Understanding autistic communities need for substance use information: developing a pragmatic resource

D G ROBERTS

PhD 2022

Understanding autistic communities need for substance use information: developing a pragmatic resource

DAVID GWYN ROBERTS

A thesis submitted in partial fulfilment of the requirements of Manchester Metropolitan University for the degree of Doctor of Philosophy

Department of Psychology

Faculty of Health and Education

Manchester Metropolitan University

2022

Acknowledgements

First and foremost, I would like to thank all of the participants who took the time to contribute to my project. Words cannot express how grateful I am for all the support received. I would also like to thank all the charities and organisations that helped me with recruitment, particularly Autistica, who were a great help in accessing autistic communities.

I would like to thank my Director of Studies, Dr. Jennifer McGahan, for all the support and encouragement throughout my time at Manchester Metropolitan University. I owe you a debt of gratitude for believing in me (even when I didn't) and always taking the time to help. Speaking of debts of gratitude, I also owe one to my supervisor, Dr, Jo Ashby. I would like to thank her for all her guidance and for awakening a love for qualitative research methodologies in me. I wish to recognise my supervisors, Elaine Reeves and Dr. Jeremy Oldfield, as well as Manchester Metropolitan University itself for all the help and support I have received.

Finally, I would like to thanks my family, friends and partner for supporting me throughout these years. I hope I don't have to say in words how much you all mean to me, because if I did, I'd require another hundred pages!

Contents

Abstract

Substance use and addiction are not typically first considered when discussing autism and the needs of autistic people. However, recent research has highlighted that autistic people do use substances and that they may be at an increased risk of developing substance-related problems compared to neurotypical people. Currently, there is very little to no support or information specifically tailored or targeted for autistic people, despite some motivations and presentations of substance-related problems being unique or highly specific to autistic communities (i.e., using substances for social camouflage). The current project aimed to address this by developing an online psychoeducational resource specifically tailored for and informed by autistic adults. The project was spilt into three stages, which adopted a pragmatic paradigm, was qualitative in nature and was analysed using summative qualitative content analysis and reflexive thematic analysis. The first stage encompassed the pre-development of the resource and consisted of an online structured interview, which sought to explore the preferences and needs for an educational resource on substance-related topics from autistic adults. The findings from this stage formed the basis for the second stage, which was the development of the resource itself. The final stage occurred post-development of the resource, which consisted of semi-structured interviews with autistic adults and parents of autistic people who provided feedback on the resource as well as discussions around their own experiences of substances. The resource developed was titled "Alcohol and Drug Information for Autistic Adults" (ADIFA: www.adifa.co.uk). This is currently, one of, if not, the only educational resource developed specifically for and informed by this community on substance-related topics. Autistic adults who participated in the project stated the importance of, and the need for, more pragmatic research to be undertaken in this area. Future directions for this project could be the quantitative evaluation of ADIFA for autistic adults and further research projects on substance-related issues in autistic communities, particularly employing participatory or co-production methodologies.

Introduction

Context of the Research Area

When considering autism, and topics that affect autistic people, substance use and addiction are not usually considered. This is because research into autism tends to focus more on the development and presentations of autism, with a particular focus on autistic children. However, more research is emerging on autistic adults and topics associated with adulthood. This includes research into employment, sexual relationships and substance use.

Previous research tended to dismiss substance-related problems as absent or a rare occurrence in autistic people, however, more recent evidence suggests the exact opposite. It appears that substance use and substance-related problems are more common than previously thought and may even be an under-explored and under-acknowledged area of autistic research literature. Despite an increase of interest in this area, there is little research on pragmatic support for autistic people on substance-related topics, and even fewer pragmatic resources for autistic people to use. As such, more research, in particular, pragmatically-focused research, is needed on this topic

Researcher’s Interest

My interest in the area of substance use and substance-related problems originated in my psychology undergraduate course. One of the areas I was most interested in, was in the unexpected presentation of behavioural addictions in some people with Parkinson’s disease due to the medication designed to slow the progress of the disease. This led me to complete a Masters’ degree in applied psychology of addiction. During my studies, I was interested in exploring substance-related problems and behavioural addictions in communities that were under-represented in the literature. This was how I came to initially explore the area of substance use in autistic people. In my studies, I believed that there was more research that could be conducted in this area, particularly in regards to providing information or support for autistic people.

