Forging chain reactions from stronger links	yeah and on like social pages, I know I don't- I really only use Instagram, I know at the top you have those like, almost like highlighted little circles where you can add like videos into them, so it's like permanent there, so people don't have to scroll through- **Interviewer:** yeah, yes **Willow:** and things like that. Just-, so there's lots of different places where people of all ages can access the information so it's not relying on being on one website or one (.) social media platform, or whatever.
Increased BCA – checking frequency Tentatively planting the seeds of powerful actions and empowering thinking	yeah, I think so. It's something that I definitely kind of think about more and kind of like-, I'd say I'd be a bit more mindful of and actively kind of checking a little bit more instead of (.) when I think about it type thing ((laughs)).
Once a month checking is reasonable Checking is easy Developing an awareness of what is normal for you Tentatively planting the seeds of powerful actions and empowering thinking	Em, I think, I think once a month is a reasonable thing. It's obviously, you know, it's easy, you can do when you're in the shower or something as well. Even if you just-, not doing like a thorough check but a daily, just, when you're washing, you're going to be a bit more mindful, you know, and hopefully notice like any changes but, yeah do like a

	thorough check once a month, or so then I think is probably a good thing.
Animation format Seeing 'live people's' breasts is uncomfortable Animation creates a protective distance Animation works for all ages Simple format means anyone can follow Animation represents diversity – anyone can have NF1 NF1 is a shared experience Anyone can have NF1 Animation is a protective shield from taboo breasts and scary facts A Goldilocks animation for inclusive and engaging learning	I thought it was good. I thought the animation was good, it was nice em I think if it was more kind of 'live people' that might make people feel uncomfortable em so, especially like younger people, I think that would make them feel, could make them feel uncomfortable. Em, so I think that's-, the animation I think it works and it works across kind of all ages really because there's, you know, it's simple enough that anyone can follow it. Em, so I thought, and it was even though it's like animation I think still think it like represented diversity and things in there as well.
A Goldilocks animation for inclusive and engaging learning	kind of all kinds of different people, from different backgrounds and ethnicities and colour, race, everything.
Research made you feel?	Em, I think it's good. I was talking to my manager earlier today saying that I had this interview em and I said that I'm really happy

Lack of research aimed at young women with NF1 Waiting to take part in something she belongs to – relatedness Feels seen and heard Taking part is doing something good Forging chain reactions from stronger links	that I've been able to take part in something because normally everything is aimed at really young people or em, yeah like, young babies or whatever and so I can't-, or pregnant people or whatever so I've never been really able to take part in anything so when I saw that there was something that I was eligible for, I was like, 'oh my god! I can actually do something good!' ((laughs))
Do/feel differently Increased BCA – increased awareness in being mindful to any changes A reminder of the importance of checking Don't forget about your breasts Tentatively planting the seeds of powerful actions and empowering thinking	Em (.) I don't know ((pause)) I think just being more kind of mindful of kind of any changes to my breasts or anything, em and yeah, just keep kind of, keep that as a focus and remember that it is important to keep checking and, yeah, not forget about them ((laughs))

Anya (YW)

Late diagnosis Joint diagnosis – when child was diagnosed	Eh, yeah sure. Well, I got diagnosed with NF em after I had my first child, em so I was 23 at the time, em, I think. Eh so that was back in 2012. That was when I first got my diagnosis, me and my son got diagnosed together.

HP – knowledge but no action HP – holds power to gain access to more services or information (gatekeeper) NF1 diagnosed through son's diagnosis Broken knowledge breaks links in the system Stuck within barriers of a powerful yet disconnected system	Well, it's a bit of a complicated really because they really-, NF got mentioned to me when I was a teenager, em, just randomly. I think I was probably about 15 at the time, em and I went to visit the GP for a continuous cough, and coincidently the GP that was em examining me, he had recently dealt with a case with NF so em, things were quite familiar to him at the time so he noticed a lot of my birthmarks and he did mention NF to me then and nothing really had come off it, and then when my first son was born he too started presenting with several birthmarks within the first couple of months. So that sort of brought me back to my teenage years when the doctor was saying about the neurofibromatosis for me, em, cos although nothing happened from it, I was always sort of suspicious, em so they pursued investigations after that, after my child was born, em and then it was all confirmed genetically.
Previous BCA – warning signs Barrier to attend HPs – stigma of younger female going to HP with a breast concern Have to be a certain age to seek help for a breast concern	Em, well I'm familiar with changes to look out for, em but it's always concerning going to the doctors, you know, especially when you are a younger female, em, cos there's always that stigma attached to it, that you know, you have to be of a certain age or, you know, it's only in older women, em so I'm always afraid of judgement, em but I do try to check myself regularly.

Stigma from misinformation about cancer age occurrence (HPs and public) Afraid of judgment being a young woman Power in own hands – check self regularly Stuck within barriers of a powerful yet disconnected system	
Previous BCA knowledge – CTT information Importance of and trust in charities for information Forging chain reactions from stronger links	Em I did have the knowledge prior to watching that animation, but the animation was very helpful, em, because, typically I wouldn't have had the knowledge if it wasn't for like the charities ,the Childhood Tumour Trust, who are always raising awareness anyway, em, so although I've previously obtained that knowledge, it was still through the charities that I feel that I've become aware of certain things to look out for, and the associated risks with the NF.
Asking about confidence to approach a HP is complex – two edged sword Increased confidence to go to HP Animation empowering action Animation giving power to young women with NF1	Yeah, again this is a bit of a tricky one for me because although watching the animation and knowing the facts, that we are greater risk, em, it would give me more confidence in approaching GPs to say, 'well look, actually, this is our condition, and you know, we are more at risk', em it would give me more confidence saying that, but because of my history of going to the doctors for like fatty tissue lumps, if I was to notice changes

Confusion shakes confidence – fibroma or benign mass? Still feel vulnerable and judged Tentatively planting the seeds of powerful actions and empowering thinking Stuck within barriers of a powerful yet disconnected system	occurring now, I would still feel very vulnerable, em and judged if I was to make an issue about it again because I have been a few times in the past.
HPs – under pressure With lack of understanding comes lack of compassion HPs perceived as patronising HPs makes you feel nervous and doubt yourself HPs remove power and empowerment from women with NF1 HPs perceived attitude a barrier to seeking help for a breast concern Broken knowledge breaks links in the system Stuck within barriers of a powerful yet disconnected system	Yeah, absolutely. Em because I know that they are always under pressure and I think that where they do lack understanding, with that comes the lack of compassion and the lack of reassurance and although they don't directly say it, they sort of patronise you, and imply that you are wasting their time, and it makes you feel nervous and doubtful in yourself, and with things like breast cancer, you shouldn't feel hesitant to want to contact your healthcare provider if you're concerned.

Prevent BCA Missed diagnosis of NF1 is a missed awareness opportunity Unmet needs with a later diagnosis – lack of information and lack of support Awareness is a shared experience – HPs need to share knowledge with patients HPs lack of knowledge means lack of knowledge for patients A need for accessible information direct from GPs The importance of charities for support and information Charities are trusted sources Broken knowledge breaks links in the system Stuck within barriers of a powerful yet disconnected system Forging chain reactions from stronger links	Well, obviously not having the diagnosis is a huge concern because a lot of adults don't always get diagnosed until they have children themselves, em so obviously they are not aware of the risks that prevent them. Em, but having knowledge of the support networks that are available to them, you know. With my diagnosis we never got recommended or diverted to any self-help or support groups, em so we weren't able to obtain that knowledge immediately, you know, so I think having access to resources and information directly from the healthcare professional, you know, even if that's directly after diagnosis it would help that individual be aware, you know. If it wasn't for the charities directly I wouldn't of known as much as I know now.
Confusion of screening age – confused information from charity	Em, I think it's pretty much the same if I remember it correctly, although I am slightly unsure. I think we're at greater risk from the

HPs should be responsible for organising screening Onus left on patient to chase Stuck within barriers of a powerful yet disconnected system Patient having to be expert/teacher	age of 30 and we can request, you know, the screening tests em but again, although we're eligible for it, that is putting the responsibility back onto the patient to want to chase it, and I feel that it should be the responsibility of the healthcare provider to make sure that happens.
Those with NF1 reluctant to speak to HPs Health is put on the back burner – other priorities come along Life gets in the way HPs organising screening alleviate anxiety to organise Stuck within barriers of a powerful yet disconnected system Broken knowledge breaks links in the system	Because I mean irrespective of what we suffer with as an individual, we are always reluctant to speak to GPs and health professionals. We always put it on the back burner, and it gets forgotten about. Other things, and life in general become priority sometimes. You know, it's something that is important and if we have to make that direct contact ourselves, it's something that we're still unsure about doing and if the doctor initiates that process for us, you know, it alleviates a lot of that anxiety that comes with it.
Going to a HP is like going to war The battle to defend, explain, and justify Patient having to be teacher/expert Patient not being heard	((in overlap)) yeah exactly. Because a lot of the time through my experience of my own appointments and my children's appointments or any time I've had to raise concerns about anything, em, in regards to NF, I always feel like I have to defend myself, explain, and justify why I am concerned or why I am requesting something, and it just

Trying to fight for what you are entitled to is exhausting Needs should be met without interrogation Stuck within barriers of a powerful yet disconnected system Broken knowledge breaks links in the system Patient having to be expert/teacher	becomes another battle, another-, another reason why we're exhausted all the time, you know, to have to try to fight for what we are entitled to, and when it's something as serious as breast cancer, we shouldn't have to justify why we want it or why we need it. It should be available to us, without question, without an interrogation, you know.
HPs – lack of knowledge Patient having to be expert/teacher The feeling of vulnerability Power struggle between HP and patient Patient not being heard HPs are supposed to give reassurance Broken knowledge breaks links in the system Patient having to be expert/teacher Stuck within barriers of a powerful yet disconnected system	yeah, it's a combination depending on who you are talking to, you know, I mean I don't think I've met one health professional yet that is fully knowledgeable with the condition and the surrounding risk factors that are associated, so there is always an element of conversation somewhere that I have to explain why I'm there, what the condition is, and why I'm concerned and then you leave feeling quite (.) quite vulnerable, quite emotional because you don't feel heard all the time. It becomes a conversation into why you are there in the first place and having to explain that to somebody who is supposed to give you reassurance. So, you end up not having any confidence in that person you are speaking to because they have no knowledge of it, or if they do it is very little, very basic knowledge.

Encouraging BCA Very simple Brief Clarifies what to look out for Awareness is a shared experience – desire to share animation The importance of sharing animation to raise awareness Wider accessibility is important. Find it even if you're not looking for it A Goldilocks animation for inclusive and engaging learning Forging chain reactions from stronger links	I think it's a very informative animation and it's very simple, easily understood and it's straight to the fact em it's a very short brief video that is also very good so it's gonna engage with that, you know, that person watching for the whole time hopefully. Yeah, so I think it clarifies exactly what to look out for, so I do think it's helpful to anybody that we can share it with. It is that initial em step as to how are we getting that information to that person because unless we are looking for it ourselves, it's not there and it should be there as part of the process of diagnosis.
Animation format Animation format – no advantage Animation can reach a wide audience A Goldilocks animation for inclusive and engaging learning	Em it being an animation it didn't particularly have any em advantages to it, in my opinion, em you know, I think it would have been equally as informative if it wasn't an animation, em so yeah, I don't really have much of an opinion on that. I think the way it was presented was absolutely fine, you know, there's no thought of em negative criticism on it at all. I think it would reach a wide audience, of course.

Taking part in research Feeling hopeful An opportunity to be heard Being involved in making changes Awareness is a shared experience – the need to help HPs increase their knowledge Proud to take part because it is an essential change that is needed Forging chain reactions from stronger links A learning culture of respectful curiosity and patient-centred benchmarks	it's made me feel hopeful in the fact that we are being provided with an opportunity to be heard, to speak out about any concerns we have. I mean, being involved in potentially making changes to support people with our condition, you know, to raise more awareness and have them met, knowledge to help healthcare professionals hopefully as this is what we want. These are the changes that need to happen. Em, I'm proud to be part of that really, you know, because it is an essential change that is needed.
Do/feel differently Previous knowledge – nothing different For others just learning – encourage to be own advocate (power and empowerment) BCA is nothing to be embarrassed about Tentatively planting the seeds of powerful actions and empowering thinking	I don't personally feel like I would change anything differently, but I think that is purely because I had that knowledge prior, em so if I didn't, then it would make me want to double check or, and just to be a bit more responsible in the sense of being my own advocate really, you know, and how that self-checking and self-awareness is important and that it's nothing to be embarrassed about.
Relatedness with researchers in field – appreciation of work being done	I appreciate the time that you are doing to get research on our condition and the risks

Forging chain reactions from stronger links	that you know, are close to us. So, thank you.

Amy (A)

Associate – cousin	Eh, she is my cousin.
Increased BCA – connection between increased risk and NF1 Increased BCA – earlier screening for women with NF1 Increased BCA – checking once a month Lack of general BCA Them and us Animation contributed to thinking from a different perspective Seeing it from the woman with NF1's perspective Forging chain reactions from stronger links Animation provides the ins and outs beyond the lump In another way, from another point of view	Em definitely, definitely changed. Em, I hadn't really put those two things together before, that em because I know obviously about NF1 and tumours, but I didn't really connect that to sort of breast cancer so, watching em, watching the animation definitely sort of put that link together for me, in quite a clear and obvious way, so it was quite helpful in that sense. Em, so it-, I can obviously see why em that increased risk would be there for young women with NF1. Em, I really-, as having not put that link together before I didn't know anything about the sort of frequency of screening, em or you know the sort of various challenges that would em sort of present for young women with NF1, sort of going to the doctor about these kinds of things, em so having had very little knowledge of it beforehand, it was all sort of new information to me, em watching that animation, so it was really interesting and (.) just kind of surprising in a way actually that, you know, once a month to me seems quite em, seems quite often so that was kind of surprising that

	that's the sort of suggested or recommended frequency em, so yeah I was surprised, I was kind of sad for my cousin thinking about em that kind of thing and I hadn't really put those things together before so yeah it's definitely made me think of my cousin, em (.) yeah. So I feel a little bit differently about-, about the whole thing em, sorry that was a bit of a ramble! ((laughs))
BCA as a taboo subject – not talked about in normal conversations in families Animation creates a consideration for women with NF1 In another way, from another point of view Breasts are taboo	Em yeah I would-, I'd definitely would encourage em my cousin to that if she weren't already, em (.) we don't talk about this stuff that much so I can't really imagine doing it in practice, but I think having that awareness would be definitely something to consider when I'm talking to her, and like thinking about her health and things. Em, so it would definitely be something that I would consider more now having watched the animation and sort of taken part in this than I would have, if I hadn't taken part so, yeah just something that I am more aware of now than before.
Increased BCA – screening Lack of BCA in general in associate Lack of association of BC with young women Animation provides the ins and outs beyond the lump	Em, yeah em ((pause)) I don't know really, I guess it's just that I know that now where I didn't before. I don't really know em (.) if it goes beyond that, I guess. I have that information now whereas I didn't before, em (.) but yeah I think that might be sort of the extent of it em (.) I guess again 40 seems quite young to be eligible for that kind of

	thing. I guess in my head, em I don’t really associate breast cancer with younger women which is probably quite a common thing and a common experience so yeah 40 does seem like it is a fair bit younger em, (.) so I guess kind of surprising in a way. Em, yeah, I don’t know.
Barrier to BCA Other health issues of young women with NF1 are a priority So many other things to worry about BCA might not be high on the list with so many other worries Embarrassment Concerned about taking up HPs time Perceived power of HPs In another way, from another point of view Stuck within barriers of a powerful yet disconnected system	Em, I guess as someone who doesn’t have NF1 obviously, but em I aware through my cousin’s experience that you know she’s had a lot of other health concerns, and you know, she’s had time in hospital, em she has periods where she uses a wheelchair em so I can imagine and this is just me sort of projecting that it might not be that high on the list, so I don’t know, and it definitely should be. But I guess having NF1 you’d know more about the condition obviously, em but it might be that you’ve got so many other things to worry about, and so many other health things going on, em like you know, being in hospital, or mobility and things like that. It might be that checking yourself for breast cancer might not be a sort of top priority. Em, although it should be obviously, or should be one of the priorities but em, it guess it might be you’ve just got so many other things to think about that that em is something you would do that often, I don’t know. Em (.) I guess it’s the common things of maybe being embarrassed or em in the sort of climate that we’re in now

	and not wanting to take up sort of healthcare professionals time, em so, there'd probably be quite a range of things, em (.) but yeah they are sort of the three things that come to mind.
Animation encouraging BCA Short and accessible Awareness is a shared experience Accessibility with subtitles Explains things clearly Awareness is a shared experience – diversity in animation. NF1 can affect anyone A Goldilocks animation for inclusive and engaging learning	Oh definitely, em it's obviously fairly em (.) short so I think it's quite an accessible video in terms of, you know, it's em not demanding too much of your time so I think it's quite an easy thing to em to watch and share. I think it would be a good way to raise awareness em it's a very accessible video in terms of the style of animation em, there are subtitles from what I can remember, so I think it is quite, you know, an accessible em, accessible video in a way. Em, I think the animation style as well, like it's a very sort of easy to watch, all of that kind of thing, and so it's engaging em and it explains things quite clearly, em so it's yeah, I think it's a good way to raise awareness em (.) yeah! I think again from what I can remember ((laughs)), it was a few days ago but even the sort of em, I think the diversity of the sort of characters or the people involved, I think that was a good thing to see, so I was pleased that that was involved, em and that was something that was considered, rather, so yeah I think it's a good way to raise awareness.
Animation	((in overlap)) mm definitely. Yeah I mean the content was obviously not overly scientific,

Not overly scientific Exposes barriers to being BCA – checking breasts Accessible learning tool Animation provides the ins and outs beyond the lump A Goldilocks animation for inclusive and engaging learning	you know, it sort of explains what NF1 is, and then talks you through em the different sort of processes of raising awareness, em and to see the different areas of the content, so I know it does obviously go into reasons why young women with NF1 wouldn't want to em approach a healthcare professional, you know, the various reasons of why they wouldn't so it's broken down in a very personal kind of way. It's not overly scientific, em which might be a barrier so I think it's very like (.) clear and obvious em, well not obvious but it's clear em and easy to understand so I think from a learning perspective obviously that's em (.) it's an accessible sort of way to, em enrich that learning I suppose.
Taking part in research Encouraged thinking from an NF1 perspective Breaking the normalisation of NF1 Encouraged reflection of challenges of NF1 Them and us In another way, from another point of view	Definitely it made me think about my cousin more. Em (.) we've, you know, known about the NF1 for a long time. I think it's easy to (.) not take it for granted because that sounds weird but, it's easy to be normalised and then you think about, you know, watching something like this, you think, 'oh that's another thing that she's got to deal with', that as I'd mentioned I hadn't put together before so you just (.), it's just another thing that she's got to be careful of, and more aware of, you know, on top of all the other things that she's got going on so, it definitely made me em reflect on some of the

	challenges my cousin might have experienced so far and may continue to experience em, having NF1 em (.) so ((pause)) maybe em, again this is going to sound weird ((laughs)) but em (.) it made me reflect on the fact that I don't have-, having not, not having NF1, I don't sort of have to worry about a monthly sort of check and having screenings at 40 rather than 50 so it definitely made me reflect on my own em (.) my own situation and circumstances em (.) and yeah it was good to learn something new as well that may impact my cousin and a-, you know, a member of my family, so em yeah, I'm pleased to have taken part, em and yeah definitely then something, and reflected on yeah a close member of my family.
Do/feel differently Awareness is a shared experience The positive ripple effect of raising awareness Forging chain reactions from stronger links	I think mostly what I kind of touched on, em (.) I think also it feels good to be taking part in something that is raising awareness of a fairly em unknown thing, again I'm not that involved with em the Childhood Tumour Trust but for my external point of view, or understanding em NF1 isn't very known about em, and I think probably the link with breast cancer even less so, so that the fact that I can be em participating in something that is-, is raising awareness and having an impact is em a good thing and I'm pleased to be doing that. Em, and yeah, you know it's important to take part in research in this kind

	of thing so I'm pleased to be doing that. Em, and yeah those sort of personal reflections that I mentioned earlier, em (.) I think that's it ((laughs)).

Christina (A)

Associate – aunt	Em, they are my niece.
Increased BCA – risk Increased BCA – earlier screening Animation provides the ins and outs beyond the lump In another way, from another point of view	Em, I didn't realise the-, how-, I knew there was a larger risk, but I didn't know how much larger. Em, and I was surprised having heard that there was a five-fold increased risk that the screening didn't start 'til 40.
Previous belief screening started younger with increased risk In another way, from another point of view	I think that was the age, wasn't it. I think in my head, it was going to start or it should start younger? Eh, so they're kind of the two stand out things from what I learnt, was the five-fold risk and what age screening started.
The assumption that screening started earlier in young women with NF1 Animation provides the ins and outs beyond the lump In another way, from another point of view	No, but I wasn't aware of an exact age but I had assumed or presumed that it was younger so when I heard it was 40, I was a bit surprised.

Nothing to base assumption on In another way, from another point of view	Well I think I thought it was 30 but I had no knowledge, yeah I had nothing to base that on-
Money the implied reason for screening only starting at 40 years Why not earlier than 40 years? Prevention is cheaper In another way, from another point of view	but if there is a five-fold risk, I would obviously-, I know money comes into everything, but I would be asking why it couldn't be earlier than 30, if there is such a higher risk and obviously prevention is cheaper than em solving a problem later on in so many different ways, em so I'm surprised it's 40. I had a feeling it was 30 but based on just, I thought. Em, but I wonder why it can't be even earlier than 30 just for so many reasons.
Increased risk means increased encouragement to contact a HP Supporting more than encouraging to contact a HP Scary to go to a HP Forging chain reactions from stronger links	Em (.) well hearing it's a five-fold increased risk, I would say I would encourage them more than I would have realised more. Em, it's made me see, but I can see it's a scary thing to do, so em you know, it's not encouraging but it's supporting em someone to go because it's very scary.
How to support? Increased risk of BC is another complication to deal with NF1 Another battle to fight	Gosh, oh. I mean (.) I-, I'm guessing if you'd have NF1 you've had lots of-, sorry I'm trying not to make assumptions, em based on the person I know, but I'm wondering if you have NF1 you've already had lots of medical appointments in your life, or maybe you've had more. So, they will, and maybe they've

Another thing to face Support is a shared experience In another way, from another point of view	been good news or bad news, I just think it's very different to someone that's generally healthy to have those mammograms. Someone with NF1 has already had probably lots of medical appointments and things may have gone well, they may have not, I can only go by the one person I know who has NF1, who has had to have operations, so already her journey has been quite complicated and I can see how they'll say, 'oh my god, it's another thing. It's another battle I've got to fight. Or another thing I've got to face', and 'what if it's a negative answer? What then?', you know, 'I've got to have more treatment'. So, I haven't got the answer to how you support them. It seems quite major, but I would hope that there would be family support, and medical and nursing and counselling support.
Barrier to BCA Women with NF1 – lack of knowledge Mistrust of the body Broken knowledge breaks links in the system	Well if they em ((pause)) I don't know. ((pause)) I don't know if they just haven't-, I don't know if they haven't heard of it, or they don't trust their bodies, or they have (.) I don't know. They're not aware of the higher risk or (.) I don't know.
Animation encouraging BCA Animation as safe Easy to watch	I thought it was em (.) it was safe. It made-, it was very easy to watch and understand and em it was encouraging, some simple tips, but not scary, not overly medical (.)