While I myself am not autistic, my brother is. From his experiences, it was clear that there was a gap in the support autistic adults can receive compared to autistic children. What pragmatic support that could be provided on adult-related topics (such as employment), was tailored more towards autistic people with additional needs (such as a learning disability or difficulty). This was reflected in the experiences of my disabled family members and friends. Pragmatic support and information was not readily available to them, and if it was, it was not necessarily appropriate for their needs. As such, my research interests tend to focus more on pragmatism, and how knowledge and research can be used to develop appropriate support and interventions for disabled or autistic communities.

Overview of the thesis structure

Chapter One:

The purpose of this chapter was to provide a critical literature review of research relating to autism and substance use and substance-related problems. The chapter begins by discussing what autism is, the common co-occurrences, and the prevalence of substance-related problems in autistic individuals. Following this, there is a discussion on the types of support available for autistic people, and how information and support can be tailored for autistic people. Finally, the chapter concludes with a discussion on psychoeducational resources and the research object for the PhD project; the development of an educational resource on substance-related topics designed specifically for and informed by autistic adults

Chapter Two:

The purpose of this chapter was to detail the methodology of the PhD project and the thought-process behind each methodological decision. The chapter begins by discussing the importance of research with practical outcomes before describing the pragmatic approach the project took. The selection of an appropriate implementational framework was then discussed and the philosophical position of the researcher were detailed. The chapter is concluded by a description of the design of each stage of the project.

Chapter Three:

The purpose of this chapter was to explore the perspectives, preferences and needs of autistic adults in relation to educational material on substance-related topics. This was done through a structured online interview, which was completed by 59 autistic adults, and was analysed using summative qualitative content analysis.

Chapter Four:

The purpose of this chapter was to detail the decisions made in the development of the educational resource. This chapter detailed the thought process and decision making that informed the production of the resource. Each of the suggestions and findings from the previous stage were considered, and if incorporated, the description was accompanied with screen shots used to display how it was implemented.

Chapter Five:

The purpose of this chapter was to gain the insights and perspectives from autistic adults and parents of autistic children on their experiences with the resource. This was achieved through semi-structured interviews. The interviews could be conducted online (through Microsoft Teams) or by email. There were 10 participants in total, half of whom had direct, personal experiences with alcohol, drugs or both. The majority of participants were autistic (7 of the 10) and the majority of participants were a parent to an autistic child (7 of the 10). Half of the participants conducted the interview over through Microsoft Teams, with the interviews lasting between 18 minutes to just over an hour.

Chapter Six:

The purpose of this chapter was to holistically discuss the PhD project. The chapter begins by discussing the implications for the approach and methodology utilised through the PhD project. The chapter then discusses each stage of the project and discusses the context and the implications of the findings from each stage.

Chapter One: Literature Review

1.0. Defining autism

Autism Spectrum Condition (ASC), also known as Autism Spectrum Disorder (ASD) or autism, is a multifaceted neurodevelopment condition that is characterised by significant impairments in reciprocal social interactions and communications, repetitive and restricted behaviours and interests, and atypical sensory processing (American Psychiatric Association, 2013). Autism is a fairly common condition, as there are reported to be around 700,000 autistic people living within the UK (National Autistic Society, 2016).

According to the latest Diagnostic and Statistics Manual (DSM-5), autism is referred to as a spectrum, with those considered to display either "mild", "moderate" or "severe" symptomology (American Psychiatric Association, 2013). This means that presentations are unique to each individual, and that their experiences are different, with some autistic individuals requiring little or no support to those requiring support more regularly. There is also a great deal of variance within these categories of "severe", "moderate" and "mild", meaning personalised care can be complicated (Masi et al., 2017). In addition to the heterogenous nature of autism, there is also a high prevalence rate for the co-occurrence of other neurodevelopmental conditions, particularly of attention deficit hyperactivity disorder (ADHD) and learning disabilities (Zauche et al., 2017; Gillberg et al., 2016).

Attention deficit hyperactivity disorder (ADHD) is a distinct condition from autism characterised by symptoms of hyperactivity, impulsion and inattention (American Psychiatric Association, 2013). In previous versions of the Diagnostic and Statistics Manual, autism and ADHD were considered to be exclusion criterions for diagnosis of each other’s conditions, meaning these conditions were studied in isolation to one another. However, subsequent research has highlighted considerable overlaps in autism and ADHD, including cognitive profiles (Karalunas et al., 2018), brain characteristics (Rommelse et al., 2017), and in clinical practise (Grzadzinski et al., 2016). As a result, autism and ADHD can be diagnosed as co-occurring within the latest Diagnostic and Statistics Manual (American Psychiatric Association, 2013). Due to this late recognition, awareness and understanding of co-occurring autism and ADHD is less established and as such prevalence rates are varied. However, a recent meta-analysis reported a prevalence rate of 21% for co-occurring autism and ADHD within children and adolescents (Hollingdale et al., 2020).

“Learning disability” is the official term used by the UK healthcare system, which is the equivalent to the internationally used term “intellectual disability” (American Psychiatric Association, 2013; WHO, 2016; Green, 2018). A learning disability is defined as a reduced intellectual ability and difficulty with everyday tasks, which can be mild, moderate or severe/profound dependent on the symptomology displayed by the individual (Mencap, no date). Although prevalence rates differ from study to study, a population study using whole country data from a UK Census found a population prevalence for individuals with co-occurring autism and learning disabilities of 1.08/1000 (Dunn et al., 2019). Within autistic populations, Autistica (no date) report that approximately 40% of autistic individuals have a learning disability. Given the high co-occurrence of both these conditions (ADHD and learning disabilities), research into autism should consider and incorporate the participation of both of these co-occurring groups in order to better reflect autistic populations as a whole.

Although symptoms of autism generally emerge in early childhood, it is important to note that autism is recognised as a lifelong condition, in which different experiences and challenges may be faced during adulthood (Lord et al., 2018). For example, autistic adults have trouble gaining and sustaining employment (Taylor et al., 2015; Frank et al., 2018), often experience feelings of social isolation and loneliness (Jackson et al., 2018), and are at a high risk of co-occurring mental health conditions, particularly anxiety and depressive conditions (Hollocks et al., 2019). As such, sufficient attention should be addressed into support, education and interventions designed for autistic individuals on topics relating to adulthood.

2.0. Substance use and problems in autistic populations

2.1. Previous attitudes and current thinking

The terminology for describing substance use and the problems associated with it are varied and have been subject to change. For example, substance use, substance abuse, substance misuse and substance dependence are all terms that have been used to describe various degrees of substance use, however, often these terms can be ill-defined or used interchangeably (Wakefield, 2015; Mahmoud et al., 2017). Although the Diagnostic and Statistics Manual previously referred to substance dependence and substance abuse separately, the latest version uses the single term "substance use disorder", which can be classed as either mild, moderate or severe depending on the number of diagnostic criteria met by the individual (American Psychiatric Association, 2013). Substance use is a term still widely used as it can refer to use more generally, as not all individuals who engage with substances will necessarily have problems associated with its use.

One growing area in the literature on substance use is in relation to autism. Previous research suggested that substance use and substance use disorders were uncommon in autistic individuals (Ramos et al., 2013; Woodbury-Smith et al., 2006). This was believed to be due to the social and communication deficits characteristic of autism, which were suggested to act as a protective factor in engaging with and having problems related to substances (Santosh & Mijovic, 2006). Furthermore, where substance use disorders were observed in autistic individuals, it was believed to be accounted for by the co-morbidity of another condition, namely ADHD (Palmqvist et al., 2014; Ramos et al., 2013).

However, more recent research has challenged this idea, suggesting that substance use and substance use disorders in autism may be more frequent than previously thought (Rengit et al., 2016).

Two population-based twin studies indicated that there may be a link between autism and substance use. Lundstron et al. (2011), looked at the relationship between autistic-like traits, measured by questions based on the diagnostic criteria relating to autism in the DSM-4, and a range of health-related problems, such as anxiety, depression and substance use, in 18, 349 adult twins. The questions assessing autistic-like traits were scored and participants were divided into one of 6 groups. They found that the percentage of reported substance use problems increased in accordance with each group, meaning the group with the highest scores for autistic-related traits also had the highest percentage of substance use problems (Lundstron et al., 2011). While this does suggest a positive association between autism and substance use disorders, the measure for substance use problems was a single dichotomous question of ‘Do you have or have you ever had problems with alcohol or drugs?’ (Lundstron et al., 2011:2426). This means that the measure for substance use may be oversimplified and allows for the participants’ subjective interpretation of a what constitutes a substance problem.