Easy to understand Encouraging Not overly medical Animation is a protective shield from taboo breasts and scary facts A Goldilocks animation for inclusive and engaging learning	
Cartoon format Non threatening A real person and their breasts are threatening Animated person could be any of us Animation is a protective shield from taboo breasts and scary facts A Goldilocks animation for inclusive and engaging learning	Eh well it gave some key points. The cartoon I guess makes it, em ((pause) well I saw it as non-threatening because it was a cartoon em and it's not a real person. Em, I don't know how it makes you learn more cos I don't know ((laughs)) I don't know why it was chosen to be cartoon but I just saw it as a friendly, non-threatening person who could be any of us.
Taking part in research Concern for people with NF1	Em (.) concerned for people with NF1. Women with NF1, em (.) probably guilty that I-, I don't always understand what my niece is going through. Em (.) and if I can support the awareness getting through or shift em

Animation beings an awareness of NF1 struggles – feeling of guilt as ‘Us’ Awareness is a shared experience In another way, from another point of view Forging chain reactions from stronger links	screening where it’s more accessible then I am pleased to help.
Do/feel differently Feel more concerned about increased risk Feeling of being stuck with this new knowledge Be ready to support In another way, from another point of view	Well, I feel more concerned that it’s a five-fold increase, em ((pause)) I don’t know what I would do. Yes I would help her, but em, gosh one hopes that it doesn’t come to that.

J

essica (YW)

A complex childhood diagnosis Struggling in school An obvious diagnosis for an obvious sign Broken knowledge breaks links in the system	em, I think I was about 10 or 11 when the process started, em, I think I was initially seen by a doctor for a number of different health problems, I think initially they thought it was (.) Type 1 diabetes because there were problems with my weight, and chronic weight symptoms. Em, they eventually worked out

An obvious diagnosis for an obvious sign	that it wasn't it, but there were still some unanswered questions. Em, and I was also struggling in certain aspects in school which they initially thought was dyspraxia as my mum as dyspraxia. Em, and eventually I was seen by a paediatrician who then noticed the café-au-lait spots on my skin em and then from that I was sent to the genetics teams at ***, em I think-, I can't remember exactly what tests I had, but I had a number of tests done there. Em, and they basically mostly checked my skin and my eyes and then from that they diagnosed me with NF1.
Disconnected system Broken knowledge breaks links in the system Stuck within barriers of a powerful yet disconnected system	Em, 'cos I accidently got discharged from the system I was in, and I've kind of not had the right treatments since- **Interviewer:** ((in overlap)) Ah, okay- **Jessica:** yeah so, I'm not really sure which of my issues are actually NF1 specific.
Disconnected system Lost in the system Unmet needs – lack of support Taking part in research to learn Taking part in research to be empowered	It was when I was around 12, I would say, I moved house, em, and I effectively got lost in the system and I'd also previously had quite a bad experience with one of the doctors. I'm not sure what his exact title was, but possibly a paediatrician. Em, and so we'd, I think tried to be seen by someone else, and that kind of didn't go through when we moved house and they just completely lost me within the system and then I've tried to go to different

Stuck within barriers of a powerful yet disconnected system Tentatively planting the seeds of powerful actions and empowering thinking	GPs to be like, 'hey can you re-refer me?' and they've not re-referred me so, I've not really had any support since I was about 12 which is not ideal obviously, given I've gone through puberty since then ((laughs)) and like, you know, I need to think about the future, and I'm not really having much help so that's also kind of one of the reasons I like signed up for this research ((laughs)), it's like learning a bit more about like, what I can do and what my risks are.
Increased BCA – frequency of breast checking Increased BCA – confirms what to look out for Increased BCA – screening eligibility Animation provides the ins and outs beyond the lump Tentatively planting the seeds of powerful actions and empowering thinking	I think it was definitely, like an increase in confidence just to see, how often I should be looking out for things, and like what the different symptoms would be because I think I was somewhat aware a bit, but it's kind of nice to have it confirmed in terms of what I need to look out for and like the frequency of it, em, and it was helpful to learn I think in the animation it said you start getting checked at 40 instead of older, em and that was quite nice to know because I knew that you would be checked a bit younger, but I wasn't sure of the specific dates. Em, so that's been useful to know as well.
Previous knowledge of general BCA Learning general BCA from attending an all girls school	I think it was mostly, sort of, general knowledge. Em, when I was in school, I went to an all-girls school, so they did try and give us that sort of information about basically breast cancer and cervical cancer, em, and

Learning general BCA from university Awareness is a shared experience – sharing general knowledge with family Personal experience of breast cancer in family Forging chain reactions from stronger links	there's also at my university quite big em societies that help with cancer awareness, so I've seen their promotional information. Em, and also my maternal grandmother had breast cancer twice so within the family they've kind of made sure that myself and my sister and my female cousins kind of knew what to look out for as well.
Increased confidence to contact HP with a breast concern Learning through animation helping to reframe previous bad encounters with HPs Negative experience with HPs Embarrassment caused by HP's attitude Animation as a reset to feel that one will be listened to Animation gives hope Tentatively planting the seeds of powerful actions and empowering thinking Stuck within barriers of a powerful yet disconnected system	I think it made me a little bit more confident, yeah cos I think em, for context when I said that I had a bad experience with a doctor previously, it's actually because I thought I'd found something which I've-, I think I thought it was a neurofibroma at the time. I think it turned out it was just like a bit of breast tissue because I was starting to go through puberty but then the doctor that I had was really dismissive and basically, just like he called like 'fat', 'oh it's just fat in your breasts', and then started making quite a lot of comments about my changes in weight over the years without taking in any context of like, the health problems that I'd had. Em, so I think I was-, I've been quite reluctant, you know, to have someone check me in that way since then, because I was quite embarrassed like I was obviously-, it was my formative years-

Tentatively planting the seeds of powerful actions and empowering thinking	**Interviewer:** ((in overlap)) yeah **Jessica:** but I think, yeah, it’s nice to sort of know that actually I’ll probably be listened to given there that the key warning signs are em-, but yeah, I think I have been quite reluctant to like have anyone sort of look at my body, in that way from that experience of when I was younger. Em, because I was made to feel like very, very embarrassed even though I was only like 12 ((laughs)) so-
Experience of relatedness – people (researchers) looking out for people with NF1 Tentatively planting the seeds of powerful actions and empowering thinking	Yeah, I think so and especially given there are clearly people looking out for people with NF1 and breast cancer. I think that does definitely, like help my opinion on it.
Earlier screening knowledge is reassuring Family experience of BC – motivation for BCA Tentatively planting the seeds of powerful actions and empowering thinking	Yeah, I think that’s really reassuring to me, em because I’d definitely go as soon as I have the opportunity to. Em, especially given that I have the family history of breast cancer as well. It’s like really reassuring to know that I can get screened younger. Em, especially because with my family’s history of it.
Barrier to BCA Lack of access to information Awareness is a shared experience	Yeah, I think a lack of access to healthcare information. Em, I think I’m quite lucky in that my family and the school that I went to was quite medically well informed, but I think if your family didn’t really have any medical knowledge, or in our school or university, or work, they just didn’t give you any

Lack of awareness can break the shared experience Disconnected system Importance of understanding the system Clearer information is needed for learning and accessing services Knowledge is power Knowledge is empowerment Broken knowledge breaks links in the system Stuck within barriers of a powerful yet disconnected system	information, I think there wouldn't be any way of knowing. Em (.) and also so people probably in my position as well, where they've not necessarily had the right healthcare through their teenage years, I think that was also a bit of a barrier to myself, but would be to other people, in terms of like learning what support they need, and what support they're eligible for.
HPs – position as provider of knowledge and awareness Schools -position as provider of knowledge and awareness Importance of charities position to provide information and awareness BCA approached as a general 'one size fits all'	Well, I think it's really important for them to learn about it. I think, they could potentially learn more though their healthcare providers but also potentially there could, sort of, like a good intervention made from, if you were promoting for example, breast cancer awareness in schools, to make sure it was mentioned that certain health conditions including NF1 could make you more vulnerable. Em, like say a breast cancer charity for example, is giving a presentation, you could maybe encourage them to say, 'well if you have NF1 or other conditions,

One PowerPoint slide can tell a story and make a difference Forging chain reactions from stronger links	you'd be more vulnerable', and 'to make sure that you, kind of learn more, check yourself more like, get checked out if you need to'. Em, because I think most of the awareness we were given in school, for example, was very generalised, whereas actually having one slide on, sort of concurrent conditions could make all the difference for a lot of people.
Animation encouraging BCA Right length – 'Goldilocks effect' Different methods of communication Did a lot to get someone's attention A Goldilocks animation for inclusive and engaging learning	I think the video was helpful in that-, it was the right length I think to engage people em, you know, it wasn't too long, it wasn't too short. I think the information was very clear, the fact that it used both verbal written information, and graphics. Em, I think it did a lot to kind of get someone's attention.
Animated format Provided accessibility Accessible to different types of learners Accessible to those with learning difficulties A Goldilocks animation for inclusive and engaging learning	I think it makes it more accessible having both kind of audible information and visual information. Em, I think obviously that would make it more accessible for different types of learners but also actually for someone in the first place maybe if they couldn't engage with written information or just being told information, even just seeing the graphics would probably be quite helpful. Em, so I think especially if someone had like learning difficulties, for example, being able to see the graphics alone would probably be quite helpful as well.

Taking part in research Participated with 'two hats' – patient and researcher Awareness is a shared experience – one participant voice helps gives a voice to those who cannot engage in research Tentatively planting the seeds of powerful actions and empowering thinking	I think it's made me feel good in that, em obviously it's something that affects me, but also, I'm quite passionate about, contributing to research just purely because that's an environment that I'm in myself. Em, and I think obviously there's going to be a lot of young women that maybe wouldn't know to engage with research in the first place, or feel that they were able to, so the fact that I'm able to I think it's nice in that, you know, not only will this affect myself but hopefully be able to give a bit of a voice to those other women as well, that wouldn't be able to engage with it, that would have the same health issues.
Do/feel differently Increased BCA – self awareness and reflection to check breasts more consistently Setting a date Setting a reminder Tentatively planting the seeds of powerful actions and empowering thinking	I think I need to be more consistent with checking my own body. Em, because I think although I know to do it, I've not been very consistent with it but I think maybe it will be useful to, for example, set like a date in the month to do it. Em, especially given that I am at a stage of my life, where like I do need to be looking out for that kind of thing. Em, just also because some of the medication I'm on, they try and make sure that you're aware of breast changes as well, so I do need to be more consistent with it, and I think hopefully-, look I feel much more encouraged to do so, so I maybe need to set myself a date to make sure I'm consistent.

Brenda (A)

Associate – friend’s daughter	Em, it’s my friend’s daughter.
Increased BCA – huge from animation Animation provides the ins and outs beyond the lump A Goldilocks animation for inclusive and engaging learning	Oh no, hugely. It definitely changed yes. It was really sort of clear and easy to understand as well from the video.
Increased BCA – risk Learning about the connection of NF1 and BC Animation provides the ins and outs beyond the lump	I didn’t realise that there was such a huge link, that there was such an increased risk for people with NF1, that there was that connection.
Contacting a HP is important for ALL women Particularly women with NF1 Them and Us Might be difficult for woman with NF1 In another way, from another point of view	I think it would be very important that they contact a health professional straight away. I think it would be for any woman but particularly for someone with NF1, it might actually be a really hard thing for them to do (.)
Catching cancer early can make a big difference to outcome Animation provides the ins and outs beyond the lump	But it’s very important to catch something early if it could be breast cancer. It makes such a big difference to the outcome or potential outcome.

Why difficult to go to HP for woman with NF1? Embarrassment Importance of support Solution offering – support Women with NF1 – lack of knowledge Assumption of fibromas In another way, from another point of view Tentatively planting the seeds of powerful actions and empowering thinking Forging chain reactions from stronger links	Em (.) especially I think in young women it's embarrassment quite often, em but if they could talk to someone else who could go with them, I think that would help. And also, I think just- (.) just the awareness, I suppose if you've got NF, you're kind of used to little lumps possibly appearing, but to be aware that actually you've got such a big increase of a risk of breast cancer that I think you should be more-, definitely more aware if you found something near your breast or your armpit or- (.) yeah it's huge really. It's massive.
Assumptions create complacencies Young women with NF1 – lack of knowledge Experience of definite urgency from associate In another way, from another point of view NF1 complexity – fibroma, cancer, or hormones?	yes, I think so. I mean I don't know but you might-, if perhaps they've got lumps and bumps elsewhere and they might just think, 'oh it's another, you know, just a little lump, I'm prone to lumps, I'm not going to worry about it', but it does need to be-, it's something they need to get checked out straight away. Definitely.

Increased BCA – screening eligibility Experience of definite urgency from associate The urgency from learning new information Animation provides the ins and outs beyond the lump In another way, from another point of view	I had no idea and that's-, and that's the really important thing to do, isn't it? I mean that's a whole 10 years earlier-
The urgency from learning new information Solution offering -support The potential supportive role of the associate Perceived lack of general awareness among young women with NF1 Forging chain reactions from stronger links	Because if you know someone with NF1 then you can prompt them if they're approaching 40 to sort of go and make sure that they are being screened.
Disconnected system Confusion surrounding the screening process for NF1 Screening assumptions Stuck within barriers of a powerful yet disconnected system	Hmm (.) I don't know (.) em ((pause)) I suppose em, it's difficult, isn't it? I don't know if GPs (.) have-, because I know that the breast, they have-, there's a breast screening programme, isn't there? Where women are written to as they approach 50, so surely women with NF1 should be on a programme via the GP so they're automatically sent out letters to offer screening when they are 40? Should they not be?

Solution offering – access to screening Support The fight for others The urgency from learning new information Disconnected system Patients having to be the right code to access services In another way, from another point of view Stuck within barriers of a powerful yet disconnected system HPs – power to give you the right code	Well, I think they should be! I guess it's a very tricky area. I know, I worked in a GP's surgery. I suppose it's all down to coding where the patients with NF1 are coded in-, I don't know. I guess it's a tricky area.
Disconnected system Assumption of a connected system Assumption of ease of access to screening because of NF1 Stuck within barriers of a powerful yet disconnected system	((in overlap)) they should really. You would imagine that the breast screening service should be writing to them all when they're 40 and should be saying, 'come in for breast screening. You're entitled to it earlier, because of the condition that you have'.
Barrier to BCA Learning difficulties	((sigh)) ((pause)) em ((pause)) I mean-, so I mean some women possibly-, I mean there are learning difficulties quite often associated

Vulnerable women Broken knowledge breaks links in the system	with NF1, so it could be that there are vulnerable women that really aren't aware.
Solution offering – add BCA NF1 information to BC leaflets Accessibility – GP's surgery Awareness is a shared experience – in general BC information Forging chain reactions from stronger links	Em (.) I mean it would be nice if it was added into-, in your doctor's surgery when you have your leaflets about breast cancer, it would be nice if there was something in there.
Clear and easy to watch Animation not patronising A Goldilocks animation for inclusive and engaging learning	I think it did. I think it was very sort of clear and easy to watch. And it wasn't patronising and yeah, I felt it was really good, actually.
Animation opens channels of communication Animation is a protective shield from taboo breasts and scary facts A Goldilocks animation for inclusive and engaging learning	I think it sort of just made it easier to talk about as well.
Animation format Sticks in the mind Animation offers a protective distance	Well, I think it did help, and I think it sort of stuck in your mind. It was much better than just reading something or, you might feel a bit uncomfortable actually watching a real

Seeing a real woman's body might be uncomfortable Animation is a protective shield from taboo breasts and scary facts A Goldilocks animation for inclusive and engaging learning	woman maybe, I don't know. I just thought-, no I just thought it was really good.
Animation suitable for a younger woman A Goldilocks animation for inclusive and engaging learning	yeah, I think so, especially for a younger woman, I think. Yes.
Taking part in research Focus of awareness on the increased risk In another way, from another point of view	Em (.) yeah it has just made me think about the increased risk.
The shock of new information – risk Animation provides the ins and outs beyond the lump	and it's just- (.), it's just, I think it's quite surprising actually that I've never heard of it before. I didn't realise that there was so much of a bigger risk.
Do/feel differently Reflection on personal experience of losing relatives to breast cancer Importance of BCA for women with NF1 – personal motivation due to family loss	I think (.) just bear in mind that any women with NF1 should know they are at increased risk. I mean I've lost a couple of close female relatives to breast cancer so; I think it's sort of-, I know how important it is to catch things early and not leave things.

Knows the importance of catching things early and not leave things In another way, from another point of view Forging chain reactions from stronger links Tentatively planting the seeds of powerful actions and empowering thinking	
Awareness is a shared experience Knowledge is power and empowerment Giving knowledge – giving power Encouraging women to check – encouraging empowerment Animation encouraged own personal BCA – checking Animation creates ripples to think about your own breast nipples Tentatively planting the seeds of powerful actions and empowering thinking	and just to get checked out and (.) yeah and I suppose to encourage women to check themselves as well regularly, which I don't do to be honest, which I should do.

Sasha (A)

Associate – mother	Em, she's, my daughter.

Increased BCA – general BCA (non NF1) Animation provides the ins and outs beyond the lump	Em it's given me more awareness. There were many things I didn't know previously and some of the signs to look out for were new to me.
Increased BCA – beyond the lump Animation provides the ins and outs beyond the lump	Em I think it was the indentation of the nipple, em-, it's more a case of there were more than I thought of because you're always told to look for lumps aren't you-
Confusion of fibroma versus malignant lump NF1 complexity – fibroma, cancer, or hormones?	em which I think with NF1 can be tricky because if you've got your tumours anyway-, but it was just that there was more signs than I had suspected.
Importance of vigilance within women with NF1 of body changes Empowerment in vigilance Tentatively planting the seeds of powerful actions and empowering thinking	[...]I think it's really important for any young lady especially those with NF1 to be vigilant and more aware of their body and their changes.
Previous BCA knowledge – risk Only recent learning of risk Forging chain reactions from stronger links	Only in the last few years. It's only something that has come to light probably in the last 5 years. Prior to that I wasn't aware of it, that there was more susceptibility for people with NF1.
Increased BCA though CTT – risk Awareness is a shared experience – forums and websites Awareness is a shared experience – sharing findings from research	Through the Childhood Tumour Trust charity because I'm a part of that. It's been on their forums, on their websites. It's taught me a lot more about the condition.

Forging chain reactions from stronger links	
Awareness needs to come from doctors Doctors need to share awareness with their patients Importance of relatedness with charities for awareness Connections shares awareness Broken knowledge breaks links in the system Stuck within barriers of a powerful yet disconnected system	I think it's really important, but I think there needs to be more awareness from doctors as well to tell their patients who have NF1 that this is available to them and it is a suggested thing for them to do, because I don't think women know that unless they have a particular contact or a charity that is telling them that they can do this.
Previous knowledge through CTT – Screening eligibility Awareness is a shared experience Forging chain reactions from stronger links	It was through Childhood Tumour Trust. Prior to that, I didn't realise that, you know, women with NF1 should be having screening earlier.
Barrier to BCA Knowledge is power Empowerment through awareness – taking responsibility for yourself Importance of connections with charities – relatedness	Em, that's a really difficult one. Em, (.) I don't know how to answer that, I'm afraid. I think, you know, it's-, it's knowledge is power as they say. It's being able to have that knowledge available to you so either through your healthcare professionals or through researching yourself. I think it's really important that people that have NF1 take some responsibility to actually research

Connections shares awareness Importance of having access to accurate and accessible information when researching Tentatively planting the seeds of powerful actions and empowering thinking Forging chain reactions from stronger links	things themselves, and you know, be- (.), be connected to the charities that are available because I think their help and their knowledge is invaluable.
Animation as ‘informal’ Animation is less intimidating Not too clinical Easy to watch	I think it was done in a nice, kind of informal way. It wasn’t too clinical. It made it-, light-hearted I suppose is the wrong word, but it made it less intimidating. And, you know, it was easy to watch.
Cartoon format Acceptable for younger people Not an old-fashioned style Animation is a protective shield from taboo breasts and scary facts A Goldilocks animation for inclusive and engaging learning	I think it’s something that younger people with NF1 are likely to watch and em respond to more easily than having to watch a documentary, or you know, the old-fashioned style of putting the information out to you. It’s (.), I can’t think of the words I’m trying to think of. Not light-hearted but it makes it easier to watch (.)
Animation does not exert power over viewer Not frightening	and it’s less old-school telling-, trying to tell somebody pieces of information because sometimes, younger women don’t always

Animation is a protective shield from taboo breasts and scary facts	concentrate or want to know about things like that because they think, 'oh, I'm too young. I don't need to think about it yet'. But I think watching that, it was easy to watch, and it wasn't frightening.
Animation creates a sense of free-will and personal choice to watch and learn The sense of agency A Goldilocks animation for inclusive and engaging learning	I don't know how to say it ((laughs)), you know, it wasn't ((pause)), kind of (.), 'oh, I've got to watch this'. It wasn't boring.
The Goldilocks effect A Goldilocks animation for inclusive and engaging learning	I think so and obviously it didn't go on for too long either. It was brief and to the point and it held your attention.
Taking part in research The hope of doing some good Awareness is a shared experience – of condition Help others Forging chain reactions from stronger links Tentatively planting the seeds of powerful actions and empowering thinking	Hopefully, it's done some good because it's a condition that is so underfunded, it's under talked about. I think it's really important to get the awareness out there and having personal experience that my daughter has lots of complications because of her current condition, I want to do as much as I can to raise awareness. And if it can help other people then that's brilliant.
Do/feel differently	Em, I will make sure that obviously as time goes by and my daughter becomes slightly

The associate as teacher Awareness is a shared experienced – mother to daughter Knowledge is power and empowerment for her daughter Tentatively planting the seeds of powerful actions and empowering thinking	older that she is aware of the possible consequences of breast cancer and make her aware that she needs to-, that it is important that she checks herself on a regular basis.
Checking once a month – reasonable Creating a new behaviour to check Becomes like on auto-pilot Tentatively planting the seeds of powerful actions and empowering thinking	I thought-, that's what I guessed when I watched it, when it asked you when I did the questionnaire beforehand, and I thought that once a month was a reasonable period of time and I think it's important that, you know, that's seen as being reasonable. It's not too often, it doesn't have to take long and once you get used to it, you'll probably do it without even thinking about it.
BCA as natural BCA as natural and automatic action Tentatively planting the seeds of powerful actions and empowering thinking	If we can sort of like almost programme the young people with NF1 to do this as a natural course, then after a while they'll do it automatically.