Following this, de Alwis et al. (2014) looked at the relationship between both substance use and substance use disorders with autistic-like traits in 3, 080 adult twins. Each substance (tobacco, alcohol and cannabis) included was defined according to use, with substance use described as ever having tried the substance, regular/repeated use defined as using the substance a certain number of times during a certain time period, and substance use disorders defined by endorsing a certain number of criteria in the relevant section of the DSM-4. Autistic-like traits were assessed using a questionnaire based on the DSM-4 criterion, mainly related to reciprocal social interaction, but also stereotyped/repetitive behaviours and communication impairment to a lesser degree. They found substance use disorders across all types of substances (tobacco, alcohol and cannabis) were associated with higher scores of autistic-like traits (de Alwis et al., 2014). In addition, only tobacco use was associated with higher scores of autistic-like traits, but not cannabis or alcohol use or repeated use.

Both of these studies show that autism and substance use disorders may be linked. However, both of these studies only looked at *traits* of autism meaning this link may not be reflected in individuals with a diagnosis of autism.

The largest and most comprehensive research conducted into this topic was Butwicka et al. (2017), who looked at the prevalence of substance-use related problems in individuals *diagnosed* as autism. Substance-use related problems were described as encompassing one or more of the following: a substance use disorder, any conviction for a substance-related crime, substance related death, and alcohol-related somatic diseases. A total of 26, 986 individuals with a diagnosis of autism were identified from longitudinal, population-based registers and compared with 1, 349, 300 non-autistic individuals who were matched on sex, birth year, and country of birth. They found that autistic individuals had a substantially and significantly higher risk of any substance use-related problems compared to non-autistic individuals (4% for autistic individuals compared to 1.3% for non-autistic individuals), particularly for substance use disorders. When analysed further, they found that while individuals with a diagnosis of just autism had increased risk for all substance-use related problems, autistic individuals with co-occurring ADHD or ADHD and learning disabilities had an even higher risk of substance-use related problems (Butwicka et al., 2017). The findings from this study contradicts earlier held beliefs about autism and substance use and supports the idea that autistic individuals are at an increased risk for substance use disorders. Additionally, it is important to note that this study was the first in this area to compare against the general population. While autistic individuals with co-occurring ADHD may be at an even greater risk, it is important to note that autistic individuals without a co-occurring condition were still at an elevated risk of substance use disorders. This is important as it is conflicts with suggestions by earlier research that substance use in autistic populations can be explained by co-occurring ADHD (Palmqvist et al., 2014). Furthermore, the previously reported extremely high risk in autistic individuals with co-occurring ADHD may be due in part to biases in diagnoses. To explore this in their sample, Butwicka et al. (2017), performed sensitivity analysis on substance-use related problems separately for autistic individuals who received all neuropsychiatric diagnoses (autism, ADHD, learning disabilities) *before* a diagnosis of substance use disorder. They found comparable risks of substance use-related problems with "just" autistic individuals and autistic individuals with co-occurring ADHD (Butwicka et al., 2017). This suggests that there may be some discrepancy or unintentional biases with subsequent diagnoses if substance use disorder is diagnosed prior to any neurodevelopmental condition.

A recent systematic review of the risk and protective factors associated with substance use and autism found that autistic individuals are susceptible to the same common risk factors that the general population are, including familiar history of substance use disorders, early substance use, certain co-occurring conditions (anxiety, ADHD, oppositional defiance disorders), psychological distress, and adverse family events (Ressel et al., 2020). This suggests that risks for substance use disorders are shared by autistic individuals and autistic individuals are more at risk than previously thought. In addition to this, a qualitative study with autistic participants diagnosed with a substance use disorder reported their inclinations for substance use to be socially motivated, indicating a desire for social contact and inclusion (Clarke et al., 2016). This is in direct contradiction to previous beliefs that autistic individuals are dissuaded from substance use as they have little inclination for social engagement (Santosh & Mijovic, 2006). Furthermore, certain substances are relatively accessible and don't require high-demanding social skills for their purchase. This could be why alcohol and cannabis are the most frequent substances to be abused in autistic populations (Lugo-Marin et al., 2019).

Not only are autistic individuals susceptible to the same risk factors as the general population, the previously mentioned systematic review also found specific autism related risk factors; low social support, late diagnosis of autism, weak executive functioning, and disengaging coping behaviours were identified as risk factors for substance use disorders that are more likely to occur in, or unique to, autistic individuals (Ressel et al., 2020). This highlights the need for autism focused and tailored support in order to address the unique autism-specific risk factors.

2.2. Prevalence in co-occurring condition

The presentation of substance use disorders in autistic individuals within clinical settings varies from study to study (Arnevik, & Helverschou, 2016). This reflects the spectrum nature of autism, and suggests that a particular subpopulation is at a greater risk of substance use disorders. For example, in a systematic review by Arnevik & Heverschou (2016), they found that co-occurring substance use disorders are more likely to occur in individuals with higher cognitive functioning or those with “mild” autistic symptomology. In addition, autistic individuals who are more socially motivated have been found to be at greater risk of substance use disorders, as they are often more socially engaged than those without substance-related problems (Sizoo et al., 2009). However, it is unclear whether this is a reason for or a consequence of substance use. As previously mentioned, autism can often co-occur with other neurodevelopmental and psychiatric conditions, in particular, ADHD and learning disabilities (e.g. Zauche et al., 2017; Gillberg et al., 2016). It is important to consider how these additional co-occurring conditions may influence substance use in autistic individuals and whether their presence may help in explaining the variation in clinical settings.

One consistent finding in autism and substance use research is that autistic individuals with co-occurring ADHD have the highest rates of substance use disorders compared to other autistic populations (Butwicka et al., 2017; Solberg et al., 2019; Ressel et al., 2020). This is not surprising, as there is substantial research to suggest that individuals with ADHD (regardless of any co-occurring conditions) have an increased risk of developing substance use disorders (Lee et al., 2011; van Emmerik-van Oortmerssen et al., 2012). This suggests autistic individuals with co-occurring ADHD are the most at risk of substance use disorders and are the group in the greatest need of autism-specific substance use support.

Another condition that could influence substance use and substance use disorders is co-occurring learning disabilities. Mild or borderline learning disabilities are thought to be a risk factor in substance use disorders (van Duijvenbode et al., 2015). Due to limited research and a lack of consistent characteristics for participant samples, prevalence rates of substance use disorders in autistic populations vary considerably from 0.5-21% (van Duijvenbode et al., 2015). Although under-researched, preliminary evidence suggests autistic individuals with co-occurring learning disabilities are not at an increased risk of substance use disorders. For example, Butwicka et al. (2017) found that out of all the autistic populations included, co-occurring ADHD was associated with further increased risk of substance use disorders, whereas, co-occurring learning disabilities were associated with a lower risk. In fact, a recent systematic review reported co-occurring learning disabilities as a potential protective factor for the development of substance use disorders in autistic individuals (Ressel et al., 2020). However, research into this topic is multifaceted, and methods may not distinguish between the severity of the learning disability as well as complications in diagnosing learning disabilities in autistic individuals. Despite this, there are those in this population who do have substance use disorders. One such case study accounted the treatment of an autistic adult with co-occurring learning disabilities and alcohol dependence (Drake et al., 2018). The researchers detailed significant difficulties in treatment for this individual in which it took 18 months to establish a suitable strategy that combined psychoeducation, psychological assessment, outcome monitoring and ultimately, strict restrictions in their tenancy. Additionally, the researcher highlighted this population as poorly understood and under researched. This suggests that there is very little appropriate and effective help available for this population and the clinicians treating them.

Given the high prevalence rates of substance use disorders for autistic individuals with co-occurring ADHD, and the potential challenges in treatment and support for those with co-occurring learning disabilities, research into autism and substance use should aim to incorporate those with co-occurring ADHD and/or learning disabilities.