Teagan (YW)

Obvious diagnosis for an obvious sign An obvious diagnosis for an obvious sign	The big giveaway I guess was the café-au-lait marks on the skin so the doctors I think when they were looking at me, they noticed that I had more than 7 café-au-lait marks, which are like a coffee colour em mark on the body, and they were an indication that I had the neurofibromatosis and then I think that's when they wanted to do all the scans in London to jut veri-, to just like double check, but in the end they didn't have to. The marks were enough.
Increased BCA – animation made me more aware Past breast concern Worry of radiation from mammogram with NF1 Increased BCA – monthly checking The reality of the confusion and worry between fibroma and benign mass Previous confidence to seek medical help NF1 complexity – fibroma, cancer, or hormones? Animation provides the ins and outs beyond the lump	Em, it's made me more aware so, eh I think it was last year because I know that we are high likely, I found a lump on my breast so I called the doctor and called him up and explained the situation with NF and they referred me to the specialist where I had some scans done which was ultrasound which is especially with people with NF was the better route to go because we don't want the radiation from the mammograms and it has made me know to keep checking on it, week, monthly, is it weekly? I think it's monthly- **Interviewer:** monthly, yeah **Teagan:** to check on me and make sure that nothing's changing em to get like aware of what it should feel like and then because of our-, I went to the doctor and got things

	looked at. Luckily, there was nothing. It was probably just a fibroma they think it was.
Previous BCA – through NF charity position Knowledge is power Importance of connections for knowledge Forging chain reactions from stronger links	yes, that was the bit that I know a bit more earlier em, that's just also due to the position I used to hold em with working within a charity. That gave me a bit more knowledge than some people.
Awareness is a shared experience – me as researcher sharing awareness from previous work Forging chain reactions from stronger links	Em I think it was a bit of a mixture so it's from a bit of the charity and also through some research similar to this in the past as well.
Increased BCA – warning signs Beyond the lump Animation provides the ins and outs beyond the lump	I have learnt some new things from the animation em somethings that I wouldn't have necessarily really thought about when checking, what kind of other signs and symptoms to check for, not just finding like a lump.
Increased BCA – confidence in detecting changes Beyond the lump Animation provides the ins and outs beyond the lump	I think it's gone up a bit. It's like confirmation of the second things to look out for. There's I think, most of the time you don't think about those things, you just think about a lump. You forget about everything else that also could be a sign if you don't feel a lump because you might not be able to feel the lump, but something could be there, but yeah a different sign.
Previous confidence contacting HP	Em, I think it's-, I feel quite comfortable and confident at contacting like a medical person,

The worry about being taken seriously HPs – lack of knowledge Patient having to be the expert/teacher Battle to be heard and taken seriously HPs as holding the power Broken knowledge breaks links in the system Stuck within barriers of a powerful yet disconnected system	it's just that the em-, are they going to take that risk seriously because I know a lot of people who are in the medical world are not aware that with NF you do have an increased risk because most of the time they know about em, the BRCA gene eh so they are aware of those higher risk factors but when it's with NF I feel like I have to really enthuse-, emphasise the risks with NF, em to try and get them to be like, 'yeah we do need to do something', and not just like, 'we'll wait and see'. So, that's always in the back of the mind.
Increased BCA – screening eligibility Animation correcting previous beliefs Animation provides the ins and outs beyond the lump	It has changed because I thought it was em earlier for women with NF so it has changed knowing that it's 40 but it's still good for me to still look em to still be aware of it now because anything could happen between now and 40.
Confusion of ages from reading information pertinent to other countries UK 'trying' 40 A struggle for breast screening in general Women's fight in healthcare	Em, I think it was 30 but that might be because of information that I've been told from other countries when they do it. So that's just in my mind because that's a different system to the UK, and they-, I think in the UK they're em, trying 40, but I don't know if it's a struggle because it's a struggle with any age if it's women with it.

Stuck within barriers of a powerful yet disconnected system	
Availability of research information UK and IRE Lack of available research/information NF1 Lack of available research/information NF1 and BC	I don't think there is enough because there's not enough within the generalised of NF, the condition in itself and then when you've added on breast cancer it's not communicated enough and it should be one, not easiest ones, but there's more understanding of breast cancer than there is of sometimes of NF1. You'd think there'd be a bit more of em like communication of it, em to just understand why is there a link to begin with.
The need for more NF inclusion within BC research Broken knowledge breaks links in the system	yeah, I think so because if you research it you know it's NF and not generalised breast cancer. I think it could help general-, within the generalised breast cancer em research.
Barrier to BCA Misinformation HPs – lack of knowledge HPs – lack of knowledge helps spreads misinformation and confusion The preference to go with who tells you the good news Broken knowledge breaks links in the system	Em (.) I think it's just misinformation, em which you get within every kind of thing with em an illness. You always will get some sort of misinformation. I know within general NF, there's a miscommunication of some doctors saying it's just a skin condition. Some doctors say it shouldn't cause pain. Some doctors just generally don't know what it is. I've had people who thought it was a cardio condition em who are in the medical profession, so I think that is one of the worries that people might have as well, they just they get some misinformation and having to-, if someone says to you, 'you are at risk', and someone

	says, 'no you're not at risk', you're going to want to believe the not at risk, because no one wants to hear that they're more risk prone to getting breast cancer than the general population.
Communication of misinformation Misinformation can come from anyone and everyone Misinformation is a shared experience Going with the ingroup The detrimental effect of misinformation by HPs Broken knowledge breaks links in the system	From everyone ((in overlap)). I think (everyone, most) get misinformation from like, you might get friends, or family or people even within the actual community, em I think sometimes if you don't, say em, get on with a doctor, or you don't like what they say, you go with someone in the community and if they say something, you like go, 'oh no I'll go with that'. But you get anyway people within-, outside the disability, you believe people within your community, you listen to them and hear what they say. It's just a thing, when it's medical professionals where they're the ones like you tend to go to for this advice, that's where it adds more of a detrimental effect on people.
Breaking barriers to BCA Educating is a shared experience Education from charities, NF and cancer Lack of information available about NF1 and BC information	It should really be coming from, like let's say charities, em medical professionals, I don't know maybe like breast cancer websites and charities as well, so not just the neurofibromatosis charities but like, the breast cancer em website or even just cancer websites because I know when I've looked on like say breast cancer websites, I couldn't find anything for NF. I could find-, I found stuff for like the BRCA genes and some other-,

NF1 is left out by breast cancer websites and charities Googling for answers Patient having to be expert/teacher Broken knowledge breaks links in the system	another genetic condition or a genetic component, but that this was a year ago so things could change then. Em, I couldn't see anything for NF so things could have from when I last looked at it, but when I looked at it that was the entire-, that was the information at that time.
All it takes is a little space to help raise awareness Knowledge is empowerment Knowledge is a shared experience Awareness is a shared experience Patient having to be teacher/expert Googling for answers Patient having to be expert/teacher Forging chain reactions from stronger links	yeah, because I think if you-, if you just type in 'breast cancer', the first thing you're going to get is like one of the organisations em, and if they had just like a little area, you'd be like, 'oh okay, right...I've got to really make sure the doctor', and then they can-, you can then em-, the person themselves can let the doctors know that they have that condition because it's like-, I mean you go to doctors, you might say, ((inaudible)) the breast cancer and that's when you look into the genetic components. You yourself-, if you're aware of it, then you can help inform the doctor. If that makes sense?
Animation is not overwhelming Goldilocks effect Inclusive – suitable for all ages Inclusive – for those with learning difficulties	I think it did. It was really clear. It wasn't too (.) too much information, or too long. It was em, it was a good like amount of time because sometimes if you have information videos that are too long, I think you can forget what they've said or it just gets a bit overwhelming. Em, I found-, I found the

Animation is not scary Animation is a protective shield from taboo breasts and scary facts A Goldilocks animation for inclusive and engaging learning	graphics were really nice, the information was clearly like put out to me. Em, and I think it was easy to show to em, people who maybe are a bit younger em, or older, like it was a good generation thing. And then also someone with NF like with specifically, we have quite a few, who have eh learning difficulties that might be a bit more severe. I don't think it would be too much-, em being a bit scary, it was clear from them as well, but I can't talk on their behalf, but I found it quite em, accessible and informed.
Animated format More fun Real-life humans makes it quite serious Animation provides a protective distance Animation provides an escape from reality Animation makes watching more comfortable Viewing real breasts is taboo Animation is a protective shield from taboo breasts and scary facts	Em, I think it makes it more fun, but not like it's fun to watch, but compared to say when it's real-life humans, I think that can make things quite serious em and if it's not something like when it's em like stop people smoking where you want to be serious, where you want them to really do it kind of like a now thing. It's more of a educational thing, where it's like, 'this can happen, this is what you need to do', em and you can get that more detail of how to check the boobs em which can be a bit more-, not too-, I think it makes-, it might make some women feel more comfortable when it's not-, what's the word? It's not like it's real, but it is like still showing you what to do, so it's not making too many things like, 'oh my god, I've got this? What do I do?' and then panic.

A Goldilocks animation for inclusive and engaging learning	
Taking part in research Awareness is a shared experience – raising awareness Beating misconception of breast cancer age The importance of catching cancer early Tentatively planting the seeds of powerful actions and empowering thinking Broken knowledge breaks links in the system Forging chain reactions from stronger links	Em, I feel it's good because I want em, people to be more aware of it because it-, I know it's quite a small handful at the moment who are aware, but it's quite a big thing to be-, to have a higher increase of like breast cancer at a younger age because most people you think 50, that's when I have to kind of look out for it. It's a bit like other things, you think, 'oh I don't have to worry until this issue, to this age'. If people are aware they can catch things earlier and stop em having-, to have any like treatments in the future, or worse, like people could pass away.
Do/feel differently Increased BCA – check for other warning signs Beyond the lump Tentatively planting the seeds of powerful actions and empowering thinking	Em, I think it will just be checking on the secondary em effects of what can happen, like the secondary sets. Oh I keep saying secondary, in my head that's the best way to explain to myself, those secondary signs or those things that I wouldn't necessarily think of. So checking like a bit more further up in the armpit em, and it's not just feeling there's lumps and stuff. Just checking how other things may feel and then checking what the skin, kind of like if there's lumps, bumps, different colour, just looking for those things as well.

Bruno (A)

Associate – partner	She's my partner.
Increased BCA – knew of increased risk but not to what extent Animation provides the 'ins and outs' beyond the lump	I knew that-, I knew there was an increased risk em in the past, but em I didn't-, I didn't know to what extent exactly. And I'll be honest I was quite surprised by some of the things in the animation. I did think that there was an increased risk in em breast cancer, and things like that, but I didn't know all the ins and outs of it, if that makes sense?
Increased BCA – five-fold risk figure Animation provides the ins and outs beyond the lump	Yeah, yeah. I knew there was an increased risk but I just didn't know to what extent.
Misinformation Lack of accessible and accurate information Having to dig for it Googling for answers Patient having to be expert/teacher Role reversals - Digging for answers and being the expert in the room	Because in the past I've had mixed messages because like with anything with NF1 it isn't out there, if you know what I mean, you have to really go digging for it.
BCA is a shared experience – learning from partner	Me partner.

Digging for answers and being the expert in the room Forging chain reactions from stronger links	
Encouraging contacting HP Being more aware of risk ‘on the ball’ for encouraging contacting HPs Animation provides the ins and outs beyond the lump	I wouldn’t really say it’s changed or encouraged anymore like, we’ve already been through the process in the past. Em, you know, regarding this and I don’t think it’s changed or encouraged. I think it’s just being more aware of what exactly em the increased risk is, and what to look out for but em, you know, I’ve always been on the ball in regards to, you know, if there is an issue, you need to em phone, you know, the doctor and stuff like that and get it looked into.
Increased BCA – warning signs Beyond the lump Animation provides the ins and outs beyond the lump	I was only aware of like, a few of them. I didn’t know like it can go, you know as far as the armpit and things like that. And I didn’t realise that it could em (.) make a change in the like, the nipple em and stuff like that. Probably a little bit of em, lack of education on my part. I just thought, oh you just look out for lumps, and that kind of thing.
Increased BCA – screening eligibility Assumption of automatic access to breast screening Solution finding - associate	I wasn’t aware of this, so I just em assumed that they would have screenings on a regular basis anyway given the condition. So when I heard about this I was a little bit confused with it, well if you have a condition that, you know, you get tumours, you know and you’re more likely to em get breast cancer with this

Too late at 40 with tumours and NF1 Knowledge is power Knowledge is empowerment to manage condition personally Animation provides the ins and outs beyond the lump In another way, from another point of view Broken knowledge breaks links in the system	condition, em you know pretty much no matter what the age like in some sense, would it make sense for it to be em compulsory, you know, at a much younger age? Em, so that shocked me that it was as late as 40 even with people with NF1. But that's a little bit too late, in my opinion. So em a person with NF1 can just em manage the situation off their own bat but to do that, you must be given the information to begin with.
Difficulty to get information Coming in from the outside Them and Us Google for learning Lack of accessible and accurate information Misinformation In another way, from another point of view Broken knowledge breaks links in the system	yeah, definitely. Definitely because like I've come into it from the outside em but even with me, like, all that-, I kind of ask em questions to is me partner and she's-, she's trying the best to answer them, but when you go on Google, and if you're like that-, there's not that much there at all. And then sometimes you go on Google, and you look at stuff, it's em, it's probably similar to what this is, so it's a ((inaudible)) of someone with, you know, NF1 talking about what they've been told, rather than an actual factual document, you know, this is what it is, you know, things like that. So, a lot of it is like eh third hand information a lot of the time and obviously, the more far down you go with people passing data along, the more the information can get lost, or you know, misinterpreted.

Barrier to BCA Autism HPs – lack of knowledge Fear of not being taken seriously by HP The perception of wasting time – HP has power Awareness as a shared experience – makes it an easier ride Patient having to be teacher/expert – mentally draining Broken knowledge breaks links in the system Stuck within barriers of a powerful yet disconnected system Digging for answers and being the expert in the room	I think as well, with NF1 like you know, they are more likely to have autism. I think also, it's just like, the unknown factor of em, doing something you're not used to, you know, going to go into the doctors, and because the condition isn't regular known about em, say a thing like, you know a potential situation of a patient with NF1 having autism, taking that away, just because the condition isn't as accurately known about, and that a lot of doctors aren't familiar with the idea, it can be a bit em (.) scary in the sense of, 'are they going to take me seriously?' kind of thing and then they might get in their own head, and think, 'oh I don't want to waste em people's time', and I think it's just em, you know, everyone having the awareness from the patients to the doctors and things like that, so it can be a bit more of an easy ride, rather than them going in telling the doctors the situation which could be mentally draining on them, em you know, to begin with, and then going from there, if that makes sense?
Women with NF1 – lack of knowledge Assumption of safety – it won't happen to me Ignorance is bliss	And also, a lot of people just have the em, the opinion, you know, I think it can be a natural opinion to have, you always say it won't happen to me, kind of thing, you know what I mean? People go through that like all the time. Or they might just be personally scared of the em, the doctors or something like that

Trauma from past experiences with HPs creates barrier for today's encounters Broken knowledge breaks links in the system	from past experiences, you know, past traumas.
Trauma from finding something again and again Is it worth the exhaustion of seeking help? Patient having to be expert/teacher A power struggle Difficult process Broken knowledge breaks links in the system Stuck within barriers of a powerful yet disconnected system NF1 complexity – fibroma, cancer, or hormones?	I think it's like when you find something, and you find something, it can become a lot more mentally draining, can't it? And you're constantly explaining the situation and it can become a lot like em, like a struggle. And like as I say, it's not like an easy process. It can put people off from going if you know what I mean?
Animation is really clever Animation good for younger audience Engaging Real people switch real people off	I think it did because em, the fact that it was an animation in my opinion, was really clever, I think because say you've got a, you know, a younger audience watching it, it would engage them more into understanding the information and the information was clearly written and done in a clever way, you know with effects and stuff like that, and I just thought it was a really good way of maybe

Real people make it morbid – cancer is morbid Animation is a protective shield from taboo breasts and scary facts A Goldilocks animation for inclusive and engaging learning	educating em, you know, younger people into, you know, into information that you need to combat a potential serious situation. So, I think if you did it with like em, you know, a reconstruction of actors or things like that, em it's-, you can kind of like switch off a little bit because it's not as engaging, like you know what I mean. Or it could become a little bit too morbid and then that could scare people away from going themselves because you could scare 'em completely away from em understanding the information and they could completely shut it out and switch the video off, if that makes sense?
Speech bubbles – closed captions Fun way for a real-life situation The change of before and after Interactive helps absorbing Animation is a protective shield from taboo breasts and scary facts A Goldilocks animation for inclusive and engaging learning	Well like I said I think the animation helped it be more clear, like you have your speech bubbles coming up and things like that, and it's kind of done in a fun way rather than a serious em, you know, a serious real-life situation because although we are talking about a real-life situation, the way it was put across was a bit of a fun thing with the information, and it did then as well like after the animation, em it said like would you change your answers, em that kind of thing, I know that by doing that you know you were seeing if people took the information in or not, but also giving them a chance to correct themselves. And even by them changing the answers, you feel like that if you're changing

	the answers yourself, you're not just like watching the video and that's it, because it can go in one ear and out the other, but when you're changing the answers directly, you more likely to absorb the information that was given in the first place.
Do/feel differently More information to go on In another way, from another point of view	Em, I guess I have the information in me head that the, you know, the animation gave me, and things like that but I feel like em (.) what we was doing beforehand was okay, but obviously we've got more information to go on now which is thanks to the animation.
Taking part in research Gaining valuable information Positive effect for the future Tentatively planting the seeds of powerful actions and empowering thinking	It's made me feel like I've gained em some very em valuable information, and that I probably wouldn't have gained the information without taking part in the research, so I see that as a positive thing for the future.
Taking part as a man Animation is inclusive for all and any viewers Welcoming to all Animation allows for a more realistic portrayal of NF1 Real life but not real life	yeah definitely yeah definitely, definitely. And just going back to what I was saying before about the animation covers all demographics really, you know, age, gender, and things like that because it's very welcoming to everyone like I was saying, if you have, like you know, reconstruction of real actors and things like that, not only could it be a bit depressing, not everyone will relate to it because you might say, you know, if it's an actor or whatever, they haven't got NF1, you can tell kind of

Animation is a protective shield from taboo breasts and scary facts A Goldilocks animation for inclusive and engaging learning	thing but when you em put animation on it, it's not really about, you know, it's a bit more like that. It's not really em real life but whilst also being real-life, if that makes sense?

Alice (A)

Associate – cousin's daughter/second cousin	The person is my cousin's daughter. So, she's probably a second cousin.
Animation clearly explains importance of checking Diagrams Exposing the barriers to breast checking Animation creates self reflection of own BCA – checking breasts frequency Animation creates a consideration of personal plan to set a reminder – behaviour change Animation makes me think, makes you think Animation experience is a shared experience Animation creates ripples to think about your own breast nipples	Well, I thought that the animation really explained really clearly that it was very important for people with NF1 to check their breasts because you are more likely to get it at a younger age or could do because you have the condition of NF1, probably like having the BRCA gene as well or something like that. You probably can get it earlier. And I thought that it was very good the way they showed diagrams and they sort of explained some of the barriers to it. It also made me aware that I know that I should check my breasts, I don't regularly check them. And the thing when it told you for me, like make a date like the first of every month, I thought that was very important so the first of every month, you know to do-, to check your breasts or just look at them, or just be more aware of them. Eh, that's what I got from the animation. I thought it was quite clear.

Animation provides the ins and outs beyond the lump A Goldilocks animation for inclusive and engaging learning	
Increased BCA – risk Animation resets old thinking Animation provides the ins and outs beyond the lump	No, I wasn't aware before. No, I hadn't really thought about it, I just put it down as one of the places that the tumours could appear. So-, I know they can appear anywhere, but I hadn't specifically thought about it. No, I didn't know that higher increase.
Awareness is a shared experience – importance of BCA support Putting a plan in place to encourage seeking help Worth getting checked Tentatively planting the seeds of powerful actions and empowering thinking Forging chain reactions from stronger links	I'd tell them that it was very important to just check straight away. I could say, 'you know, it could be nothing, but it's just worth getting it checked every ti-, any small thing'. It's worth getting it checked.
Increased BCA – screening eligibility Them and Us Animation provides the ins and outs beyond the lump	No, I wasn't aware of that at all. So, they go and it's once a year, whereas I think for most people it's every three years. I don't go once a year, maybe I'm older now, yeah so, it's every three years, so once a year probably would be good if they can get from 40.

Barrier BCA Fear Assumption of knowledge of increased BC risk among women with NF1 Easy to put something off Disconnected system A connected system can support BCA A connected system allows women with NF1 to access system with ease by being called up Broken knowledge breaks links in the system Stuck within barriers of a powerful yet disconnected system In another way, from another point of view	Em, it might be fear sometimes, but I'd have thought they'd be sort of (know) their condition and know that they could get cancerous tumours but I think, you know, it's still fear and what you're going to be diagnosed-, it's sort of-, for me it would be a bit-, even though I knew it was important, for me it might be a bit of sort of, 'ah, it doesn't matter', or I put it off doing. It's easy to put something off and 'oh I'll do that later', you know like say like checking every month you'd think, 'oh I will check', and then I don't. But I don't know if they are called up, do you have a letter and are you called up and given the appointment? Then I'd be more likely to go if I had the actual appointment.
Barrier to checking once a month Women with NF1 – lack of knowledge (BCA) Animation can bridge BCA knowledge gap Empowering – get to know what's normal for you	Em (.) maybe they wouldn't know exactly what to check for, you know, they wouldn't know. But I know that the animation is quite good at explaining it once they've seen that but it's knowing exactly what to check for. And I know that they can be all lumpy and bumpy anyway, but it's getting used to their own breasts, of what they're like, you know

Broken knowledge breaks links in the system Animation provides the ins and outs beyond the lump Tentatively planting the seeds of powerful actions and empowering thinking	of getting them used to them and they'd know if there was a change in them.
Animation encouraging BCA Keeping it simple Encouraging BCA in women with NF1 – the importance and how to do Animation provides the ins and outs beyond the lump A Goldilocks animation for inclusive and engaging learning	Em, I think it helped because it was just simple and the way it showed the breasts, you know, how it showed the discharge, or the nipple, or-, it was quite simple. Lots of ((inaudible)) but it was quite clear and straightforward. I thought it did help, you know, to make it clear that this is something that you do have to do and that everyone has to do it, if they can. So, I thought it was quite clear from the animation.
Animation format Clear and simple Better than using real people Know what to look out for – giving power Animation is a protective shield from taboo breasts and scary facts	Em (.), I think it did help because as I said it was so clear and it was very simple, you know. It's probably better than using real people or things because it just like-, it kept it simple so that you can really take it in and learn, and you know, just know what you have to look out for. It makes it very clear what you have to look out for.

A Goldilocks animation for inclusive and engaging learning	
Animated breasts offer more uniformity A Goldilocks animation for inclusive and engaging learning	[...] I don’t know how you could just really use (.) sort of other people to do it because you know, it’s just filming their breasts and everyone’s breasts are different anyway but it just kept it more uniform, it was clear so you know, so I thought it was better to relay it to something like em, something that’s not a real person really.
Taking part in research Pleased something is being done Awareness is a shared experience – encourages lots of people Importance of regular access to learning Forging chain reactions from stronger links	Em (.) it’s made me feel quite pleased that something is being done about it so the people can-, I know it spreads out-, I’m sure by looking at it that it will encourage lots of people and keep reminding them. And again, it’s something that if you can keep watching it, not just once, if you got access to it, sort of quite regularly, it becomes something that you get in your mind. If you see it more than once, I think, so you get it into your mind more exactly what the avatar or whatever it is, is showing you, you know?
How to share? Awareness is a shared experience – sharing for learning on various platforms Forging chain reactions from stronger links	Could it not be shown on the phone, like a regular, I don’t know sort of a regular email or something, or a sort of like in a message that could be sent out? Or attached to an NF, like you know a helper’s group, you know, what’s it called, you know if someone’s got something wrong with them, you belong to sort of the group, and like a family, if it can be posted on something like that or the NF

	websites? Just so they can go and for them to look at.
Do/feel differently Awareness is a shared experience – associate's awareness to share BCA screening and checking information Tentatively planting the seeds of powerful actions and empowering thinking	Yeah so, it's certainly made me aware to advice people to get their regular screening done and check themselves at least, you know, once a month.
Awareness is a shared experience – eager to share animation Forging chain reactions from stronger links	I just was going to say about, can it be put out, you know, as a regular little thing on the em, social media, and things like that? So that is what I was just going to ask at the end as we sort of covered that as well.

Step 2: Codes raw list

Broken knowledge breaks links in the system
Stuck within barriers of a powerful yet disconnected system
Tentatively planting the seeds of powerful actions and empowering thinking
Animation provides the ins and outs beyond the lump
NF1 complexity – fibroma, cancer, or hormones?
The struggle of digging for answers and being the expert in the room
An obvious diagnosis for an obvious sign
A learning culture of respectful curiosity and patient-centred benchmarks
Breasts are taboo
Animation is a protective shield from taboo breasts and scary facts
A Goldilocks animation for inclusive and engaging learning
Forging chain reactions from stronger links
Animation creates ripples to think about your own breast nipples

In another way, from another point of view

HPs – rare knowledge of rare disease

Broken links in the system

Strong links create a chain reaction

Broken knowledge breaks links in the system

Googling for answers

An obvious diagnosis for an obvious sign

Unmet needs create struggles

Awareness is a shared experience

General rare knowledge of rare disease

Patient having to be expert/teacher

Animation provides the ins and outs

Knowledge empowers

NF1 complexity – fibroma or cancer?

Barriers to seeking help goes beyond BCA

Unmet needs

Broken links in the system

Power play barriers

Power play barriers in a disconnected system

Knowledge is potential power

A strained system in power

A strained system strains patient power/empowerment

HPs – lack of knowledge (HPs qualified years ago)

HPs – growing knowledge of rare diseases (newly qualified HPs)

Patient having to be expert/teacher

How has taking part in research made you feel?

Empowerment through animation

Awareness is a shared experience

Do or feel differently?- Check breasts more within struggle to figure out differences

Self-efficacy confusion

Confidence to seek medical help - Empowerment through animation

Late diagnosis

HPs – lack of knowledge

Unmet needs (pain)

HPs – growing knowledge of rare diseases (optometrist)

Googling for answers

Patient having to be expert/teacher

In the power of ‘lost’ healthcare professionals

Patient having to be researcher

Awareness is a shared experience (The importance of charities)

HPs – An obvious diagnosis for an obvious sign

HPs – lack of knowledge

Unmet needs - abandoned

HPs – lack of knowledge (NF1 and women’s health)

Unmet needs – abandoned

Lack of resources and support for rare diseases/NF1

Persistence needed to have needs met

The power of knowledgeable HPs

Awareness is a shared experience - Importance of charities

Unmet needs (by being undiagnosed as a child)

Struggle (childhood – learning)

Unmet needs – the negative effect on the perception of the childhood self

Unmet needs due to late diagnosis (unfamiliar with fibromas which contribute to confusion with BCA)

Increased BCA – wider knowledge of warning signs

Unmet needs – the push for a doctor’s appointment

The power of knowledgeable HPs (charity support)

HPs – lack of knowledge a barrier to confidence in seeking medical help

Patient having to be expert/teacher

HPs – lack of knowledge a barrier to seeking medical help

HPs – the desire to learn about rare diseases

Patient as specimen

HP – lack of knowledge

HPs – lack of knowledge a barrier to seeking medical help

Empowerment through animation

Confidence to seek help through learning

HP – the power of knowledgeable HPs (charity NF nurse)

Patient having to be expert/teacher

HPs Lack of knowledge a barrier to accessing screening

A disconnected system

Passed from pillar to post

HPs – the power of knowledgeable HPs (charity NF nurse)

HPs – lack of knowledge

Barriers to BCA -HPs – lack of knowledge

Patient having to be expert/teacher

Power struggle

HPs – growing knowledge of rare diseases

HPs – growing knowledge of rare disease

HPs – the desire to learn about rare diseases

Rare disease reality – difficulty of getting diagnosed

HP – lack of knowledge

HP lack of knowledge – a barrier to seeking medical help

Patient having to be expert/teacher

HP lack of knowledge – a barrier to seeking medical help

Power struggle

Increased BCA – warning signs

Beyond the lump

Beyond the lump

Breast cancer is a taboo subject

The assumption of 50 years for all

Confusion in age for increased risk – issue with Breast-CAM-NF1 items

Increased BCA – warning signs

Increased BCA – breast checking

Behaviour change – Checking once a month

Setting a reminder

Payday is breast day

A visual learner

Seeing human breasts is taboo

Seeing human breasts is stressful

Animated breasts are not so taboo

Animation has the safety of a children's programme

Taking part in the research - Protection of anonymity when raising awareness

Awareness is a shared experience

The desire to reduce unmet needs of others

Awareness is a shared experience – Reducing unmet needs for daughter

Animation to empower others (daughter)

Knowledge is power

Child as motivation to be breast cancer aware

Increased BCA – checking and warning signs

Awareness is a shared experience (partner)

Increased BCA – Confidence

Increased BCA – self-efficacy

Awareness is a shared experience

HPs lack of knowledge

Rare disease reality – difficulty of getting diagnosed

Awareness is a shared experience

Lack of knowledge of rare disease makes it taboo

Late and recent diagnosis

Shock of diagnosis

Only diagnosed through son's diagnosis

30 years of not knowing

Only diagnosed through son's diagnosis

Personal suspicion of NF1

NF1 clues

Unmet needs (late diagnosis)

Struggle (childhood – learning)

HPs – an obvious diagnosis for an obvious sign

HPs – growing knowledge of rare diseases

Increased BCA (Risk) – learning through son’s genetic consultant

Googling to fill in the blanks

Learning through NF charities

Learning from others on social platforms

Awareness is a shared experience

HPs – Lack of knowledge

Previous BCA knowledge

Knowledge is empowerment to check

BCA can lack diversity (breast sizes)

Confidence to check if all is okay

Is it cancer or something else?

The general confusions of BCA

Confidence is undermined by lack of HPs knowledge

HPs – lack of knowledge

HPs – potentially dangerous assumptions comes with lack of knowledge

The fight to get an appointment

Unfairly treated because of being a young woman – lack of HPs knowledge

Previous BCA (screening)

Knowledge does not always mean power

Power dimensions – GP has power to screening access

Difficult in gaining screening access

Going private to get screened to get into the system

Knowledge is empowerment

Perceived power and opinions of HPs

Awareness is a shared experience

The importance of HPs having NF1 knowledge

The importance of empowering HPs with NF1 knowledge

The need for HPs to meet unmet needs of HP patients

Barriers to BCA - Busy life

Breaking barriers to BCA- Make screening accessible – pop up clinics

Cut out the middle GP

Take back power

GPs as obstructing screening

Take back power

Disconnected system

The animation gets you more

No skimming

More attractive to watch videos

Animated versus real body – no difference as a personal opinion

People are more comfortable watching animation

Awareness is a shared experience – considers others

Watching animation offers more privacy to the topic

Taking part in research - BCA – not just something that can be ignored

I think I need to be more aware

Stop ignoring everything

Embracing the truth and actions of being BC aware with NF1

Do or feel differently

BCA – can be an inconvenience

BCA – not being taken seriously

BCA is the power to potentially stop a bad outcome

BCA and NF1 – power to potentially stop a bad outcome as a young woman

Take health more seriously

BCA – added complexity with NF1

BCA and NF1 – It's for a good reason

Shift in attitude – knowledge is power

The ability to face reality

Empowerment through animation

Self-efficacy

Confidence – not a waste of time to check

Early diagnosis

HPs – knowledge allows for early testing

NF1 family history

BCA knowledge – not really changed

History of BC in family

Power of family with BCA

Loss of empowerment (‘Do this’, ‘do that’)

Previous knowledge of screening

Anxiety with BCA

Always checking

Anxiety

Always going to the doctor

Surprised by advice of ‘once a month’ checking

Over checking

Effect of animation – reduce frequency of breast checking

Misinformation (family)

Always in contact with HPs, but HPs have a lack of knowledge

HPs – lack of knowledge

Memory from childhood remains

HPs – online search for information

Lack of confidence in HPs’ knowledge continues

Lack of confidence in HPs’ desire to know

HPs – lack of knowledge (‘older’ doctors)

HPs – growing knowledge of rare diseases (junior doctors)

Qualified doctors not given a chance to learn about NF

Patient having to be expert/teacher

Fight against the power of HPs

Knowledge is power

Fight against the power of HPs

Sticking up for yourself

Barriers to being BCA - Fear of the increased risk of breast cancer

Facts in video might scare them

Avoidance of BC reality

Cartoon format - Helped

Not scary

No orders so no power taking

Animated interventions are eye catching

Seeing real people is boring

Animation makes you think of childhood

Animation is best to reassure young people

Screening eligibility- Previous knowledge from family member going earlier

HPs – lack of knowledge

Animation to fight against HPs' lack of knowledge

Animation provides a chance of empowerment and of giving power

Increasing HP knowledge - The need for basic training to be prepared to care for a patient with NF

A compromise to accepting that it's not possible to know about every condition

The need to fight against HPs' lack of knowledge as medical negligence

The perception that HPs don't care about NF patients as much as those with other conditions

Misinformation about the statistical prevalence of other conditions (DS occurs in 1/1000 births).

Knowledge barrier of HPs to learn about NF at university

The desire for patient centred care

HPs need to place patients at the centre to help them learn about the individual's experience of NF

Creating the individual benchmark for future consultations

A lucky dip of care for the patient

Disconnected system

Taking part in research - Helping

The effect of lack of knowledge of NF on research and subsequently BCA

Do/feel differently- Changes in checking – no longer continuously checking

Feeling a lot more calmer

Diagnoses in childhood

Diagnoses genetically recently

Learning difficulties

Scoliosis

Depression

Animation suitable for young people

Easy to understand

Awareness is a shared experience – sharing with child

Awareness is a shared experience – animation for everyone, including children without NF1 to learn

Animation provides empowerment (check themselves)

Animation paints a thousand words

Animation keeps the eye on it

Animation format - Animation as providing protective distance

Actual person's breasts embarrassing to watch

Diversity of characters – not only one race with NF1

Previous scare of breast concern

Breast cancer is scary

Increased BCA from 'scare'

Animation instils confidence to know what to be aware of when checking breasts

Creating confidence through creating animation

Animation 'shows' you what to do

Animation instils confidence to seek help for a breast concern

Power to go and seek help

Empowerment to instruct HP

Knowledge is power

Previous knowledge of screening eligibility

Knowledge does not always mean power

Difficulty accessing screening

HPs knowledge of rare disease empowers patients with NF1

Awareness is a shared experience

HPs knowledge provides power to patients with NF

Disconnected system

Fallout felt by the patient

Disconnected system effects BCA

Awareness is a shared experience – for daughter

Knowledge is power

Empowering daughter with BCA knowledge

Awareness is a shared experience – for all ages

Awareness is a shared experience – animation should be available to all

Barrier to being BCA- Lack of internet access

Low income

Importance of information available in different formats to reach everyone

HPs (genetics) – desire of patients to be kept more up to date

NF patients – forgotten

HPs – perceived as dismissive

HPs – barrier to getting appointments

HPs – hold the power

The desire for extra support

A waiting game to be seen

HPs – dismissive to patients

A dichotomous experience with NF1

HPs – lack of knowledge

Postcode lottery for care

Lack of learning resources for HPs

Lack of information provided to HPs and trainee HPs

NF1 patient as a guinea pig

Power dimensions – HP over patient

One size does not fit all with NF1

Unmet needs

Student doctors – more curiosity rather than knowledge

Different attitudes to rare disease research

HPs – learning on the floor

NF1 potentially being misdiagnosed

Importance of genetic testing

HPs – lack of knowledge

Lack of information about NF1 in textbooks

Barrier for the shared experience of BCA

Taking part in research - Voice is being heard

Diversity in the voices of NF1

NF1 affects different people, and different places

Do or feel differently - Increased BCA – checking properly

Increased BCA – what to look out for

Empowerment – for myself

Awareness is a shared experience – for child

Providing power – for mother and daughter

Awareness as a shared experience – for all

Animation as a powerful learning tool for all children

NF1 and precocious puberty

Animation to raise awareness that some need to be screened early

Awareness as a shared experience – desire to see animation everywhere

Awareness as a shared experience – partner watched animation with woman

Early diagnosis

Proactive parent

HPs – an obvious diagnosis for an obvious sign

HPs – knowledge is power ‘leading expert’

Positive mindset

No holding back

From the animation

Increased BCA – checking more frequently

Booster to be more vigilant

Increased BCA – wider warning signs to be aware of

Previous knowledge of increased risk

Proactive mother

Mother as expert/teacher

HPs knowledge provides patient empowerment

Awareness is a shared experience

Having the right connections increases BCA

Animation as motivation to be breast cancer aware

Increased BCA (animation) – checking once a month

Increased BCA – detecting any breast changes

Increased BCA – seeking medical help if concerned about breast changes

Increased BCA comes with practice

Animation instils empowerment and self-confidence to seek medical help

Animation provides power to the watcher

Previous knowledge of screening eligibility

Barriers to being BCA - Women with NF1 – lack of knowledge

Personal misdiagnosis

Assumption ‘it’s just NF1’

Barriers to being BCA - Confusion knowing difference between fibroma and malignant mass

If in doubt just go

Nipping something potentially sinister in the bud

Animation emphasises vigilance

Animation bridges gap of an unmet need

Animation as a BCA reminder

Animation format - Perception of more informal

Easier to digest a serious message

Allows for a different mindset

Real people means a really heavy message

Animation is more friendly to watch

Animation keeps you ‘switched on’

Taking part in research - Awareness is a shared experience

Research allows for sharing of experiences within a condition of many variables

Helping raise awareness

Do/feel differently - Feel reassured

Promoted self-efficacy and confidence to get checked out

Early diagnosis

NF1 in the family

Increased BCA – accurate information on risk

Not much change with detecting changes

Animation made it clearer on identifying what changes are

General confusion with breast changes

Quicker contact with HP from watching animation

Previous knowledge of screening eligibility

HPs – knowledge of NF1 helps create patient empowerment

Animation encouraging BCA - Encourages watcher to be more aware of NF1 information

Animated format - Easier to digest in animated format

Easier to understand

Webpage of information is difficult to read

Animation allows for clearer communication instead of using 'actual humans' (protective distance)

Taking part in research - Happy research is being done

Feeling seen and heard

Research can increase knowledge among HPs

HPs – lack of knowledge

Perception of HP disregarding NF1 patient

HPs lack of knowledge potentially dangerous

Danger of power of GPs with a lack of knowledge

HPs – lack of knowledge means a lack of access of breast screening

Do/feel differently - Check breasts more often

Diagnosed as a child

HPs – knowledge of rare diseases

Knowledge means meeting needs of the patient

Discharged of care at 18 – left to deal with NF on own

BCA awareness – probably increased a bit

Previous knowledge of BCA

Googling information fill in gaps

Animation as inclusive

HP – lack of knowledge

HP – lack of knowledge but desire to learn and research

Contraception as an increased risk of developing BC in general

Missed opportunity for empowerment - Increased risk of BC with NF1 not communicated previously

Gap of knowledge acquisition and sharing in adulthood

Isolating - Having to manage the condition yourself

Disconnected system – assumption medical records on a shared system

Disconnected system – disconnects the ability of a shared experience for knowledge and care

Increased confidence to contact a HP with a breast concern

Strained health system – difficulty to get an appointment

Disconnected system – information not being shared with other HPs

Struggle to communicate with a GP

GP holds power to access other services

HPs – lack of knowledge

HPs – lack of knowledge a barrier to access services

Improved BCA – detecting changes and warning signs in a more extensive area

Improved BCA – the need to be more thorough

Previous awareness of screening eligibility (GUM clinic)

HP – desire to learn and research if unsure

HPs sharing of knowledge empowers the patient

Barrier to BCA - Women with NF1 – lack of knowledge

Lack of ongoing conversations about the condition and associated risks after healthcare ends after childhood

Worry and fear

Lack of doctor availability for an appointment

How to reduce these barriers? - Access to information where people look

Awareness is a shared experience (information availability on social media)

Importance of accessibility on various platforms that is wide reaching

Increased BCA – checking frequency

Once a month checking is reasonable

Checking is easy

Developing an awareness of what is normal for you

Animation format - Seeing ‘live people’s’ breasts is uncomfortable

Animation creates a protective distance

Animation works for all ages

Simple format means anyone can follow

Animation represents diversity – anyone can have NF1

NF1 is a shared experience

Anyone can have NF1

Research made you feel? - Lack of research aimed at young women with NF1

Waiting to take part in something she belongs to – relatedness

Feels seen and heard

Taking part is doing something good

Do/feel differently - Increased BCA – increased awareness in being mindful to any changes

A reminder of the importance of checking

Don’t forget about your breasts

Late diagnosis

Joint diagnosis – when child was diagnosed

HP – knowledge but no action

HP – holds power to gain access to more services or information (gatekeeper)

NF1 diagnosed through son’s diagnosis

Previous BCA – warning signs

Barrier to attend HPs – stigma of younger female going to HP with a breast concern

Have to be a certain age to seek help for a breast concern

Stigma from misinformation about cancer age occurrence (HPs and public)

Afraid of judgment being a young woman

Power in own hands – check self regularly

Previous BCA knowledge – CTT information

Importance of and trust in charities for information

Asking about confidence to approach a HP is complex – two edged sword

Increased confidence to go to HP

Animation empowering action

Animation giving power to young women with NF1

Confusion shakes confidence – fibroma or benign mass?

Still feel vulnerable and judged

HPs – under pressure

With lack of understanding comes lack of compassion

HPs perceived as patronising

HPs makes you feel nervous and doubt yourself

HPs remove power and empowerment from women with NF1

HPs perceived attitude a barrier to seeking help for a breast concern

Prevent BCA - Missed diagnosis of NF1 is a missed awareness opportunity

Unmet needs with a later diagnosis – lack of information and lack of support

Awareness is a shared experience – HPs need to share knowledge with patients

HPs lack of knowledge means lack of knowledge for patients

A need for accessible information direct from GPs

The importance of charities for support and information

Charities are trusted sources

Confusion of screening age – confused information from charity

HPs should be responsible for organising screening

Onus left on patient to chase

Those with NF1 reluctant to speak to HPs

Health is put on the back burner – other priorities come along

Life gets in the way

HPs organising screening alleviate anxiety to organise

Going to a HP is like going to war

The battle to defend, explain, and justify

Patient having to be teacher/expert

Patient not being heard

Trying to fight for what you are entitled to is exhausting

Needs should be met without interrogation

HPs – lack of knowledge

Patient having to be expert/teacher

The feeling of vulnerability

Power struggle between HP and patient

Patient not being heard

HPs are supposed to give reassurance

Encouraging BCA - Very simple

Brief

Clarifies what to look out for

Awareness is a shared experience – desire to share animation

The importance of sharing animation to raise awareness

Wider accessibility is important. Find it even if you’re not looking for it

Animation format – no advantage

Animation can reach a wide audience

Taking part in research - Feeling hopeful

An opportunity to be heard

Being involved in making changes

Awareness is a shared experience – the need to help HPs increase their knowledge

Proud to take part because it is an essential change that is needed

Do/feel differently - Previous knowledge – nothing different

For others just learning – encourage to be own advocate (power and empowerment)

BCA is nothing to be embarrassed about

Relatedness with researchers in field – appreciation of work being done

A complex childhood diagnosis

Struggling in school

An obvious diagnosis for an obvious sign

Disconnected system

Disconnected system

Lost in the system

Unmet needs – lack of support

Taking part in research to learn

Taking part in research to be empowered

Increased BCA – frequency of breast checking

Increased BCA – confirms what to look out for

Increased BCA – screening eligibility

Previous knowledge of general BCA

Learning general BCA from attending an all girls school

Learning general BCA from university

Awareness is a shared experience – sharing general knowledge with family

Personal experience of breast cancer in family

Increased confidence to contact HP with a breast concern

Learning through animation helping to reframe previous bad encounters with HPs

Negative experience with HPs

Embarrassment caused by HP's attitude

Animation as a reset to feel that one will be listened to

Animation gives hope

Experience of relatedness – people (researchers) looking out for people with NF1

Earlier screening knowledge is reassuring

Family experience of BC – motivation for BCA

Barrier to BCA - Lack of access to information

Awareness is a shared experience

Lack of awareness can break the shared experience

Disconnected system

Importance of understanding the system

Clearer information is needed for learning and accessing services

Knowledge is power

Knowledge is empowerment

HPs – position as provider of knowledge and awareness

Schools -position as provider of knowledge and awareness

Importance of charities position to provide information and awareness

BCA approached as a general 'one size fits all'

One PowerPoint slide can tell a story and make a difference

Animation encouraging BCA - Right length – 'Goldilocks effect'

Different methods of communication

Did a lot to get someone's attention

Animated format - Provided accessibility

Accessible to different types of learners

Accessible to those with learning difficulties

Taking part in research - Participated with 'two hats' – patient and researcher

Awareness is a shared experience – one participant voice helps gives a voice to those who cannot engage in research

Do/feel differently - Increased BCA – self awareness and reflection to check breasts more consistently

Setting a date

Setting a reminder

Important to consider birth control and the link to BC within young women with NF1

Obvious diagnosis for an obvious sign

Increased BCA – animation made me more aware

Past breast concern

Worry of radiation from mammogram with NF1

Increased BCA – monthly checking

The reality of the confusion and worry between fibroma and benign mass

Previous confidence to seek medical help

Previous BCA – through NF charity position

Knowledge is power

Importance of connections for knowledge

Awareness is a shared experience – me as researcher sharing awareness from previous work

Increased BCA – warning signs

Beyond the lump

Previous knowledge – checking once a month

Increased BCA – confidence in detecting changes

Beyond the lump

Previous confidence contacting HP -The worry about being taken seriously

HPs – lack of knowledge

Patient having to be the expert/teacher

Battle to be heard and taken seriously

HPs as holding the power

Increased BCA – screening eligibility

Animation correcting previous beliefs

Confusion of ages from reading information pertinent to other countries

UK ‘trying’ 40

A struggle for breast screening in general

Women’s fight in healthcare

Lack of available research/information NF1

Lack of available research/information NF1 and BC

The need for more NF inclusion within BC research

Barrier to BCA - Misinformation

HPs – lack of knowledge

HPs – lack of knowledge helps spreads misinformation and confusion

The preference to go with who tells you the good news

Misinformation can come from anyone and everyone

Misinformation is a shared experience

Going with the ingroup

The detrimental effect of misinformation by HPs

Breaking barriers to BCA - Educating is a shared experience

Education from charities, NF and cancer

Lack of information available about NF1 and BC information

NF1 is left out by breast cancer websites and charities

All it takes is a little space to help raise awareness

Knowledge is empowerment

Knowledge is a shared experience

Awareness is a shared experience

Patient having to be teacher/expert

Animation is not overwhelming

Goldilocks effect

Inclusive – suitable for all ages

Inclusive – for those with learning difficulties

Animation is not scary

Animated format - More fun

Real-life humans makes it quite serious

Animation provides a protective distance

Animation provides an escape from reality

Animation makes watching more comfortable

Viewing real breasts is taboo

Taking part in research - Awareness is a shared experience – raising awareness

Beating misconception of breast cancer age

The importance of catching cancer early

Do/feel differently - Increased BCA – check for other warning signs

Beyond the lump

Associates

Associate - mother

HPs – lack of knowledge as a barrier to being diagnosed

Diagnosis in childhood

HPs – knowledge is power

An obvious diagnosis for an obvious sign

Lack of information

HPs – lack of knowledge

An obvious diagnosis for an obvious sign

Increased BCA – risk

Personal experience of breast cancer – family friend

Motivation to be BCA – death of family friend to BC

Awareness is a shared experience – providing information to daughter

Animation bridges a knowledge gap to be shared

Animation reinforces importance of seeking medical help for a breast concern

Animation highlights importance of BCA within an NF1 context

Increased BCA – in general for associate

Increased BCA – provision motivation for associate to be more BC aware

Increased BCA – screening eligibility

Perception of increased risk, screening should be earlier than 40 years

Increased BCA – monthly checking for daughter with NF1

Setting a reminder good for those who like a routine

Barrier to being BCA - HPs – lack of knowledge

Animation has provided the BCA information needed

Hearing it all for the first time

The complexity of NF1

So much information to be communicated

BCA never discussed

HPs – lack of knowledge

Patient having to be expert/teacher

Specialists not communicating BCA information

The search for answers

Potential assumption of knowledge on patient/associate part

Animation appropriate for younger ages

Animation makes a serious message more fun

Animation format - Body as taboo

Animated character provides a protective distance

Animated helps break taboos

Animation helps open channels of communication

Taking part in research - Helping 'spread the word'

Awareness is a shared experience

Awareness is a shared experience – the importance of being part of a charity

Sharing stories has the potential to share accurate breast cancer awareness information

Do/feel differently - Help raise awareness of NF1 and BCA

Awareness is a shared experience – for all

The power of social networks

Relatedness – researcher and participant

Desire to raise awareness

Eagerness – importance of raising and sharing awareness

Awareness is a shared experience

Associate – mother

Precocious puberty

Animation increases confidence to speak with daughter about BCA

Animation opens channels of communication

Simple and clear

Awareness is a shared experience – watch together

Previous knowledge of BCA (warning signs- general)

Power of BCA information available in public

Personal experience of cancer in family (BCA motivation)

Previous knowledge of increased risk

Increased BCA – screening eligibility

Would encourage anyone to go for a breast concern

Positive mindset – proactive

Importance of spotting something early

Barrier to being BCA - Woman with NF1 – lack of knowledge

Assumption a lump is NF1

Importance of a shared awareness

Importance of open channels of communication

HPs – lack of knowledge

HPs lack of knowledge a barrier to seeking help

Encouraging BCA - Easy to understand

Easy to watch

Awareness is a shared experience - Easy to discuss with either family or professional

Animation opens channels of communication

Animation reduces fear

Animation empowers women with NF1 to go to the doctor

Animation as reassuring to seek help

Animation format - Helps with learning

Helps with understanding

Format helps open channel of communication

Format encourages help seeking

Taking part in research - Research allows for rare disease lived experiences to be shared

Awareness is a shared experience

Do/feel differently - Animation opens channels of communication

Awareness is a shared experience

A two-way experience

Animation has the potential to support young women with NF1

Associate - cousin

Family connections don't mean NF1 knowledge

Increased BCA – connection between increased risk and NF1

Increased BCA – earlier screening for women with NF1

Increased BCA – checking once a month

Lack of general BCA

Them and us

Animation contributed to thinking from a different perspective

Seeing it from the woman with NF1's perspective

BCA as a taboo subject – not talked about in normal conversations in families

Animation creates a consideration for women with NF1

Increased BCA – screening

Lack of BCA in general in associate

Lack of association of BC with young women

Barrier to BCA - Other health issues of young women with NF1 are a priority

So many other things to worry about

BCA might not be high on the list with so many other worries

Embarrassment

Concerned about taking up HPs time

Perceived power of HPs

Animation encouraging BCA - Short and accessible

Awareness is a shared experience

Accessibility with subtitles

Explains things clearly

Awareness is a shared experience – diversity in animation. NF1 can affect anyone

Animation - Not overly scientific

Exposes barriers to being BCA – checking breasts

Accessible learning tool

Taking part in research - Encouraged thinking from an NF1 perspective

Breaking the normalisation of NF1

Encouraged reflection of challenges of NF1

Lack of awareness of BCA of associate – frequency of breast checking

Them and us

Do/feel differently - Awareness is a shared experience

The positive ripple effect of raising awareness

Associate - aunt

Increased BCA – risk

Increased BCA – earlier screening

Previous belief screening started younger with increased risk

The assumption that screening started earlier in young women with NF1

Nothing to base assumption on

Money the implied reason for screening only starting at 40 years

Why not earlier than 40 years?