3.0. Motivations for substance use and problems

3.1. Camouflaging

Interestingly, the motivations for substance use in autism may be unique to their condition. One such theory that may apply to substance use is the idea of social camouflaging. This is defined as the use of strategies by autistic people to minimise the visibility of their autism during social situations and interactions (Lai et al., 2011). Camouflaging is driven by a desire to appear non-autistic, to “fit in”, and form relationships with others, through the use of conscious or unconscious techniques in order to “mask” their autistic characteristics (Hull et al., 2017). Tentative research suggests that substances are a technique employed to facilitate social camouflaging. For example, some autistic adults have indicated using alcohol to camouflage their autism in order to “fit in” in social situations, such as in feigning an interest in conversation topics they had no interest in (Bargiela et al., 2016; Clarke et al., 2016). Furthermore, Kronenberg et al. (2015) found that autistic individuals may use substances (particularly alcohol) in order to help manage their autistic symptoms in social situations, making them feel more relaxed, focused and less agitated. This suggests that autistic individuals may use substances as a coping mechanism to mitigate or mask their symptoms in order to adapt more easily to their surroundings. Interestingly, this display of a “normal” façade by autistic adults when they drink alcohol, may help explain why their alcohol dependency is not better diagnosed (Lalanne et al., 2015). In the cases studies discussed, developmental illnesses (ADHD & autism) were difficult to detect and received delayed diagnosis due to the individual using substances to improve their neurocognitive abilities (Lalanne et al., 2015). This suggests the hidden nature of substance use in autistic adults, as diagnosis of substance use disorders and even autism itself may go undetected due to substances masking symptoms.

3.2. Self-Medication

Another theory that may apply to autistic individuals is the self-medication hypothesis. This hypothesis was first developed in order to help explain the high co-morbidity of mood and anxiety disorders and substance use (Khantzian, 1985). This theory proposes that substances are used in order to alleviate and moderate psychological distress (Khantzian, 1985). There is support to suggest that some individuals from various clinical groups do engage with substances in order to alleviate negative mood, fluctuations in mood, and anxiety (Shadur et al., 2015; Turner et al., 2018). This may apply to autistic individuals, as anxiety, both generally and socially-specific, and depression are common problems within this population (Hollocks et al., 2019). In support of this, a qualitative study in which interviews were conducted with autistic adults and a co-occurring diagnosis of a substance use disorder identified that they used substances in order to help self-medicate their psychological distress (Clarke et al., 2016). They reported using substances in order to blunt the emotional responses to their negative self-appraisals, to reduce the accessibility of memories that may fuel such negative appraisals, or to generally improve their mood and perceptions of the world around them (Clarke et al., 2016). Research such as this highlights the use of substances to self-medicate the negative effects felt by the individual specifically relating to symptoms of their autism. However, the use of camouflaging and self-medication are not mutually exclusive. In fact, Clarke et al. (2016) identified the presence of both mechanisms in autistic individuals with a substance use disorder. This suggests that motives for substance use in autistic individuals is multi-faceted, and that use may be related to autism-specific experiences and challenges.

As well as qualitative measures, there has been some research into the quantification of substance use motivation for autistic individuals. Guimarães (2019) states that usually, autistic individuals experience mesothalamic dopaminergic hypoactivity, which is thought to hinder attentional shift, enhancing attentional high focusing and mental rigidity that are common characteristics in autism. Guimarães (2019) proposes that exposure to alcohol stimulates this area allowing for cognitive flexibility and less rigid focusing in autistic individuals. This may be why autistic individuals are more susceptible to alcohol-related problems and why alcohol may be an effective coping mechanism for such individuals until the alcohol becomes a problem itself. Additionally, this study suggests that attentional focus is important in the susceptibility to substance use for this population. However, this theory only applies to alcohol-related behaviours and not substance use as a whole in autism.

3.3. Environmental and sub-group factors

Interestingly, functions for substance use may differ between autistic sub-groups. Kronenberg et al., (2015) found that autistic individuals with ADHD sought mainly a calming, tranquil effect from their substance use, whereas, autistic individuals without ADHD sought a variety of different functions, ranging from social facilitation to forgetting their problems and getting over frustrations. This further suggests the complex motivations behind substance use for autistic individuals and that co-occurring conditions may present their own unique motivations for substance use.