Prevention is cheaper

Increased risk means increased encouragement to contact a HP

Supporting more than encouraging to contact a HP

Scary to go to a HP

How to support? - Increased risk of BC is another complication to deal with NF1

Another battle to fight

Another thing to face

Support is a shared experience

Barrier to BCA - Women with NF1 – lack of knowledge

Mistrust of the body

Animation encouraging BCA - Animation as safe

Easy to watch

Easy to understand

Encouraging

Not overly medical

Cartoon format - Nonthreatening

A real person and their breasts are threatening

Animated person could be any of us

Taking part in research - Concern for people with NF1

Animation beings an awareness of NF1 struggles – feeling of guilt as 'Us'

Awareness is a shared experience

Do/feel differently - Feel more concerned about increased risk

Feeling of being stuck with this new knowledge

Be ready to support

The desire to raise awareness – sharing the animation

An important piece of work

Associate – friend's daughter

Increased BCA – huge from animation

Increased BCA – risk

Learning about the connection of NF1 and BC

Contacting a HP is important for ALL women

Particularly women with NF1

Them and Us

Might be difficult for woman with NF1

Catching cancer early can make a big difference to outcome

Why difficult to go to HP for woman with NF1? - Embarrassment

Importance of support

Solution offering - support

Women with NF1 – lack of knowledge

Assumption of fibromas

Assumptions create complacencies

Young women with NF1 – lack of knowledge

Experience of definite urgency from associate

Increased BCA – screening eligibility

Experience of definite urgency from associate

The urgency from learning new information

Perceived lack of BCA among young women with NF1

The urgency from learning new information

Solution offering -support

The potential supportive role of the associate

Perceived lack of general awareness among young women with NF1

Disconnected system

Confusion surrounding the screening process for NF1

Screening assumptions

Solution offering – access to screening

Support

The fight for others

The urgency from learning new information

Disconnected system

Patients having to be the right code to access services

HPs – power to give you the right code

Disconnected system

Assumption of a connected system

Assumption of ease of access to screening because of NF1

Barrier to BCA - Learning difficulties

Vulnerable women

Solution offering – add BCA NF1 information to BC leaflets

Accessibility – GP’s surgery

Awareness is a shared experience – in general BC information

Clear and easy to watch

Animation not patronising

Animation opens channels of communication

Animation format - Sticks in the mind

Animation offers a protective distance

Seeing a real woman’s body might be uncomfortable

Animation suitable for a younger woman

Taking part in research - Focus of awareness on the increased risk

The shock of new information – risk

Do/feel differently - Reflection on personal experience of losing relatives to breast cancer

Importance of BCA for women with NF1 – personal motivation due to family loss

Knows the importance of catching things early and not leave things

Awareness is a shared experience

Knowledge is power and empowerment

Giving knowledge – giving power

Encouraging women to check – encouraging empowerment

Animation encouraged own personal BCA - checking

Associate - mother

Increased BCA – general BCA (non NF1)

Increased BCA – beyond the lump

Confusion of fibroma versus malignant lump

Importance of vigilance within women with NF1 of body changes

Empowerment in vigilance

Previous BCA knowledge – risk

Only recent learning of risk

Increased BCA though CTT - risk

Awareness is a shared experience – forums and websites

Awareness is a shared experience – sharing findings from research

Awareness needs to come from doctors

Doctors need to share awareness with their patients

Importance of relatedness with charities for awareness

Connections shares awareness

Previous knowledge through CTT - Screening eligibility

Awareness is a shared experience

Barrier to BCA - Knowledge is power

Empowerment through awareness – taking responsibility for yourself

Importance of connections with charities – relatedness

Connections shares awareness

Importance of having access to accurate and accessible information when researching

Animation as ‘informal’

Animation is less intimidating

Not too clinical

Easy to watch

Cartoon format - Acceptable for younger people

Not an old-fashioned style

Animation does not exert power over viewer

Not frightening

Animation creates a sense of free-will and personal choice to watch and learn

The sense of agency

The Goldilocks effect

Taking part in research - The hope of doing some good

Awareness is a shared experience – of condition

Help others

Do/feel differently - The associate as teacher

Awareness is a shared experienced – mother to daughter

Knowledge is power and empowerment for her daughter

Checking once a month – reasonable

Creating a new behaviour to check

Becomes like on auto-pilot

BCA as natural

BCA as natural and automatic action

Associate - partner

Increased BCA – knew of increased risk but not to what extent

Animation provides the ‘ins and outs’

Increased BCA – five-fold risk figure

Misinformation

Lack of accessible and accurate information

Having to dig for it

BCA is a shared experience – learning from partner

Patient having to be expert/teacher

Encouraging contacting HP - No change - previous breast concern with partner

‘on the ball’ for encouraging contacting HPs

Increased BCA – warning signs

Beyond the lump

Increased BCA – screening eligibility

Assumption of automatic access to breast screening

Solution finding - associate

Too late at 40 with tumours and NF1

Knowledge is power

Knowledge is empowerment to manage condition personally

Difficulty to get information

Coming in from the outside

Them and Us

Google for learning

Lack of accessible and accurate information

Misinformation

Barrier to BCA - Autism

HPs – lack of knowledge

Fear of not being taken seriously by HP

The perception of wasting time – HP has power

Awareness as a shared experience – makes it an easier ride

Patient having to be teacher/expert – mentally draining

Women with NF1 – lack of knowledge

Assumption of safety – it won't happen to me

Ignorance is bliss

Trauma from past experiences with HPs creates barrier for today's encounters

Trauma from finding something again and again

Is it worth the exhaustion of seeking help?

Patient having to be expert/teacher

A power struggle

Difficult process

Animation is really clever

Animation good for younger audience

Engaging

Real people switch real people off

Real people make it morbid – cancer is morbid

Speech bubbles – closed captions

Fun way for a real life situation

The change of before and after

Interactive helps absorbing

Do/feel differently - More information to go on

Taking part in research - Gaining valuable information

Positive effect for the future

Taking part as a man - Animation is inclusive for all and any viewers

Welcoming to all

Animation allows for a more realistic portrayal of NF1

Real life but not real life

Associate – cousin's daughter/second cousin

Animation clearly explains importance of checking

Diagrams

Exposing the barriers to breast checking

Animation creates self reflection of own BCA – checking breasts frequency

Animation creates a consideration of personal plan to set a reminder – behaviour change

Animation makes me think, makes you think

Animation experience is a shared experience

Increased BCA – risk

Animation resets old thinking

Awareness is a shared experience – importance of BCA support

Putting a plan in place to encourage seeking help

Worth getting checked

Increased BCA – screening eligibility

Them and Us

Barrier BCA - Fear

Assumption of knowledge of increased BC risk among women with NF1

Easy to put something off

Disconnected system

A connected system can support BCA

A connected system allows women with NF1 to access system with ease by being called up

Barrier to checking once a month - Women with NF1 – lack of knowledge (BCA)

Animation can bridge BCA knowledge gap

Empowering – get to know what's normal for you

Animation encouraging BCA - Keeping it simple

Encouraging BCA in women with NF1 – the importance and how to do

Animation format - Clear and simple

Better than using real people

Know what to look out for – giving power

Animated breasts offer more uniformity

Taking part in research - Pleased something is being done

Awareness is a shared experience – encourages lots of people

Importance of regular access to learning

How to share? - Awareness is a shared experience – sharing for learning on various platforms

Do/feel differently - Personal behaviour change – setting a date for a reminder to check breasts

Awareness is a shared experience – associate's awareness to share BCA screening and checking information

Awareness is a shared experience – eager to share animation

Step 3: Code grouping

Barriers to seek medical help goes beyond BCA

Knowledge of NF1 and BCA specific to NF1

HPs – lack of knowledge

HPs – lack of knowledge (HPs qualified years ago)

HPs – lack of knowledge (NF1 and women's health)

HPs – lack of knowledge a barrier to confidence in seeking medical help

HPs – lack of knowledge a barrier to seeking medical help

HPs Lack of knowledge a barrier to accessing screening

Barriers to BCA -HPs – lack of knowledge

Lack of knowledge of rare disease makes it taboo

HPs – potentially dangerous assumptions comes with lack of knowledge

Always in contact with HPs, but HPs have a lack of knowledge

HPs – lack of knowledge ('older' doctors)

The effect of lack of knowledge of NF on research and subsequently BCA

HPs lack of knowledge potentially dangerous

HP – lack of knowledge but desire to learn and research

HPs – lack of knowledge a barrier to access services

HPs lack of knowledge means lack of knowledge for patients

HPs – lack of knowledge helps spreads misinformation and confusion

Googling for answers

Rare knowledge of rare diseases

Unmet needs (breast concerns/screening)

Lack of knowledge of rare disease makes it taboo

Confidence is undermined by lack of HPs knowledge

HPs – potentially dangerous assumptions comes with lack of knowledge

HPs – online search for information

Lack of confidence in HPs' knowledge continues

Lack of confidence in HPs' desire to know

HPs – lack of knowledge ('older' doctors)

HPs lack of knowledge potentially dangerous

HPs – lack of knowledge means a lack of access of breast screening

Contraception as an increased risk of developing BC in general

Missed opportunity for empowerment - Increased risk of BC with NF1 not communicated previously

Prevent BCA - Missed diagnosis of NF1 is a missed awareness opportunity

Unmet needs with a later diagnosis – lack of information and lack of support

HPs lack of knowledge means lack of knowledge for patients

Lack of available research/information NF1

Lack of available research/information NF1 and BC

The need for more NF inclusion within BC research

Barrier to BCA - Misinformation

HPs – lack of knowledge

HPs – lack of knowledge helps spreads misinformation and confusion

The preference to go with who tells you the good news

Misinformation can come from anyone and everyone

Misinformation is a shared experience

Going with the ingroup

The detrimental effect of misinformation by HPs

HPs – growing knowledge of rare diseases

HPs – growing knowledge of rare diseases (optometrist)

HPs – An obvious diagnosis for an obvious sign

The power of knowledgeable HPs

The power of knowledgeable HPs (charity support)

HP – the power of knowledgeable HPs (charity NF nurse)

HPs – the desire to learn about rare diseases

Patient as specimen

Increased BCA (Risk) – learning through son's genetic consultant

Googling to fill in the blanks

Learning through NF charities

Learning from others on social platforms

The importance of HPs having NF1 knowledge

HPs – growing knowledge of rare diseases (junior doctors)

HPs knowledge of rare disease empowers patients with NF1

HPs knowledge provides power to patients with NF

NF1 patient as a guinea pig

Student doctors – more curiosity rather than knowledge

Different attitudes to rare disease research

HPs – learning on the floor

NF1 potentially being misdiagnosed

Importance of genetic testing

HP – desire to learn and research if unsure

HPs sharing of knowledge empowers the patient

The importance of empowering HPs with NF1 knowledge

The need for HPs to meet unmet needs of HP patients

Qualified doctors not given a chance to learn about NF

Knowledge barrier of HPs to learn about NF at university

The effect of lack of knowledge of NF on research and subsequently BCA

Lack of information about NF1 in textbooks

Important to consider birth control and the link to BC within young women with NF1

Lack of information available about NF1 and BC information

NF1 is left out by breast cancer websites and charities

All it takes is a little space to help raise awareness

Assoc HPs – knowledge is power

Assoc An obvious diagnosis for an obvious sign

Barriers to being BCA - Women with NF1 – lack of knowledge

Googling information fill in gaps

Gap of knowledge acquisition and sharing in adulthood

Assoc HPs – lack of knowledge as a barrier to being diagnosed

Assoc HPs – lack of knowledge

Assoc *Barrier to being BCA* - HPs – lack of knowledge

Assoc HPs lack of knowledge a barrier to seeking help

Assoc *Barrier to BCA* - Women with NF1 – lack of knowledge

Assoc *Barrier to checking once a month* - Women with NF1 – lack of knowledge (BCA)

Assoc Women with NF1 – lack of knowledge

Assoc Assumption of fibromas

Assoc Assumptions create complacencies

Assoc Young women with NF1 – lack of knowledge

Assoc Perceived lack of general awareness among young women with NF1

Assoc *Barrier to BCA* - Knowledge is power

Assoc Empowerment through awareness – taking responsibility for yourself

Assoc Importance of connections with charities – relatedness

Assoc Connections shares awareness

Assoc Importance of having access to accurate and accessible information when researching

The need to fight against HPs' lack of knowledge as medical negligence

Increasing HP knowledge - The need for basic training to be prepared to care for a patient with NF

A compromise to accepting that it's not possible to know about every condition

Lack of learning resources for HPs

Lack of information provided to HPs and trainee HPs

Assoc Lack of information

Assoc Google for learning

Assoc Lack of accessible and accurate information

Assoc Misinformation

Assoc Family connections don't mean NF1 knowledge

Assoc Assumption of knowledge of increased BC risk among women with NF1

A disconnected system that still holds the power

Stuck

A strained system in power

A strained system strains patient power/empowerment

In the power of 'lost' healthcare professionals

Unmet needs – abandoned

Unmet needs – the push for a doctor's appointment

Passed from pillar to post

Power struggle

The fight to get an appointment

Unfairly treated because of being a young woman – lack of HPs knowledge

Knowledge does not always mean power

Power dimensions – GP has power to screening access

Difficult in gaining screening access

Going private to get screened to get into the system

Perceived power and opinions of HPs

GPs as obstructing screening

Fight against the power of HPs

Sticking up for yourself

The perception that HPs don't care about NF patients as much as those with other conditions

The desire for patient centred care

HPs need to place patients at the centre to help them learn about the individual's experience of NF

Creating the individual benchmark for future consultations

A lucky dip of care for the patient

Disconnected system

Knowledge does not always mean power – difficulty accessing screening

Fallout felt by the patient

Disconnected system effects BCA

HPs (genetics) – desire of patients to be kept more up to date

NF patients – forgotten

HPs – perceived as dismissive

HPs – barrier to getting appointments

HPs – hold the power

The desire for extra support

A waiting game to be seen

HPs – dismissive to patients

A dichotomous experience with NF1

Postcode lottery for care

Power dimensions – HP over patient

One size does not fit all with NF1

Unmet needs

Having the right connections increases BCA

Perception of HP disregarding NF1 patient

Danger of power of GPs with a lack of knowledge

Discharged of care at 18 – left to deal with NF on own

Disconnected system – assumption medical records on a shared system

Disconnected system – disconnects the ability of a shared experience for knowledge and care

Strained health system – difficulty to get an appointment

Disconnected system – information not being shared with other HPs

Struggle to communicate with a GP

GP holds power to access other services

Lack of ongoing conversations about the condition and associated risks after healthcare ends after childhood

Lack of doctor availability for an appointment

HP – knowledge but no action

HP – holds power to gain access to more services or information (gatekeeper)

Asking about confidence to approach a HP is complex – two edged sword

Still feel vulnerable and judged

HPs – under pressure

With lack of understanding comes lack of compassion

HPs perceived as patronising

HPs makes you feel nervous and doubt yourself

HPs remove power and empowerment from women with NF1

HPs perceived attitude a barrier to seeking help for a breast concern

Those with NF1 reluctant to speak to HPs

The feeling of vulnerability

Power struggle between HP and patient

Patient not being heard

HPs are supposed to give reassurance

Lost in the system

Unmet needs – lack of support

Negative experience with HPs

Embarrassment caused by HP’s attitude

Disconnected system

Importance of understanding the system

Clearer information is needed for learning and accessing services

Previous confidence contacting HP -The worry about being taken seriously

HPs as holding the power

A struggle for breast screening in general

Women’s fight in healthcare

Assoc The complexity of NF1

Assoc So much information to be communicated

Assoc BCA never discussed

Assoc Specialists not communicating BCA information

Assoc Potential assumption of knowledge on patient/associate part

Assoc *Barriers to BCA* Concerned about taking up HPs time

Assoc *Barriers to BCA* Perceived power of HPs

Assoc Disconnected system

Assoc Confusion surrounding the screening process for NF1

Assoc Screening assumptions

Assoc Solution offering – access to screening

Assoc Patients having to be the right code to access services

Assoc HPs – power to give you the right code

Assoc Disconnected system

Assoc Assumption of a connected system

Assoc Assumption of ease of access to screening because of NF

Assoc Fear of not being taken seriously by HP

Assoc The perception of wasting time – HP has power

Assoc A power struggle

Assoc Difficult process

Assoc Disconnected system

Assoc A connected system can support BCA

Assoc A connected system allows women with NF1 to access system with ease by being called up

Earlier diagnosis of NF helps meet needs

Rare disease reality – difficulty of getting diagnosed

Late diagnosis - HPs – lack of knowledge

Nothing to worry about

Unmet needs (late diagnosis)

Struggle (childhood -learning)

Unmet needs (by being undiagnosed as a child)

Struggle (childhood – learning)

Unmet needs – the negative effect on the perception of the childhood self

Unmet needs due to late diagnosis (unfamiliar with fibromas which contribute to confusion with BCA)

Late and recent diagnosis

Shock of diagnosis

Only diagnosed through son's diagnosis

30 years of not knowing

Personal suspicion of NF1 - NF1 clues

Late diagnosis

Joint diagnosis – when child was diagnosed

A complex childhood diagnosis

Struggling in school

Early diagnosis

NF1 family history

HPs – knowledge allows for early testing

Early diagnosis

HPs – knowledge allows for early testing

NF1 family history

HPs – knowledge of rare diseases

Knowledge means meeting needs of the patient

Awareness is a shared experience

Awareness is a shared experience – social media (TikTok)

Awareness is a shared experience

Awareness is a shared experience (The importance of charities)

Awareness is a shared experience - Importance of charities

Awareness is a shared experience – Reducing unmet needs for daughter

Awareness is a shared experience (partner)

Awareness is a shared experience – considers others

Awareness is a shared experience – sharing with child

Awareness is a shared experience – animation for everyone, including children without NF1

Awareness is a shared experience – for daughter

Awareness is a shared experience – for all ages

Awareness is a shared experience – animation should be available to all

Awareness is a shared experience – for child

Taking part in research - Awareness is a shared experience

Awareness is a shared experience (information availability on social media)

Awareness is a shared experience – HPs need to share knowledge with patients
Awareness is a shared experience – desire to share animation
Awareness is a shared experience – the need to help HPs increase their knowledge
Awareness is a shared experience – sharing general knowledge with family
Awareness is a shared experience – one participant voice helps gives a voice to those who cannot engage in research
Awareness is a shared experience – me as researcher sharing awareness from previous work
Taking part in research - Awareness is a shared experience – raising awareness
Taking part in the research - Protection of anonymity when raising awareness

The desire to reduce unmet needs of others
Taking part in research - Helping
Taking part in research - Voice is being heard
Diversity in the voices of NF1
NF1 affects different people, and different places
Animation as a reset to feel that one will be listened to
Animation gives hope
Experience of relatedness – people (researchers) looking out for people with NF1

The importance of charities for support and information
Charities are trusted sources

HPs – position as provider of knowledge and awareness
Schools -position as provider of knowledge and awareness
Importance of charities position to provide information and awareness

Assoc Awareness is a shared experience – providing information to daughter
Assoc Awareness is a shared experience – the importance of being part of a charity
Assoc Sharing stories has the potential to share accurate breast cancer awareness information
Assoc *Do/feel differently* - Help raise awareness of NF1 and BCA

Assoc Awareness is a shared experience – for all

Assoc The power of social networks

Assoc Relatedness – researcher and participant

Assoc Desire to raise awareness

Assoc Eagerness – importance of raising and sharing awareness

Assoc Awareness is a shared experience

Assoc Would encourage anyone to go for a breast concern

Assoc Positive mindset – proactive

Assoc Importance of spotting something early

Assoc Importance of a shared awareness

Assoc Importance of open channels of communication

Assoc A two-way experience

Assoc Animation has the potential to support young women with NF1

Assoc The positive ripple effect of raising awareness

Assoc Support is a shared experience

Assoc Contacting a HP is important for ALL women

Assoc Particularly women with NF1

Assoc Catching cancer early can make a big difference to outcome

Assoc Importance of support

Assoc Solution offering - support

Assoc The potential supportive role of the associate

Assoc Awareness is a shared experience – in general BC information

Assoc Doctors need to share awareness with their patients

Assoc Importance of relatedness with charities for awareness

Assoc Connections shares awareness

Assoc Previous knowledge through CTT - Screening eligibility

Assoc Awareness is a shared experience

Awareness is a shared experience

Awareness is a shared experience – the importance of being part of a charity

Awareness is a shared experience – for all

Awareness is a shared experience – watch together

Awareness is a shared experience - Easy to discuss with either family or professional

Awareness is a shared experience – diversity in animation. NF1 can affect anyone

Awareness is a shared experience – in general BC information

Awareness is a shared experience – forums and websites

Awareness is a shared experience – sharing findings from research

Awareness is a shared experience – of condition

Awareness is a shared experienced – mother to daughter

Awareness is a shared experience – importance of BCA support

Awareness is a shared experience – encourages lots of people

How to share? - Awareness is a shared experience – sharing for learning on various platforms

Awareness is a shared experience – associate's awareness to share BCA screening and checking information

Awareness is a shared experience – eager to share animation

Awareness is a shared experience - The desire to reduce unmet needs of others

Awareness is a shared experience – Reducing unmet needs for daughter

Awareness is a shared experience - Child as motivation to be breast cancer aware

Awareness is a shared experience (partner)

Awareness is a shared experience – sharing general knowledge with family

Knowledge is a shared experience

Assoc Awareness as a shared experience – makes it an easier ride

Assoc Awareness is a shared experience – importance of BCA support

Assoc Putting a plan in place to encourage seeking help

Assoc Worth getting checked

Research allows for sharing of experiences within a condition of many variables

Helping raise awareness

Taking part in research - Happy research is being done

Feeling seen and heard

Research made you feel? - Lack of research aimed at young women with NF1

Waiting to take part in something she belongs to – relatedness

Feels seen and heard

Taking part is doing something good

Taking part in research - Feeling hopeful

An opportunity to be heard

Being involved in making changes

Proud to take part because it is an essential change that is needed

Relatedness with researchers in field – appreciation of work being done

Taking part in research to learn

Taking part in research to be empowered

Taking part in research - Participated with ‘two hats’ – patient and researcher

Taking part in research - Awareness is a shared experience – raising awareness

Assoc *Taking part in research* - Helping ‘spread the word’

Assoc *Taking part in research* - Research allows for rare disease lived experiences to be shared

Assoc *Taking part in research* - The hope of doing some good

Awareness is a shared experience – of condition

Help others

Assoc *Do/feel differently* - The associate as teacher

Assoc Awareness is a shared experienced – mother to daughter

Assoc *Do/feel differently* - More information to go on

Assoc *Taking part in research* - Gaining valuable information

Assoc Positive effect for the future

Importance of and trust in charities for information

The importance of sharing animation to raise awareness

Wider accessibility is important. Find it even if you’re not looking for it

Lack of awareness can break the shared experience

Importance of connections for knowledge

Breaking barriers to BCA - Educating is a shared experience

Education from charities, NF and cancer

Assoc BCA is a shared experience – learning from partner

Assoc *Taking part in research* - Pleased something is being done

Assoc Awareness is a shared experience – encourages lots of people

Assoc Importance of regular access to learning

Assoc *How to share?* - Awareness is a shared experience – sharing for learning on various platforms

Assoc Awareness is a shared experience – associate's awareness to share BCA screening and checking information

Assoc Awareness is a shared experience – eager to share animation

General barriers to BCA and breaking them

Busy life

Breaking barriers to BCA- Make screening accessible – pop up clinics

Cut out the middle GP

Take back power

Power of family with BCA

Loss of empowerment ('Do this', 'do that')

Misinformation (family)

Always in contact with HPs, but HPs have a lack of knowledge

Memory from childhood remains

Barriers to being BCA - Fear of the increased risk of breast cancer

Facts in video might scare them

Avoidance of BC reality

Barrier to being BCA- Lack of internet access

Low income

Importance of information available in different formats to reach everyone

Women with NF1 – lack of knowledge

Personal misdiagnosis

Assumption 'it's just NF1'

Barriers to being BCA - Confusion knowing difference between fibroma and malignant mass

Worry and fear

How to reduce these barriers? - Access to information where people look

Importance of accessibility on various platforms that is wide reaching

Barrier to attend HPs – stigma of younger female going to HP with a breast concern

Have to be a certain age to seek help for a breast concern

Stigma from misinformation about cancer age occurrence (HPs and public)

Afraid of judgment being a young woman

A need for accessible information direct from GPs

Confusion of screening age – confused information from charity

Health is put on the back burner – other priorities come along

Life gets in the way

Barrier to BCA - Lack of access to information

BCA approached as a general 'one size fits all'

One PowerPoint slide can tell a story and make a difference

Lack of information available about NF1 and BC information

NF1 is left out by breast cancer websites and charities

All it takes is a little space to help raise awareness

Assoc Assumption a lump is NF1

Assoc *Barrier to BCA* - Other health issues of young women with NF1 are a priority

Assoc So many other things to worry about

Assoc BCA might not be high on the list with so many other worries

Assoc Embarrassment

Assoc Scary to go to a HP

Assoc *How to support?* - Increased risk of BC is another complication to deal with NF1

Assoc Another battle to fight

Assoc Another thing to face

Assoc Mistrust of the body

Assoc *Barrier to BCA* - Learning difficulties

Assoc Vulnerable women

Assoc Solution offering – add BCA NF1 information to BC leaflets

Assoc add BCA NF1 information to BC leaflets – accessibility GPs surgery

Assoc Autism

Assoc Assumption of safety – it won't happen to me

Assoc Ignorance is bliss

Assoc Trauma from past experiences with HPs creates barrier for today's encounters

Assoc Trauma from finding something again and again

Assoc Is it worth the exhaustion of seeking help?

Assoc Easy to put something off

The persistent patient expert for unmet needs

Patient having to be expert/teacher

Patient having to be researcher

Persistence needed to have needs met

Lack of resources and support for rare diseases/NF1

Mother as expert/teacher

Isolating - Having to manage the condition yourself

HPs should be responsible for organising screening

Onus left on patient to chase

HPs organising screening alleviate anxiety to organise

Going to a HP is like going to war

The battle to defend, explain, and justify

Patient having to be teacher/expert

Patient not being heard

Trying to fight for what you are entitled to is exhausting

Needs should be met without interrogation

Unmet needs – lack of support

Patient having to be the expert/teacher

Battle to be heard and taken seriously

Assoc Patient having to be expert/teacher

Assoc The search for answers

Assoc The fight for others

Assoc Misinformation

Assoc Lack of accessible and accurate information

Assoc Having to dig for it

Assoc Patient having to be expert/teacher

Assoc Patient having to be teacher/expert – mentally draining

An awareness animation – knowledge, power, and empowerment

Animation increases BCA

‘Ins and outs’ through animation

Knowledge as empowerment (‘myself’ = ownership)

Screening knowledge – not much change

Knowledge is power

Empowerment through animation

Do or feel differently?- Check breasts more within struggle to figure out differences

Self-efficacy confusion

Confidence – not a waste of time to check

Increased BCA – wider knowledge of warning signs

Confidence to seek help through learning

Increased BCA – warning signs

Beyond the lump

The assumption of 50 years for all

Confusion in age for increased risk – issue with Breast-CAM-NF1 items

Increased BCA – warning signs

Increased BCA – breast checking

Behaviour change – Checking once a month

Setting a reminder

Payday is breast day

Animation to empower others (daughter)

Increased BCA – checking and warning signs

Increased BCA – Confidence

Increased BCA – self-efficacy

Knowledge is empowerment to check

Confidence to check if all is okay

Is it cancer or something else?

The general confusions of BCA

Animation to fight against HPs’ lack of knowledge

Taking part in research - BCA – not just something that can be ignored

I think I need to be more aware

Stop ignoring everything

Embracing the truth and actions of being BC aware with NF1

Do or feel differently

BCA – can be an inconvenience

BCA – not being taken seriously

BCA is the power to potentially stop a bad outcome

BCA and NF1 – power to potentially stop a bad outcome as a young woman

Take health more seriously

BCA – added complexity with NF1

BCA and NF1 – It’s for a good reason

Shift in attitude – knowledge is power

The ability to face reality

Empowerment through animation

Self-efficacy

Confidence – not a waste of time to check

BCA knowledge – not really changed

History of BC in family

Previous knowledge of screening

Anxiety with BCA

Always checking

Anxiety

Always going to the doctor

Surprised by advice of ‘once a month’ checking

Over checking

Effect of animation – reduce frequency of breast checking

Screening eligibility- Previous knowledge from family member going earlier

Animation to fight against HPs’ lack of knowledge

Animation provides a chance of empowerment and of giving power

Do/feel differently- Changes in checking – no longer continuously checking

Feeling a lot more calmer

No orders so no power taking

Easy to understand

Animation provides empowerment (check themselves)

Increased BCA from ‘scare’

Animation instils confidence to know what to be aware of when checking breasts

Creating confidence through creating animation

Animation ‘shows’ you what to do

Animation instils confidence to seek help for a breast concern

Power to go and seek help

Empowerment to instruct HP

Knowledge is power

Previous knowledge of screening eligibility

Ripple effect of animation: Empowering daughter with BCA knowledge

Do or feel differently - Increased BCA – checking properly

Increased BCA – what to look out for

Empowerment – for myself

Providing power – for mother and daughter

Animation as a powerful learning tool for all children

NF1 and precocious puberty

Animation to raise awareness that some need to be screened early

HPs – an obvious diagnosis for an obvious sign

Increased BCA – checking more frequently

Booster to be more vigilant

Increased BCA – wider warning signs to be aware of

Previous knowledge of increased risk (proactive mother)

Animation as motivation to be breast cancer aware

Increased BCA (animation) – checking once a month

Increased BCA – detecting any breast changes

Increased BCA – seeking medical help if concerned about breast changes

Increased BCA comes with practice

Animation instils empowerment and self-confidence to seek medical help

Animation provides power to the watcher

Previous knowledge of screening eligibility

If in doubt just go

Nipping something potentially sinister in the bud

Animation emphasises vigilance

Animation bridges gap of an unmet need

Animation as a BCA reminder

Do/feel differently - Feel reassured

Promoted self-efficacy and confidence to get checked out

Increased BCA – accurate information on risk

Not much change with detecting changes

Animation made it clearer on identifying what changes are

General confusion with breast changes

Quicker contact with HP from watching animation

Previous knowledge of screening eligibility

Research can increase knowledge among HPs

Do/feel differently - Check breasts more often

BCA awareness – probably increased a bit

Previous knowledge of BCA

Increased confidence to contact a HP with a breast concern

Improved BCA – detecting changes and warning signs in a more extensive area

Improved BCA – the need to be more thorough

Previous awareness of screening eligibility (GUM clinic)

Increased BCA – checking frequency

Once a month checking is reasonable

Checking is easy

Developing an awareness of what is normal for you

Do/feel differently - Increased BCA – increased awareness in being mindful to any changes

A reminder of the importance of checking

Don’t forget about your breasts

Previous BCA – warning signs

Power in own hands – check self regularly

Increased confidence to go to HP

Animation empowering action

Animation giving power to young women with NF1

Confusion shakes confidence – fibroma or benign mass?

Still feel vulnerable and judged

Previous BCA knowledge – CTT information

Do/feel differently - Previous knowledge – nothing different

For others just learning – encourage to be own advocate (power and empowerment)

BCA is nothing to be embarrassed about

Increased BCA – frequency of breast checking

Increased BCA – confirms what to look out for

Increased BCA – screening eligibility

Previous knowledge of general BCA

Learning general BCA from attending an all girls school

Learning general BCA from university

Personal experience of breast cancer in family

Increased confidence to contact HP with a breast concern

Learning through animation helping to reframe previous bad encounters with HPs

Earlier screening knowledge is reassuring

Family experience of BC – motivation for BCA

Knowledge is power

Knowledge is empowerment

Do/feel differently - Increased BCA – self awareness and reflection to check breasts more consistently

Setting a date

Setting a reminder

Increased BCA – animation made me more aware

Past breast concern

Increased BCA – monthly checking

The reality of the confusion and worry between fibroma and benign mass

Previous confidence to seek medical help

Previous BCA – through NF charity position

Knowledge is power

Increased BCA – warning signs

Beyond the lump

Previous knowledge – checking once a month

Increased BCA – confidence in detecting changes

Beyond the lump

Increased BCA – screening eligibility

Animation correcting previous beliefs

Confusion of ages from reading information pertinent to other countries

UK ‘trying’ 40

Knowledge is empowerment

Beating misconception of breast cancer age

The importance of catching cancer early

Do/feel differently - Increased BCA – check for other warning signs

Beyond the lump

Assoc Increased BCA – risk

Assoc Personal experience of breast cancer – family friend

Assoc Motivation to be BCA – death of family friend to BC

Assoc Animation bridges a knowledge gap to be shared

Assoc Animation reinforces importance of seeking medical help for a breast concern

Assoc Animation highlights importance of BCA within an NF1 context

Assoc Increased BCA – in general for associate

Assoc Increased BCA – provision motivation for associate to be more BC aware

Assoc Increased BCA – screening eligibility

Assoc Perception of increased risk, screening should be earlier than 40 years

Assoc Increased BCA – monthly checking for daughter with NF1

Assoc Setting a reminder good for those who like a routine

Assoc Animation has provided the BCA information needed

Assoc Hearing it all for the first time

Assoc Precocious puberty

Assoc Animation increases confidence to speak with daughter about BCA

Assoc Animation opens channels of communication

Assoc Simple and clear

Assoc Previous knowledge of BCA (warning signs- general)

Assoc Power of BCA information available in public

Assoc Personal experience of cancer in family (BCA motivation)

Assoc Previous knowledge of increased risk

Assoc Increased BCA – screening eligibility

Assoc Animation empowers women with NF1 to go to the doctor

Assoc Animation as reassuring to seek help

Assoc Increased BCA – connection between increased risk and NF1

Assoc Increased BCA – earlier screening for women with NF1

Assoc Increased BCA – checking once a month

Assoc Increased BCA – screening

Assoc Increased BCA – risk

Assoc Increased BCA – earlier screening

Assoc Previous belief screening started younger with increased risk

Assoc Increased BCA – huge from animation

Assoc Increased BCA – risk

Assoc Learning about the connection of NF1 and BC

Assoc Increased BCA – screening eligibility

Assoc Knowledge is power and empowerment

Assoc Giving knowledge – giving power

Assoc Encouraging women to check – encouraging empowerment

Assoc Animation encouraged own personal BCA - checking

Assoc Increased BCA – general BCA (non NF1)

Assoc Increased BCA – beyond the lump

Assoc Confusion of fibroma versus malignant lump

Assoc Importance of vigilance within women with NF1 of body changes

Assoc Empowerment in vigilance

Assoc Previous BCA knowledge – risk

Assoc Only recent learning of risk

Assoc Increased BCA though CTT - risk

Assoc Knowledge is power and empowerment for her daughter

Assoc Checking once a month – reasonable

Assoc Creating a new behaviour to check

Assoc Becomes like on auto-pilot

Assoc BCA as natural

Assoc BCA as natural and automatic action

Assoc Increased BCA – knew of increased risk but not to what extent

Assoc Animation provides the 'ins and outs'

Assoc Increased BCA – five-fold risk figure

Assoc *Encouraging contacting HP* - No change - previous breast concern with partner

Assoc 'on the ball' for encouraging contacting HPs

Assoc Increased BCA – warning signs

Assoc Beyond the lump

Assoc Increased BCA – screening eligibility

Assoc Assumption of automatic access to breast screening

Assoc Solution finding - associate

Assoc Too late at 40 with tumours and NF1

Assoc Knowledge is power

Assoc Knowledge is empowerment to manage condition personally

Assoc Animation clearly explains importance of checking

Assoc Exposing the barriers to breast checking

Assoc Animation creates self reflection of own BCA – checking breasts frequency

Assoc Animation creates a consideration of personal plan to set a reminder – behaviour change

Assoc Animation makes me think, makes you think

Assoc Animation experience is a shared experience

Assoc Increased BCA – risk

Assoc Animation resets old thinking

Assoc Increased BCA – screening eligibility

Assoc Animation can bridge BCA knowledge gap

Assoc Empowering – get to know what's normal for you

Assoc Encouraging BCA in women with NF1 – the importance and how to do

Assoc Know what to look out for – giving power

Assoc *Do/feel differently* - Personal behaviour change – setting a date for a reminder to check breasts

Animation as a protective shield – safe to watch

Breast cancer is a taboo subject
Seeing human breasts is taboo
Seeing human breasts is stressful
Animated breasts are not so taboo
Animation has the safety of a children's programme
A visual learner
The animation gets you more
No skimming
More attractive to watch videos
Animated versus real body – no difference as a personal opinion
People are more comfortable watching animation
Watching animation offers more privacy to the topic
Cartoon format - Helped
Not scary
Animated interventions are eye catching
Seeing real people is boring
Animation makes you think of childhood
Animation is best to reassure young people
Animation suitable for young people
Animation keeps the eye on it
Animation paints a thousand words
Animation format - Animation as providing protective distance
Actual person's breasts embarrassing to watch
Diversity of characters – not only one race with NF1
Previous scare of breast concern
Breast cancer is scary
Animation format - Perception of more informal

Easier to digest a serious message

Allows for a different mindset

Real people means a really heavy message

Animation is more friendly to watch

Animation keeps you ‘switched on’

Animation encouraging BCA - Encourages watcher to be more aware of NF1 information

Animated format - Easier to digest in animated format

Easier to understand

Webpage of information is difficult to read

Animation allows for clearer communication instead of using ‘actual humans’ (protective distance)

Animation as inclusive

Animation format - Seeing ‘live people’s’ breasts is uncomfortable

Animation creates a protective distance

Animation works for all ages

Simple format means anyone can follow

Animation represents diversity – anyone can have NF1

NF1 is a shared experience

Anyone can have NF1

Encouraging BCA - Very simple

Brief

Clarifies what to look out for

Animation format – no advantage

Animation can reach a wide audience

Animation encouraging BCA - Right length – ‘Goldilocks effect’

Different methods of communication

Did a lot to get someone’s attention

Animated format - Provided accessibility

Accessible to different types of learners

Accessible to those with learning difficulties

Animation is not overwhelming

Goldilocks effect

Inclusive – suitable for all ages

Inclusive – for those with learning difficulties

Animation is not scary

Animated format - More fun

Real-life humans makes it quite serious

Animation provides a protective distance

Animation provides an escape from reality

Animation makes watching more comfortable

Viewing real breasts is taboo

Assoc Animation appropriate for younger ages

Assoc Animation makes a serious message more fun

Assoc *Animation format* - Body as taboo

Assoc Animated character provides a protective distance

Assoc Animated helps break taboos

Assoc Animation helps open channels of communication

Assoc *Encouraging BCA* - Easy to understand

Assoc Easy to watch

Assoc Animation opens channels of communication

Assoc Animation reduces fear

Assoc *Animation format* - Helps with learning

Assoc Helps with understanding

Assoc Format helps open channel of communication

Assoc Format encourages help seeking

Assoc *Animation encouraging BCA* - Short and accessible

Assoc Awareness is a shared experience

Assoc Accessibility with subtitles

Assoc Explains things clearly

Assoc Awareness is a shared experience – diversity in animation. NF1 can affect anyone

Assoc *Animation* - Not overly scientific

Assoc Exposes barriers to being BCA – checking breasts

Assoc Accessible learning tool

Assoc *Animation encouraging BCA* - Animation as safe

Assoc Easy to watch

Assoc Easy to understand

Assoc Encouraging

Assoc Not overly medical

Assoc *Cartoon format* - Nonthreatening

Assoc A real person and their breasts are threatening

Assoc Animated person could be any of us

Assoc Clear and easy to watch

Assoc Animation not patronising

Assoc Animation opens channels of communication

Assoc *Animation format* - Sticks in the mind

Assoc Animation offers a protective distance

Assoc Seeing a real woman's body might be uncomfortable

Assoc Animation suitable for a younger woman

Assoc Animation as 'informal'

Assoc Animation is less intimidating

Assoc Not too clinical

Assoc Easy to watch

Assoc *Cartoon format* - Acceptable for younger people

Assoc Not an old-fashioned style

Assoc Animation does not exert power over viewer

Assoc Not frightening

Assoc Animation creates a sense of free-will and personal choice to watch and learn

Assoc The sense of agency

Assoc The Goldilocks effect

Assoc Animation is really clever

Assoc Animation good for younger audience

Assoc Engaging

Assoc Real people switch real people off

Assoc Real people make it morbid – cancer is morbid

Assoc Speech bubbles – closed captions

Assoc Fun way for a real life situation

Assoc The change of before and after

Assoc Interactive helps absorbing

Assoc *Taking part as a man* - Animation is inclusive for all and any viewers

Assoc Welcoming to all

Assoc Animation allows for a more realistic portrayal of NF1

Assoc Real life but not real life

Assoc Diagrams

Assoc *Animation encouraging BCA* - Keeping it simple

Assoc *Animation format* - Clear and simple

Assoc Better than using real people

Assoc Animated breasts offer more uniformity

Associate reflections and communications

Them and us

Animation contributed to thinking from a different perspective

Seeing it from the woman with NF1's perspective

BCA as a taboo subject – not talked about in normal conversations in families

Animation creates a consideration for women with NF1

Lack of BCA in general in associate

Lack of association of BC with young women

Taking part in research - Encouraged thinking from an NF1 perspective

Breaking the normalisation of NF1

Encouraged reflection of challenges of NF1

Lack of awareness of BCA of associate – frequency of breast checking

Them and us

The assumption that screening started earlier in young women with NF1

Nothing to base assumption on

Money the implied reason for screening only starting at 40 years

Why not earlier than 40 years?

Prevention is cheaper

Increased risk means increased encouragement to contact a HP

Supporting more than encouraging to contact a HP

Taking part in research - Concern for people with NF1

Animation beings an awareness of NF1 struggles – feeling of guilt as 'Us'

However, awareness is a shared experience

Do/feel differently - Feel more concerned about increased risk

Feeling of being stuck with this new knowledge

Be ready to support

An important piece of work

Experience of definite urgency from associate from learning

Taking part in research - Focus of awareness on the increased risk

The shock of new information – risk

Do/feel differently - Reflection on personal experience of losing relatives to breast cancer

Importance of BCA for women with NF1 – personal motivation due to family loss

Knows the importance of catching things early and not leave things

Coming in from the outside

Them and Us

Step 4: Code grouping candidate themes

- **An obvious diagnosis for an obvious sign – the importance of power and empowerment through respectful curiosity and patient-centred learning and sharing.**
- **Healthcare professionals 'having not a scooby do about what the condition is' in a powerful yet disconnected system – 'why bother going?'**
- **'Knowledge is power, as they say'...but only if it's shared and trusted.**
- **'It's not just the lumps you've got to feel' – gaining knowledge and demonstrating self-efficacy.**

- **‘I can’t be pushed away as I have been before’ – tentatively planting the seeds of empowering thoughts, behaviours, and actions within a young woman with NF1.**

- **‘It was safe’ – Animation as a protective distance from breast taboos and scary facts.**

- **‘it’s simple enough that anyone can follow it’ – animation format as an inclusive learning tool.**

- **Ripple effects and shifting perspectives among associates.**

An obvious diagnosis for an obvious sign – power and empowerment through respectful curiosity and patient-centred learning and sharing

HPs – growing knowledge of rare diseases

HPs – An obvious diagnosis for an obvious sign

The power of knowledgeable HPs

HPs knowledge of rare disease empowers patients with NF1

NF1 patient as a guinea pig

HP – desire to learn and research if unsure

The importance of empowering HPs with NF1 knowledge

Qualified doctors not given a chance to learn about NF

Important to consider birth control and the link to BC within young women with NF1

HPs – knowledge is power

Increasing HP knowledge - The need for basic training to be prepared to care for a patient with NF

A compromise to accepting that it’s not possible to know about every condition

Lack of learning resources for HPs

Lack of information provided to HPs and trainee HPs

Earlier diagnosis of NF helps meet needs

Late diagnosis - HPs – lack of knowledge

Unmet needs (late diagnosis)

Struggle (childhood -learning)

Unmet needs (by being undiagnosed as a child)

Unmet needs – the negative effect on the perception of the childhood self

HPs – knowledge allows for early testing

Knowledge means meeting needs of the patient

Patient having to be expert/teacher – mentally draining

Persistence needed to have needs met

Lack of resources and support for rare diseases/NF1 (Having to dig for it)

Mother as expert/teacher

Isolating - Having to manage the condition yourself

Organising screening should be an easy process with GP

The battle to defend, explain, and justify

Patient not being heard and taken seriously

Trying to fight for what you are entitled to is exhausting

Needs should be met without interrogation

Unmet needs – lack of support

The search for answers

Misinformation

Health is put on the back burner – other priorities come along

Assoc *Barrier to BCA* - Other health issues of young women with NF1 are a priority

Assoc So many other things to worry about

Assoc BCA might not be high on the list with so many other worries

Assoc *How to support?* - Increased risk of BC is another complication to deal with NF1

Assoc Another battle to fight

Assoc Another thing to face

Assoc Mistrust of the body

Assoc *Barrier to BCA* - Learning difficulties

Assoc Vulnerable women

Assoc Autism

Assoc Ignorance is bliss

Assoc Easy to put something off

Assoc Assumption of fibromas

Assoc Assumptions create complacencies

Women with NF1 – lack of knowledge

Personal misdiagnosis

Assumption 'it's just NF1'

Worry and fear

Assoc Assumption a lump is NF1

Assoc Assumption of safety – it won't happen to me

Animation as a reset to feel that one will be listened to

Animation gives hope

HPs – position as provider of knowledge and awareness

Experience of relatedness – people (researchers) looking out for people with NF1

Assoc Doctors need to share awareness with their patients

Healthcare professionals 'having not a scooby do about what the condition is' in a powerful yet disconnected system – 'why bother going?'