Environmental factors may also influence substance use and abuse for autistic populations. For example, those with more pronounced, severe symptoms of autism (as opposed to those with mild symptomology) may require greater levels of care and/or live in specialist care units, therefore find access to substances challenging (Nylander et al., 2018). This may help to explain why those with mild symptomology are more likely to engage with substances than those with more severe symptomology. Furthermore, unemployment, difficulties in gaining employment, and coping with the pressures of employment have also been suggested as factors in substance use and abuse in autistic individuals (Lalanne et al., 2015). This could be particularly important, as autistic individuals have relatively low employment rates.

4.0. Current support and interventions for autistic adults

4.1. General support available

In general terms, autistic adults have identified a need for more medical services and supports, particularly for those who live outside of supported living facilities (Dudley et al., 2019). Autistic adults have indicated that they have unmet service needs in general and that service needs actually increase with age, therefore requiring support targeted at autistic adults (Dudley et al., 2019). Additionally, autistic adults have also identified perceived barriers to support, including judgement and stigma from neurotypical therapists, specific to treatment and support with substance-related problems (Brosnan & Adams, 2020). This is particularly important, as most interventions are aimed at young autistic children and adolescents.

In regards to substance-related support and information for autistic individuals, many traditional interventions involve aspects that may not be effective for these populations. For example, current popular therapies for substance abuse involve reciprocal and often group social interaction, which may not be the most effective course of action for supporting autistic individuals who typically struggle with these types of interactions (Rengit et al., 2016). This is mirrored by Brown (2018), who identified a need for “reasonable adjustments” for substance use services specifically for autistic individuals, with a particular focus of service engagement from autistic individuals. More generally, those with similar neurodevelopmental disorders are disinclined to use mainstream substance abuse services, preferring to use related disability services which often lack the ability to provide substance abuse and use related support (Taggart et al., 2007). Research such as these highlight the importance of developing or tailoring substance use support and information specifically for autistic individuals.

The current process for seeking support and treatment for substance use disorders in the UK is geographically dependant, as changes over the past decade have resulted in the devolution of responsibility to local areas for treatment (Clinical Guidelines on Drug Misuse and Dependence, 2017). According to the NHS and related sites, individuals struggling with substance use seeking support should first either go to their GP or self-refer to their local substance use services (NHS, 2019; FRANK, no date). Individuals will then be assessed and a treatment plan will be offered. The treatment plan should be reflective of the individual's circumstances and specific needs, which could provide the potential for discussions around co-occurring conditions, such as autism. However, a fairly recent systematic review noted that screening for substance use disorders in autistic individuals is not common in routine assessments within psychiatric settings, whereas, many other conditions (e.g. ADHD) in the same settings are becoming increasingly screened for substance use disorders (Arnevik & Helverschou, 2016). Interestingly however, within the UK government's guidelines on substance use disorder, there is a mention of autism and is as follows:

> *"All young people with significant drug and alcohol problems receive a comprehensive assessment of their mental health, including for issues of self-harm, autistic spectrum disorders, hyperactivity disorders..." (Clinical Guidelines on Drug Misuse and Dependence, 2017: 247).*

However, it is interesting to note that the guidelines only refer to this screening for "young people" with "significant" problems, suggesting that this is not common practise for all but the most severe cases. The inclusion of autism in the UK guidelines, while brief and ambiguous, does act as an acknowledgement that more specific or tailored support might be required and should be provided for autistic individuals with a substance use disorder.

While greater acknowledgement and provision of care for autistic adults on substance use and addiction is required, one barrier health professionals—and autistic adults themselves—may face is in distinguishing between substance use and addiction. Substance-related problems are usually diagnosed from a neurotypical perspective. This is an issue as motivations for substance use expressed by autistic adults are linked to presentations and/or experiences of autism and autistic people (e.g., camouflaging to "fit in" with neurotypical society). This means that diagnosis of substance-related problems may be difficult in autistic communities as they are not presented within a neurotypical framework. While there is no research on the identification of substance-related problems in autistic communities, health professionals have expressed difficulty in identifying other health conditions in autistic individuals—such as trauma and PTSD—due to a lack of understanding of how they may present in autistic communities (Kildahl et al., 2020). Tailored educational resources on alcohol, drugs and addiction topics could help not only autistic individuals better understand their relationships with substances but may help neurotypical health professionals better understand how problems may be presented within autistic communities.