Healthcare professionals' lack of NF1 knowledge – potentially dangerous assumptions

Healthcare professionals' lack of knowledge a barrier to access services

HPs lack of knowledge means lack of knowledge for patients

HPs – lack of knowledge helps spreads misinformation and confusion

Confidence to seek help is undermined by lack of HPs knowledge

HPs – online search for information

Missed opportunity for empowerment - Increased risk of BC with NF1 not communicated

Prevent BCA - Missed diagnosis of NF1 is a missed awareness opportunity

Unmet needs with a later diagnosis – lack of information and lack of support

Lack of available research/information NF1

Lack of available research/information NF1 and BC

The need for more NF inclusion within BC research

HPs – lack of knowledge helps spreads misinformation and confusion

Stuck

A strained system in power

A strained system strains patient power/empowerment

Unmet needs – abandoned

Unmet needs – the push for a doctor’s appointment

Passed from pillar to post

The fight to get an appointment

Knowledge does not always mean power

Power dimensions – GP has power to screening access

Difficult in gaining screening access

Going private to get screened to get into the system

Perceived power and opinions of HPs

GPs as obstructing screening

Fight against the power of HPs

Power struggle

Unfairly treated because of being a young woman – lack of HPs knowledge

Sticking up for yourself

The perception that HPs don’t care about NF patients as much as those with other conditions

The desire for patient centred care

HPs need to place patients at the centre to help them learn about the individual’s experience of NF

Creating the individual benchmark for future consultations

A lucky dip of care for the patient

Disconnected system

Knowledge does not always mean power – difficulty accessing screening

Fallout felt by the patient

Disconnected system affects BCA

HPs (genetics) – desire of patients to be kept more up to date

NF patients – forgotten

HPs – perceived as dismissive

HPs – barrier to getting appointments

HPs – hold the power

The desire for extra support

A waiting game to be seen

HPs – dismissive to patients

A dichotomous experience with NF1

Postcode lottery for care

Power dimensions – HP over patient

One size does not fit all with NF1

Unmet needs

Having the right connections increases BCA

Perception of HP disregarding NF1 patient

Danger of power of GPs with a lack of knowledge

Discharged of care at 18 – left to deal with NF on own

Disconnected system – assumption medical records on a shared system

Disconnected system – disconnects the ability of a shared experience for knowledge and care

Strained health system – difficulty to get an appointment

Disconnected system – information not being shared with other HPs

Struggle to communicate with a GP

GP holds power to access other services

Lack of ongoing conversations about the condition and associated risks after healthcare ends after childhood

Lack of doctor availability for an appointment

HP – knowledge but no action

HP – holds power to gain access to more services or information (gatekeeper)

Asking about confidence to approach a HP is complex – two edged sword

Still feel vulnerable and judged

HPs – under pressure

With lack of understanding comes lack of compassion

HPs perceived as patronising

HPs makes you feel nervous and doubt yourself

HPs remove power and empowerment from women with NF1

HPs perceived attitude a barrier to seeking help for a breast concern

Those with NF1 reluctant to speak to HPs

The feeling of vulnerability

Power struggle between HP and patient

Patient not being heard

HPs are supposed to give reassurance

Lost in the system

Unmet needs – lack of support

Negative experience with HPs

Embarrassment caused by HP’s attitude

Disconnected system

Importance of understanding the system

Previous confidence contacting HP -The worry about being taken seriously

HPs as holding the power

A struggle for breast screening in general

Women’s fight in healthcare

Barrier to attend HPs – stigma of younger female going to HP with a breast concern

Have to be a certain age to seek help for a breast concern

Afraid of judgment being a young woman

Assoc The complexity of NF1

Assoc So much information to be communicated

Assoc BCA never discussed

Assoc Specialists not communicating BCA information

Assoc Potential assumption of knowledge on patient/associate part

Assoc *Barriers to BCA* Concerned about taking up HPs time

Assoc *Barriers to BCA* Perceived power of HPs

Assoc Disconnected system

Assoc Fear of not being taken seriously by HP

Assoc The perception of wasting time – HP has power

Assoc A power struggle

Assoc Difficult process

Assoc Disconnected system

Assoc A connected system can support BCA

Assoc A connected system allows women with NF1 to access system with ease by being called up

Assoc Is it worth the exhaustion of seeking help?

Busy life

Assoc Trauma from past experiences with HPs creates barrier for today's encounters

Assoc Trauma from finding something again and again

Assoc Embarrassment

Assoc Scary to go to a HP

'Knowledge is power, as they say'...but only if it's shared and trusted.

Having one slide 'could make all the difference for a lot of people'. Sharing NF1 specific details within general breast cancer information

Assoc Solution offering – add BCA NF1 information to BC leaflets

Assoc add BCA NF1 information to BC leaflets – accessibility GPs surgery

NF1 is left out by breast cancer websites and charities

All it takes is a little space to help raise awareness

Lack of information available about NF1 and BC information

A need for accessible information direct from GPs

BCA approached as a general 'one size fits all'

One PowerPoint slide can tell a story and make a difference

Access to information where people look

Importance of accessibility on various platforms that is wide reaching

Assoc Google for learning

Assoc Misinformation

Awareness is a shared experience (The importance of charities)

Awareness is a shared experience (information availability on social media)

Awareness is a shared experience – social media (TikTok)

Patient - Googling to fill in the blanks

Gap of knowledge acquisition and sharing in adulthood

Assoc Awareness is a shared experience – the importance of being part of a charity

Assoc Sharing stories has the potential to share accurate breast cancer awareness information

Assoc The power of social networks

Awareness is a shared experience – me as researcher sharing awareness from previous work

Assoc Importance of relatedness with charities for awareness

Assoc Connections shares awareness

Awareness is a shared experience – the importance of being part of a charity

Awareness is a shared experience – forums and websites

Importance of and trust in charities for information

Wider accessibility is important. Find it even if you're not looking for it

Importance of connections for knowledge

Learning through NF charities

Learning from others on social platforms

Importance of information available in different formats to reach everyone

Barrier to BCA - Lack of access to information

Assoc BCA is a shared experience – learning from partner

Awareness is a shared experience – animation for everyone, including children without NF1

Awareness is a shared experience – animation should be available to all

Awareness is a shared experience – the need to help HPs increase their knowledge

Schools -position as provider of knowledge and awareness

Importance of charities position to provide information and awareness

Lack of awareness can break the shared experience

Assoc Awareness is a shared experience – encourages lots of people

Assoc Awareness is a shared experience – providing information to daughter

Assoc Awareness is a shared experienced – mother to daughter

Assoc Importance of regular access to learning

Assoc *How to share?* - Awareness is a shared experience – sharing for learning on various platforms

Assoc Awareness is a shared experience – eager to share animation

Awareness is a shared experience – of condition

Awareness is a shared experience – importance of BCA support

Awareness is a shared experience – encourages lots of people

How to share? - Awareness is a shared experience – sharing for learning on various platforms

Awareness is a shared experience – eager to share animation

Research allows for sharing of experiences within a condition of many variables

‘It’s not just the lumps you’ve got to feel’ – gaining knowledge and demonstrating self-efficacy

Animation increases BCA

‘Ins and outs’ through animation

Screening knowledge – not much change

Do or feel differently?- Check breasts more within struggle to figure out differences

Self-efficacy confusion

Increased BCA – wider knowledge of warning signs

Increased BCA – warning signs

Beyond the lump

The assumption of 50 years for all

Confusion in age for increased risk – issue with Breast-CAM-NF1 items

Is it cancer or something else?

The general confusions of BCA

BCA – added complexity with NF1

BCA and NF1 – It’s for a good reason

Shift in attitude – knowledge is power

The ability to face reality

History of BC in family

Empowerment through animation

Self-efficacy

Confidence – not a waste of time to check

BCA knowledge – not really changed

Previous knowledge of screening

Anxiety with BCA

Always checking

Anxiety

Always going to the doctor

Surprised by advice of ‘once a month’ checking

Over checking

Effect of animation – reduce frequency of breast checking

Screening eligibility- Previous knowledge from family member going earlier

Animation to fight against HPs’ lack of knowledge

Animation provides a chance of empowerment and of giving power

Do/feel differently- Changes in checking – no longer continuously checking

Feeling a lot more calmer

No orders so no power taking

Easy to understand

Animation provides empowerment (check themselves)

Increased BCA from ‘scare’

Animation instils confidence to know what to be aware of when checking breasts

Creating confidence through creating animation

Animation ‘shows’ you what to do

Animation instils confidence to seek help for a breast concern

Power to go and seek help

Empowerment to instruct HP

Knowledge is power

Previous knowledge of screening eligibility

Ripple effect of animation: Empowering daughter with BCA knowledge

Do or feel differently - Increased BCA – checking properly

Increased BCA – what to look out for

Empowerment – for myself

Providing power – for mother and daughter

Animation as a powerful learning tool for all children

NF1 and precocious puberty

Animation to raise awareness that some need to be screened early

HPs – an obvious diagnosis for an obvious sign

Increased BCA – checking more frequently

Booster to be more vigilant

Increased BCA – wider warning signs to be aware of

Previous knowledge of increased risk (proactive mother)

Animation as motivation to be breast cancer aware

Increased BCA (animation) – checking once a month

Increased BCA – detecting any breast changes

Increased BCA – seeking medical help if concerned about breast changes

Increased BCA comes with practice

Animation instils empowerment and self-confidence to seek medical help

Animation provides power to the watcher

Previous knowledge of screening eligibility

If in doubt just go

Nipping something potentially sinister in the bud

Animation emphasises vigilance

Animation bridges gap of an unmet need

Animation as a BCA reminder

Do/feel differently - Feel reassured

Promoted self-efficacy and confidence to get checked out

Increased BCA – accurate information on risk

Not much change with detecting changes

Animation made it clearer on identifying what changes are

General confusion with breast changes

Quicker contact with HP from watching animation

Previous knowledge of screening eligibility

Research can increase knowledge among HPs

Do/feel differently - Check breasts more often

BCA awareness – probably increased a bit

Previous knowledge of BCA

Increased confidence to contact a HP with a breast concern

Improved BCA – detecting changes and warning signs in a more extensive area

Improved BCA – the need to be more thorough

Previous awareness of screening eligibility (GUM clinic)

Increased BCA – checking frequency

Once a month checking is reasonable

Checking is easy

Developing an awareness of what is normal for you

Do/feel differently - Increased BCA – increased awareness in being mindful to any changes

A reminder of the importance of checking

Don’t forget about your breasts

Previous BCA – warning signs

Power in own hands – check self regularly

Increased confidence to go to HP

Animation empowering action

Animation giving power to young women with NF1

Confusion shakes confidence – fibroma or benign mass?

Still feel vulnerable and judged

Previous BCA knowledge – CTT information

Do/feel differently - Previous knowledge – nothing different

For others just learning – encourage to be own advocate (power and empowerment)

BCA is nothing to be embarrassed about

Increased BCA – frequency of breast checking

Increased BCA – confirms what to look out for

Increased BCA – screening eligibility

Previous knowledge of general BCA

Learning general BCA from attending an all girls school

Learning general BCA from university

Personal experience of breast cancer in family

Increased confidence to contact HP with a breast concern

Learning through animation helping to reframe previous bad encounters with HPs

Earlier screening knowledge is reassuring

Family experience of BC – motivation for BCA

Knowledge is power

Knowledge is empowerment

Do/feel differently - Increased BCA – self awareness and reflection to check breasts more consistently

Setting a date

Setting a reminder

Increased BCA – animation made me more aware

Past breast concern

Increased BCA – monthly checking

The reality of the confusion and worry between fibroma and benign mass

Previous confidence to seek medical help

Previous BCA – through NF charity position

Knowledge is power

Increased BCA – warning signs

Beyond the lump

Previous knowledge – checking once a month

Increased BCA – confidence in detecting changes

Beyond the lump

Increased BCA – screening eligibility

Animation correcting previous beliefs

Confusion of ages from reading information pertinent to other countries

UK ‘trying’ 40

Knowledge is empowerment

Beating misconception of breast cancer age

The importance of catching cancer early

Do/feel differently - Increased BCA – check for other warning signs

Beyond the lump

Confusion of screening age – confused information from charity

Memory from childhood remains

Assoc Increased BCA – risk

Assoc Personal experience of breast cancer – family friend

Assoc Motivation to be BCA – death of family friend to BC

Assoc Animation bridges a knowledge gap to be shared

Assoc Animation reinforces importance of seeking medical help for a breast concern

Assoc Animation highlights importance of BCA within an NF1 context

Assoc Increased BCA – in general for associate

Assoc Increased BCA – provision motivation for associate to be more BC aware

Assoc Increased BCA – screening eligibility

Assoc Perception of increased risk, screening should be earlier than 40 years

Assoc Increased BCA – monthly checking for daughter with NF1

Assoc Setting a reminder good for those who like a routine

Assoc Animation has provided the BCA information needed

Assoc Hearing it all for the first time

Assoc Precocious puberty

Assoc Animation increases confidence to speak with daughter about BCA

Assoc Animation opens channels of communication

Assoc Simple and clear

Assoc Previous knowledge of BCA (warning signs- general)

Assoc Power of BCA information available in public

Assoc Personal experience of cancer in family (BCA motivation)

Assoc Previous knowledge of increased risk

Assoc Increased BCA – screening eligibility

Assoc Animation empowers women with NF1 to go to the doctor

Assoc Animation as reassuring to seek help

Assoc Increased BCA – connection between increased risk and NF1

Assoc Increased BCA – earlier screening for women with NF1

Assoc Increased BCA – checking once a month

Assoc Increased BCA – screening

Assoc Increased BCA – risk

Assoc Increased BCA – earlier screening

Assoc Previous belief screening started younger with increased risk

Assoc Increased BCA – huge from animation

Assoc Increased BCA – risk

Assoc Learning about the connection of NF1 and BC

Assoc Increased BCA – screening eligibility

Assoc Knowledge is power and empowerment

Assoc Giving knowledge – giving power

Assoc Encouraging women to check – encouraging empowerment

Assoc Animation encouraged own personal BCA - checking

Assoc Increased BCA – general BCA (non NF1)

Assoc Increased BCA – beyond the lump

Assoc Confusion of fibroma versus malignant lump

Assoc Importance of vigilance within women with NF1 of body changes

Assoc Empowerment in vigilance

Assoc Previous BCA knowledge – risk

Assoc Only recent learning of risk

Assoc Increased BCA though CTT - risk

Assoc Knowledge is power and empowerment for her daughter

Assoc Checking once a month – reasonable

Assoc Creating a new behaviour to check

Assoc Becomes like on auto-pilot

Assoc BCA as natural

Assoc BCA as natural and automatic action

Assoc Increased BCA – knew of increased risk but not to what extent

Assoc Animation provides the 'ins and outs'

Assoc Increased BCA – five-fold risk figure

Assoc *Encouraging contacting HP* - No change - previous breast concern with partner

Assoc 'on the ball' for encouraging contacting HPs

Assoc Increased BCA – warning signs

Assoc Beyond the lump

Assoc Increased BCA – screening eligibility

Assoc Assumption of automatic access to breast screening

Assoc Solution finding - associate

Assoc Too late at 40 with tumours and NF1

Assoc Knowledge is power

Assoc Knowledge is empowerment to manage condition personally

Assoc Animation clearly explains importance of checking

Assoc Exposing the barriers to breast checking

Assoc Animation creates self reflection of own BCA – checking breasts frequency

Assoc Animation creates a consideration of personal plan to set a reminder – behaviour change

Assoc Animation makes me think, makes you think

Assoc Increased BCA – risk

Assoc Animation resets old thinking

Assoc Increased BCA – screening eligibility

Assoc Animation can bridge BCA knowledge gap

Assoc Empowering – get to know what's normal for you

Assoc Encouraging BCA in women with NF1 – the importance and how to do

Assoc Know what to look out for – giving power

Assoc Previous knowledge through CTT - Screening eligibility

Assoc *Do/feel differently* - More information to go on

Assoc *Taking part in research* - Gaining valuable information

'I can't be pushed away as I have been before' – tentatively planting the seeds of empowering thoughts, behaviours, and actions

Knowledge as empowerment ('myself' = ownership)

Empowerment through animation

Confidence – not a waste of time to check

Confidence to seek help through learning

Increased BCA – breast checking

Behaviour change – Checking once a month

Setting a reminder

Payday is breast day

Knowledge is power

Animation to empower others (daughter)

Increased BCA – Confidence

Increased BCA – self-efficacy

Knowledge is empowerment to check

Confidence to check if all is okay

Animation to fight against HPs' lack of knowledge

Taking part in research - BCA – not just something that can be ignored

I think I need to be more aware

Stop ignoring everything

Embracing the truth and actions of being BC aware with NF1

Do or feel differently

BCA – can be an inconvenience

BCA – not being taken seriously

BCA is the power to potentially stop a bad outcome

BCA and NF1 – power to potentially stop a bad outcome as a young woman

Take health more seriously

Loss of empowerment ('Do this', 'do that')

Awareness is a shared experience – sharing with child

Awareness is a shared experience – for child

Awareness is a shared experience – Reducing unmet needs for daughter

Assoc Empowerment through awareness – taking responsibility for yourself

Awareness is a shared experience - The desire to reduce unmet needs of others

Power and empowerment in taking part in research

Taking part in research – helping, being heard

The desire to reduce unmet needs of others

NF1 affects different people, and different places

Awareness is a shared experience – one participant voice helps gives a voice to those who cannot engage in research

Taking part in research - Awareness is a shared experience – raising awareness

Assoc *Taking part in research* - Helping 'spread the word'

Assoc *Taking part in research* - Research allows for rare disease lived experiences to be shared

Assoc *Taking part in research* - The hope of doing some good

Awareness is a shared experience – of condition

Help others

Assoc *Do/feel differently* - Help raise awareness of NF1 and BCA

Assoc Relatedness – researcher and participant

Assoc Desire to raise awareness

Assoc Eagerness – importance of raising and sharing awareness

Awareness is a shared experience - The desire to reduce unmet needs of others

Assoc Awareness is a shared experience – associate's awareness to share BCA screening and checking information

Awareness is a shared experience – watch together

Awareness is a shared experience - Easy to discuss with either family or professional

'It was safe' – Animation as a protective distance from breast taboos and scary facts

Breast cancer is a taboo subject

Seeing human breasts is taboo

Seeing human breasts is stressful

Animated breasts are not so taboo

Animation has the safety of a children's programme

Animated versus real body – no difference as a personal opinion

People are more comfortable watching animation

Watching animation offers more privacy to the topic

Not scary

Actual person's breasts embarrassing to watch

Breast cancer is scary

Real people means a really heavy message

Animation makes you think of childhood

Easier to digest a serious message

Animation is best to reassure young people

Animation suitable for young people

Allows for a different mindset

Animation format - Seeing 'live people's' breasts is uncomfortable

Animation format - Perception of more informal

Animation is more friendly to watch

Animation allows for clearer communication instead of using 'actual humans' (protective distance)

Animation is not scary

Animated format - More fun

Real-life humans makes it quite serious

Animation provides a protective distance

Animation provides an escape from reality

Animation makes watching more comfortable

Viewing real breasts is taboo

Assoc Animation opens channels of communication

Assoc Animation offers a protective distance

Assoc Seeing a real woman's body might be uncomfortable

Assoc Animation is less intimidating

Assoc Not frightening

Assoc Real people switch real people off

Assoc Real people make it morbid – cancer is morbid

Assoc Fun way for a real-life situation

Assoc *Animation encouraging BCA* - Animation as safe

Assoc Animation makes a serious message more fun

Assoc *Animation format* - Body as taboo

Assoc Animated character provides a protective distance

Assoc Animated helps break taboos

Assoc Animation reduces fear

Assoc Real life but not real life

Assoc Animation opens channels of communication

Assoc *Cartoon format* - Nonthreatening

Assoc A real person and their breasts are threatening

Barriers to being BCA - Fear of the increased risk of breast cancer

Facts in video might scare them

Avoidance of BC reality

‘it’s simple enough that anyone can follow it’ – animation format as an inclusive learning tool

Seeing real people is boring

A visual learner

The animation gets you more

No skimming

Animated interventions are eye catching

Animation keeps the eye on it

Animation paints a thousand words

Diversity of characters – not only one race with NF1

Animation keeps you ‘switched on’

Animation encouraging BCA - Encourages watcher to be more aware of NF1 information

Animated format - Easier to digest in animated format

Easier to understand

Webpage of information is difficult to read

Animation as inclusive

Animation works for all ages

Simple format means anyone can follow

Animation represents diversity – anyone can have NF1

NF1 is a shared experience

Anyone can have NF1

Encouraging BCA - Very simple

Brief

Clarifies what to look out for

Animation format – no advantage

Animation can reach a wide audience

Animation encouraging BCA - Right length – ‘Goldilocks effect’

Different methods of communication

Did a lot to get someone’s attention

Animated format - Provided accessibility

Accessible to different types of learners

Accessible to those with learning difficulties

Animation is not overwhelming

Goldilocks effect

Inclusive – suitable for all ages

Inclusive – for those with learning difficulties

Assoc Animation appropriate for younger ages

Assoc Animation helps open channels of communication

Assoc *Encouraging BCA* - Easy to understand

Assoc Easy to watch

Assoc *Animation format* - Helps with learning

Assoc Helps with understanding

Assoc Format encourages help seeking

Assoc *Animation encouraging BCA* - Short and accessible

Assoc Awareness is a shared experience

Assoc Accessibility with subtitles

Assoc Explains things clearly

Assoc Awareness is a shared experience – diversity in animation. NF1 can affect anyone

Assoc *Animation* - Not overly scientific

Assoc Exposes barriers to being BCA – checking breasts

Assoc Accessible learning tool

Assoc Easy to watch

Assoc Easy to understand

Assoc Encouraging

Assoc Not overly medical

Assoc Animated person could be any of us

Assoc Clear and easy to watch

Assoc Animation not patronising

Assoc *Animation format* - Sticks in the mind

Assoc Animation suitable for a younger woman

Assoc Animation as ‘informal’

Assoc Not too clinical

Assoc Easy to watch

Assoc *Cartoon format* - Acceptable for younger people

Assoc Not an old-fashioned style

Assoc Animation does not exert power over viewer

Assoc Animation creates a sense of free-will and personal choice to watch and learn

Assoc The sense of agency

Assoc The Goldilocks effect

Assoc Animation is really clever

Assoc Animation good for younger audience

Assoc Engaging

Assoc Speech bubbles – closed captions

Assoc The change of before and after

Assoc Interactive helps absorbing

Assoc *Taking part as a man* - Animation is inclusive for all and any viewers

Assoc Welcoming to all

Assoc Animation allows for a more realistic portrayal of NF1

Assoc Diagrams

Assoc *Animation encouraging BCA* - Keeping it simple

Assoc *Animation format* - Clear and simple

Assoc Animated breasts offer more uniformity

Awareness is a shared experience – for all ages

Awareness is a shared experience – watch together

Awareness is a shared experience - Easy to discuss with either family or professional

Ripple effects and shifting perspectives among associates

Them and us

Animation contributed to thinking from a different perspective

Seeing it from the woman with NF1’s perspective

BCA as a taboo subject – not talked about in normal conversations in families

Animation creates a consideration for women with NF1

Lack of BCA in general in associate

Lack of association of BC with young women

Taking part in research - Encouraged thinking from an NF1 perspective

Breaking the normalisation of NF1

Encouraged reflection of challenges of NF1

Lack of awareness of BCA of associate – frequency of breast checking

Them and us

The assumption that screening started earlier in young women with NF1

Nothing to base assumption on

Money the implied reason for screening only starting at 40 years

Why not earlier than 40 years?

Prevention is cheaper

Increased risk means increased encouragement to contact a HP

Supporting more than encouraging to contact a HP

Taking part in research - Concern for people with NF1

Animation beings an awareness of NF1 struggles – feeling of guilt as ‘Us’

However, awareness is a shared experience

Do/feel differently - Feel more concerned about increased risk

Feeling of being stuck with this new knowledge

Be ready to support

An important piece of work

Experience of definite urgency from associate from learning

Taking part in research - Focus of awareness on the increased risk

The shock of new information – risk

Do/feel differently - Reflection on personal experience of losing relatives to breast cancer

Importance of BCA for women with NF1 – personal motivation due to family loss

Knows the importance of catching things early and not leave things

Coming in from the outside

Them and Us

Assoc *Do/feel differently* - Personal behaviour change – setting a date for a reminder to check breasts

Assoc Confusion surrounding the screening process for NF1

Assoc Screening assumptions

Assoc Solution offering – access to screening

Assoc Patients having to be the right code to access services

Assoc HPs – power to give you the right code

Assoc Disconnected system

Assoc Assumption of a connected system

Assoc Assumption of ease of access to screening because of NF

Assoc The positive ripple effect of raising awareness

Assoc Contacting a HP is important for ALL women

Assoc Particularly women with NF1

Assoc Catching cancer early can make a big difference to outcome

Assoc Awareness as a shared experience – makes it an easier ride

Assoc Awareness is a shared experience – importance of BCA support

Assoc Putting a plan in place to encourage seeking help

Appendix AC

Iterative Coding Process of Breast-CAM-NF1 Participant Reflexive Section

Breast-CAM-NF1 Question: How was your experience of watching the NF1 breast cancer awareness intervention?

(e.g., How has it changed your awareness and attitudes, if at all? How has it made you feel?).

Please feel free to share anything about your experience.

Control Reassurance Keeping safe Notice changes Power and empowered	**YW** I feel a little more in control and reassured that my anxious checks aren't just that. They are there to ensure I keep myself safe and notice any changes
Nice and clear Breasts are embarrassing Takes taboo away Education of NF1 and BC risk Not scary Nice and clear Breasts are taboo Animation beats taboo Highlight of risk	**A** Nice and clear video, takes away the embarrassment of the subject and more importantly links it to NF1 and highlights the increased risk, but in a non scary way
Clear and to the point More confidence for young women to spot changes Tentative confidence to seek medical help Nice and clear Power and empowered	**A** think the video was very good, clear and to the point. It would give young womeIn with NF1 more confidence in what they need to be looking for and hopefully going to the doctor to get it checked.
Helpful	**YW** It was very helpful, and I would love to help make a change for young women! It

Awareness is shared – desire to help to make a change Helpful to know signs Power and empowered Nice and clear Informative Informative and clear	was also helpful to know what could be a sign.
Appropriate for younger people Easy to understand Easy for getting others to watch (not taboo?) Informative and clear Animation beats taboo	**YW** It's is more appropriate for younger people watch and easy to understand about changes and easy to get someone to watch it
Empowerment to check boobs more often Power and empowered	**YW** I've previously seen the GP as I did have some nf lumps/ skin tags that were really large on my breasts. I think the video made me realise I should check my boobs more often!
Learning about increased risk Shocking and worrying Important to be a confident checker Importance of earlier screening Highlight of risk Power and empowered	**A** I didn't know women with NF1 were at such an increased risk of having breast cancer. It is shocking and worrying, and it's important for women with NF1 to be confident about checking their breasts and to be screened regularly from an earlier age.
Confidence awareness is support Power and empowered	**A** I am more aware & more confident to support my daughter
Unawareness of risk Learning about increased risk relatively recently Pot luck of getting information Highlight of risk	**YW** The video was well done and well presented. I feel I already had relatively good knowledge of breast cancer. I feel the risk of breast cancer for people with nf1 should b discussed at a much younger age. I

Power and empowered Providing power and developing empowerment	was only made aware of it about 3 years ago when I went to get a pill check at a new clinic..
Learning about increased risk Highlight of risk	**YW** I didn't know that having nf1 increase my risk of breast cancer fivefold
Subtitles not seen – mobile phone? Previous awareness – family history of breast cancer Accessibility issues - subtitles	**YW** It was easy to explain and somewhat accessible. It might have been better if there were subtitles for those hard of hearing or with audio processing issues which can be a common thing in those with NF. It hasn't really changed how i feel as my family already has a history of breast cancer
Informative Informative and clear	**YW** Animation was very informative.
Screening wait Powerful system Powerful doctor Barriers to power and empowerment in a powerful system	**YW** I turned 40 last June and knew I was able to get breast screening because I have regular NF appointments with my 3 year old little girl and got told at these appointments that I should ask for screening. I don't believe we should have to ask for this we should just get offered it. I asked my Dr to refer me over 1 year ago now and I am still waiting!!
Amazing Informative and clear	**A** Amazing
Really easy watching Really informative Not patronising Informative and clear	**A** It was a brilliant video - really easy to watch, really informative and not at all patronising.

Providing power and developing empowerment	
Lack of NF1 knowledge of HPs Loosing battle Not being heard Young age a barrier Beneficial to explain ‘right way’ to check breasts Barriers to power and empowerment in a powerful system Continuing barriers to power and empowerment by a powerful system	**YW** Doctors still need to be educated and be made more aware of what NF1 is and the associated risks of having it. Its can be a loosing battle trying to push for things NF causes and puts you at risk, you aren't always listened to because of your age and doctors not understanding what nf is and the increased risk of other heath issues. I think it would be useful for the video to explain how to check your breasts as your always advised to check them but never been told the right way to do to it
Learning about increased risk Surprise of monthly checking - Lack of own BCA Burden of other health concerns to consider Reluctance to check with other concerns Highlight of risk An Increased awareness, particularly of an increased risk.	**A** I did not previously know about the increased risk of breast cancer for women with NF1, so I have definitely learnt something by watching the intervention video. I was not previously aware that women with NF1 should check their breasts once a month, so I was surprised at this frequency, and feel sad at the thought that women with NF1 would have to think about this risk so much/often. I understand why women with NF1 would feel nervous or reluctant to check, given that they often have other health concerns to think about too.
Learning about other warning signs	**A** It listed a few more things to look out for than I was aware of.

An Increased awareness, particularly of an increased risk.	
Informative Informative and clear	**A** yes a little bit very informative
Clear Encouraging for all to check breasts regularly Providing self-awareness Setting a reminder – learning from animation Informative and clear Providing power and developing empowerment	**A** I think it was a very clear animation that would encourage people with NF1 and those without to check their breasts regularly. Being the age I am and having had mammograms and finding cysts in my breasts I had pretty good idea of what to look out for before but a lot of younger people who haven't reached the age to have mammograms may not know as much information. I personally do not check my breasts as much as I should. This animation has made me think to look at them once a month either by having the same date eg 1st of the month or setting a reminder on the phone which was an idea I picked up from the animation.

Collation of codes

Control

Reassurance

Keeping safe

Notice changes

Nice and clear

Breasts are embarrassing

Takes taboo away

Education of NF1 and BC risk

Not scary

Clear and to the point

More confidence for young women to spot changes

Tentative confidence to seek medical help

Helpful

Awareness is shared – desire to help to make a change

Helpful to know signs

Appropriate for younger people

Easy to understand

Easy for getting others to watch (not taboo?)

Empowerment to check boobs more often

Learning about increased risk

Shocking and worrying

Important to be a confident checker

Importance of earlier screening

Confidence awareness is support

Unawareness of risk

Learning about increased risk relatively recently

Pot luck of getting information

Learning about increased risk

Subtitles not seen – mobile phone?

Previous awareness – family history of breast cancer

Informative

Screening wait

Powerful system

Powerful doctor

Amazing

Really easy watching

Really informative

Not patronising

Lack of NF1 knowledge of HPs

Loosing battle

Not being heard

Young age a barrier

Beneficial to explain ‘right way’ to check breasts

Learning about increased risk

Surprise of monthly checking - Lack of own BCA

Burden of other health concerns to consider

Reluctance to check with other concerns

Learning about other warning signs

Informative

Clear

Encouraging for all to check breasts regularly

Providing self-awareness

Setting a reminder – learning from animation

Appendix AD

The Development and Naming of Themes (Thematic Maps Included)

Step 5: Final theme decision process of Interviews

1. Broken knowledge breaks links in the system
2. Stuck within barriers of a powerful yet disconnected system
3. Patient having to be expert/teacher
4. The need for a learning culture of respectful curiosity and patient-centred benchmarks
5. Tentatively planting the seeds of powerful actions and empowering thinking
6. Animation provides the ins and outs beyond the lump
7. NF1 complexity – fibroma, cancer, or hormones?
8. An obvious diagnosis for an obvious sign
9. A Goldilocks animation for inclusive and engaging learning
10. Forging chain reactions from stronger links
11. Animation creates ripples to think about your own breast nipples
12. In another way, from another point of view
13. Breasts are taboo
14. Animation is a protective shield from taboo breasts and scary facts

Animation creates ripples to think about your own breast nipples

In another way, from another point of view

Creating shifts in associate perspectives, and ripples for their own nipples

Breasts are taboo

Animation is a protective shield from taboo breasts and scary facts

Keeping safe from taboo(bs) and scary facts by a friendly ‘cartoonish character’.

Broken knowledge breaks links in the system

Stuck within barriers of a powerful yet disconnected system

Broken knowledge and broken patient experts within a powerful yet disconnected health system.

Animation provides the ins and outs beyond the lump

NF1 complexity – fibroma, cancer, or hormones?

Animation moves knowledge beyond the lump...but watch out for other bumps along the way!

Tentatively planting the seeds of powerful actions and empowering thinking

‘I can’t be pushed away as I have been before!’ The tentative emergence of powerful actions and empowering thinking

Forging chain reactions from stronger links

Expanding awareness energy produces a sequence of positive chain reaction.

A Goldilocks animation for inclusive and engaging learning

Goldilocks and the three learning snares: Engagement, Clarity, and Inclusivity.

An obvious diagnosis for an obvious sign

‘I can tell by looking at you that you have the condition’: A potentially obvious diagnosis for a potentially obvious sign.

Final theme development

- **Tentative action and empowered thinking with learning beyond the lump.**

(includes ripples for their own nipples)

Learning beyond the lump: Risk, Warning signs

Action: Setting a reminder, checking breasts more frequently

Empowered thinking: Speaking up, be taken seriously

- **Keeping safe from taboo(bs) and scary facts by a ‘cartoonish character’.**

Protective distance

Breasts as taboo

Cancer as taboo

More comfortable to watch

Not as embarrassing

- **In the middle of a chain reaction: Stronger links to action through a shared awareness.**

(includes Shifts in associate perspectives)

The benefits of having the knowledge to share awareness

The urge to want to share awareness

One person’s learning can lead to another’s

The change of perspective for associates – being able to want to be involved

- **Broken knowledge and broken patient experts within a powerful disconnected system.**

How the patient has to be the expert all the time

Lack of knowledge is the barrier to accessing help and screening

System is not fit for purpose as it’s fragmented and does not help with those with rare diseases

- **Goldilocks and the three learning cares: Engaging design, content clarity, and deliberate inclusivity.**

(includes ‘I can tell by looking at you that you have the condition’: The potential for learning to spot a complex condition from a simple animation)

Engaging design

Content clarity

Deliberative inclusivity – a sense of belonging

Content of including brief snippet of café-au-lait macules may increase potential for diagnosis of NF1.

Grouping of codes – developing initial themes from Breast-CAM-NF1 Participant Reflexivity

Initial themes

1. Informative and clear – An informative and clear animation

2. Providing power and developing empowerment (as it is)

3. Animation beats taboo – beating the breast taboo

4. An Increased awareness, particularly of an increased risk (as it is)

5. Continuing barriers to power and empowerment by a powerful system (as it is)

Further theme development

1. **Providing power and developing empowerment.**
2. **Beating the breast taboo.**
3. **An Informative and clear animation.**
4. **An Increased awareness, particularly of an increased risk.**
5. **Continuing barriers to power and empowerment by a powerful system.**

Above highlighted in yellow on initial theme sheet (fed into final themes)

Providing power and developing empowerment.

Control

Reassurance

Keeping safe

More confidence for young women to spot changes

Tentative confidence to seek medical help

Awareness is shared – desire to help to make a change

Empowerment to check breasts more often

Confidence through awareness helps provide support

Not patronising

Encouraging for all to check breasts regularly

Providing self-awareness

Setting a reminder – learning from animation

Appropriate for younger people

Important to be a confident checker

Importance of earlier screening

Beating the breast taboo

Breasts are embarrassing

Takes taboo away

Not scary

Easy for others to watch (not taboo?)

An Informative and clear animation.

Nice and clear

Clear and to the point

Helpful

Helpful to know signs

Easy to understand

Subtitles not seen – mobile phone?

Informative

Amazing

Really easy watching

Really informative

Beneficial to explain 'right way' to check breasts

Informative

Clear

An Increased awareness, particularly of an increased risk.

Education of NF1 and BC risk

Learning about increased risk

Unawareness of risk

Learning about increased risk relatively recently

Learning about increased risk

Learning about other warning signs

Continuing barriers to power and empowerment.

Screening wait

Powerful system

Powerful doctor

Lack of NF1 knowledge of HPs

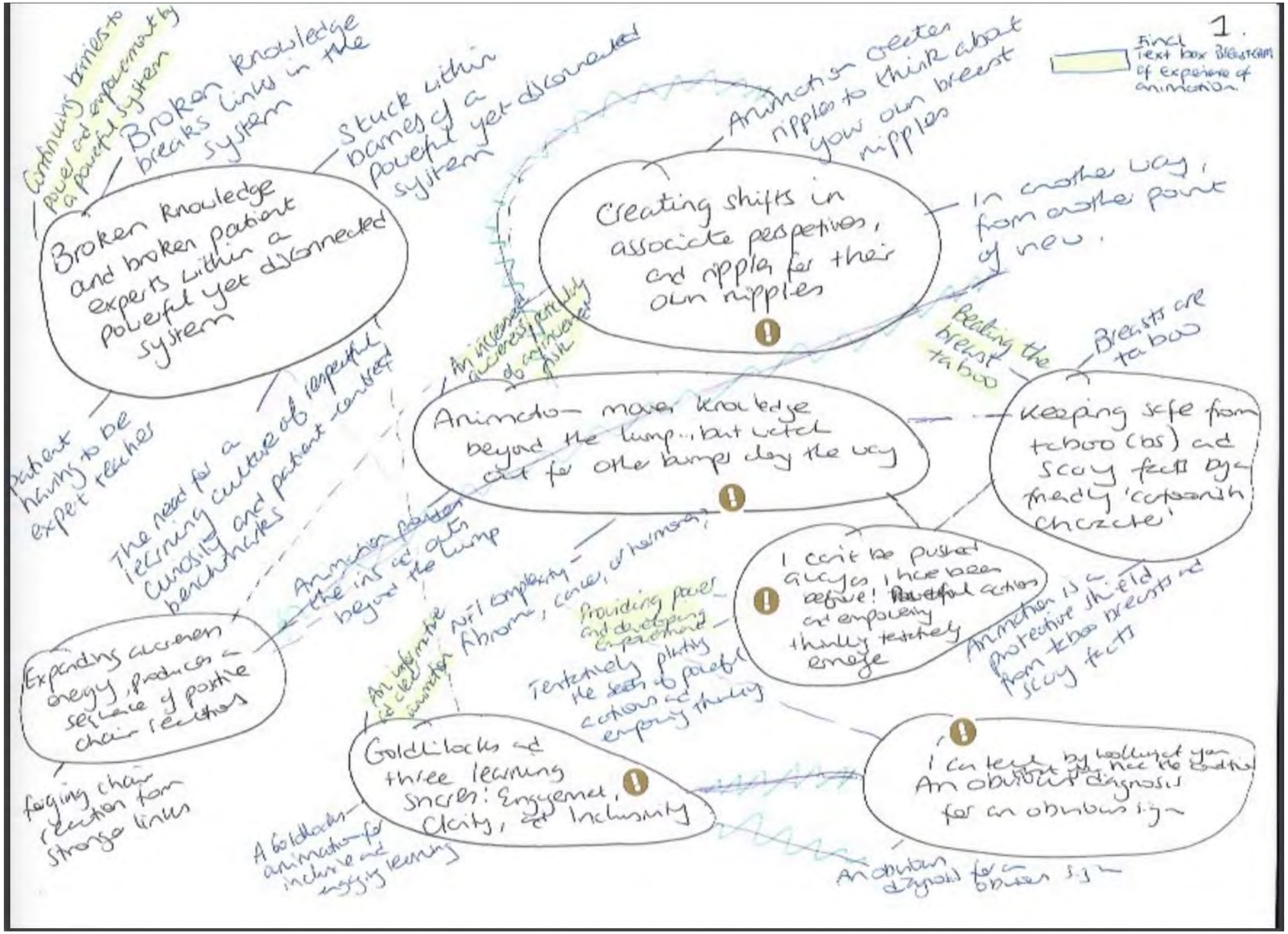
Loosing battle

Not being heard

Young age barrier

Surprise of monthly checking – lack of own BCA

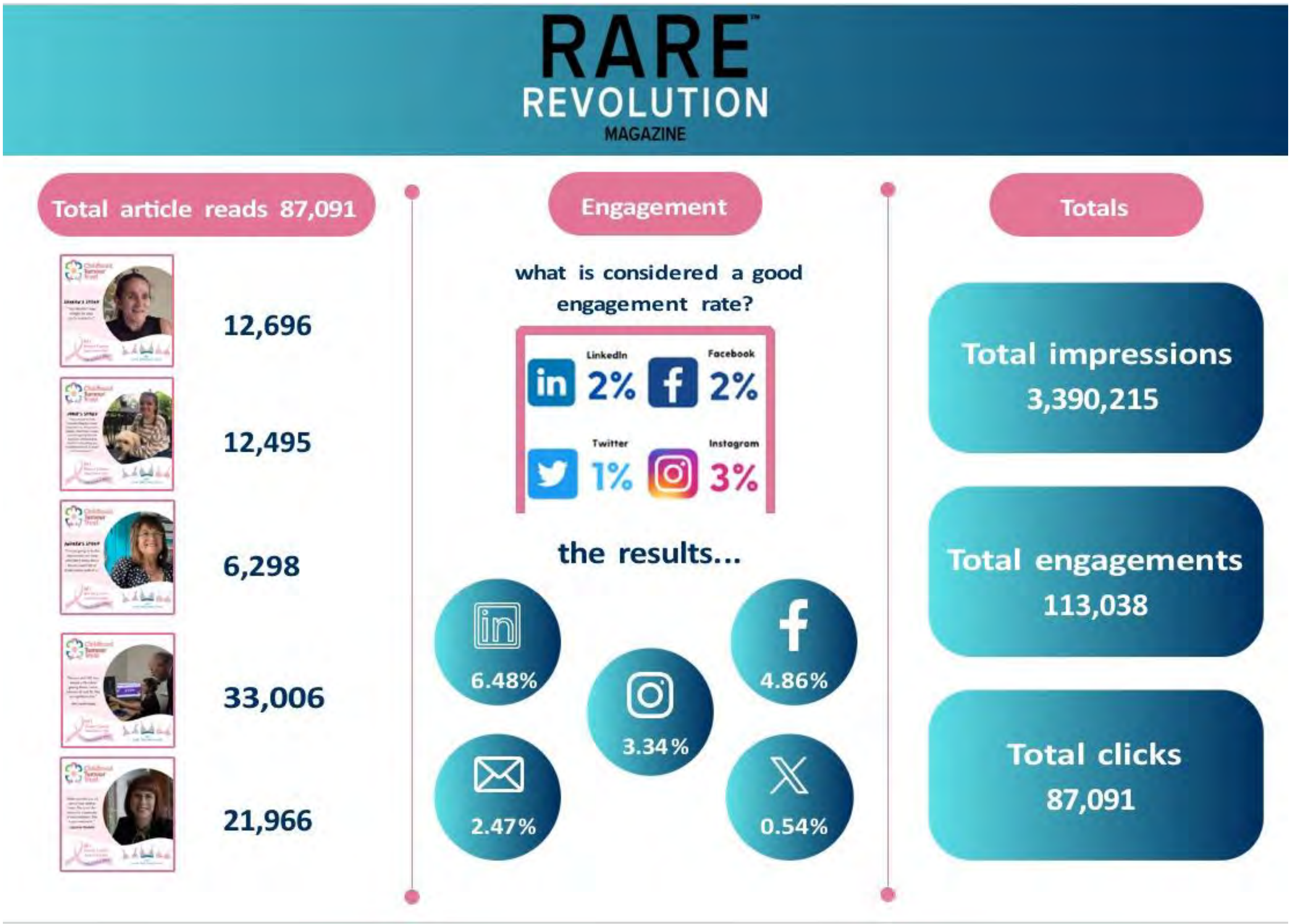
Burden of other health concerns to consider


1.
Final text box Brainstorm of experience of animation
Continuing barriers to power and empowerment by a powerful system
Broken knowledge breaks links in the system
Stuck within barriers of a powerful yet disconnected system
Broken knowledge and broken patient experts within a powerful yet disconnected system
Patient having to be expert teacher
The need for a learning culture of respectful curiosity and patient centred benchmarks
An increased awareness potentially of an informed risk
Animation creates ripples to think about your own breast ripples
Creating shifts in associate perspectives, and ripples for their own ripples
In another way, from another point of view.
Beating the breast taboo
Breasts are taboo
Animation moves knowledge beyond the lump... but watch out for other bumps along the way
Keeping safe from taboo (bs) and scary facts by a friendly 'cartoonish character'
Animation points the ins and outs beyond the lump
NF1 complexity – fibroma, cancer, or harmless?
Providing power and developing empowerment
Tentatively planting the seeds to powerful actions and empowering thinking
I can't be pushed always, I have been before! Powerful actions and empowering thinking tentatively emerge
Animation is a protective shield from taboo breasts and scary facts
Expending awareness energy, produces a sequence of positive chain reactions
Feigning chain reaction from stronger links
An informative and clear animation
Goldilocks and three learning snares: Engagement, Clarity, and Inclusivity
A Goldilocks animation for inclusive and engaging learning
I can tell by looking at you that you have the condition
An obvious diagnosis for an obvious sign
An obvious diagnosis for an obvious sign


2.
'I can't be pushed away as I have been before'! Powerful actions and empowering thinking tentatively emerge.
Ripples for their (associates) own ripples
Tentative action and empowered thinking with learning beyond the lump.
RESEARCH AIM
Explore the feasibility of a breast cancer awareness intervention for young women with NF1 and their associates
Keeping safe from taboo(bs) and scary facts by a 'cartoonish character'.
Breast cancer risk knowledge
warning signs
Broken knowledge and broken 'patient experts' within a powerful disconnected system.
In the middle of a chain reaction: Stronger links to action through a shared awareness.
Employing an animated format
Goldilocks and the three animation learning cores: Engaging design, content clarity, and inclusivity.
Creating shifts in associate perspectives
Increase self-efficacy to recognise and promptly seek medical consultation for a breast concern.
I can tell by looking at you that you have the condition': The potential for learning to spot a complex condition from a simple animation

Appendix AE

Rare Revolution Engagements



RARE™ REVOLUTION MAGAZINE

Total article reads 87,091

12,696

12,495

6,298

33,006

21,966

Engagement

what is considered a good engagement rate?

LinkedIn	Facebook
2%	2%

Twitter	Instagram
1%	3%

the results...

Totals

Total impressions
3,390,215

Total engagements
113,038

Total clicks
87,091