4.2. Autism specific substance intervention research

To date there are only two studies that have tackled this issue in practice. Helverschou et al. (2019) aimed to improve services for autistic individuals and co-occurring substance use disorders by enhancing the competence of therapists in substance-related outpatient clinics. The therapists were given monthly group education and supervision by a psychologist with extended experience in the field of autism, in which characteristics of autism and how to conduct and adjust therapy for autistic audiences were discussed. Seven autistic individuals with a co-occurring substance use disorder were referred for participation and were given cognitive behavioural therapy (CBT), which the therapists had modified for an autistic audience. Three participants ended treatment before it was finished resulting in a final participant sample of four. Post-treatment results were mixed, as two of the individuals had ended their drug use completely, one individual had reduced their drug use and the final individual still had heavy alcohol use. While definitive conclusions cannot be established due to the small sample, this preliminary study does suggest that modifications for autistic audiences to substance abuse treatments are feasible and can be effective. However, it is uncertain whether the outcomes from this study would remain over time as there was no long term follow up. Additionally, adjustments were made for the therapists and did not take into consideration the perspective or preference of the autistic individual. Accommodating interventions and support more for the individual may result in improved results and a higher completion rate.

The second study to address substance-related problems treatments for autistic people was conducted by Walhout et al., (2022). This study also focused on the use of CBT as a treatment option for alcohol or drug problems. While the process of employing an adapted CBT programme was similar to the study conducted by Helverschou et al. (2019), this study included one significant difference; The CBT was delivered in a group setting, with the patient groups consisting of autistic adults. The results were positive, as participants reported lower levels of alcohol use and substance cravings. Additionally, participants reported a change in their coping styles, employing more social support coping styles than before the intervention. This research indicates the benefits of tailoring support for autistic adults. In particular, incorporating a group dynamic consisting of autistic adults resulted in a supportive environment. Inclusion of more interventions involving autistic groups could help in providing a more conducive environment for treatment of substance-related problems for this group.

While they may have used a different approach to the two aforementioned studies, Brosnan & Adams (2022) also addressed adaptations to substance use therapies. Their approach differed from the previously mentioned studies as they aimed to produce actionable guidelines for therapists to implement in their sessions. This was achieved through an online survey of drug and alcohol therapist to explore their thoughts and experiences followed by a focus group comprised of autistic individuals and members of the wider autistic community (e.g., family members). This approached resulted in a list of guidelines recommended for use by therapist in sessions with autistic clients. Furthermore, a "top ten tips" of how the guidelines could be successfully implemented by the therapists was developed by the autistic focus group. This demonstrates how inclusion of autistic voices and within the development of adaptations can lead to more comprehensive results.

5.0. Tailoring information for autistic adults

5.1. Involvement of family

Strategies and interventions should consider the wants – in addition to the needs – of the autistic individual when designing said tools (Anderson et al., 2019). This is particularly important as many autistic adults and their families want research priority to focus on lifespan issues (such as life and social skills training), which is contradictory to the areas that receive the greatest funding and attention (Gotham et al., 2015). This is echoed in a review on post-secondary support for autistic individuals, in which the review described a lack of support featured that autistic individuals say they often prefer, such as sensory friendly spaces and practices (Anderson et al., 2019). This suggests that without involving or asking the perspectives and preferences of autistic individuals a potential resource may not be greatly received or adequately used. Furthermore, research suggests that the social networks of autistic adults is fairly restricted, with family members providing support throughout adulthood (van Asselt-Goverts et al., 2015; Marsack & Samuel, 2017). This suggests that input from family members – particularly parents – is important in developing resources for autistic adults, as they provide social and practical support for their relative and would have a keen insight on what would be helpful or unhelpful. Furthermore, many current support and interventions include participation from both the autistic individual and their family, with group, family centred approaches (e.g., Gordon et al., 2015; Patra et al., 2015). This suggests that potential resources should be accessible for both the autistic individual and their family.

5.2. Medium of intervention delivery

One particular adjustment that could be made for resources and interventions for autistic adults is the medium in which it is delivered. Internet-based support has been suggested to be beneficial for autistic individuals (Backman et al., 2018). Internet-based information and support for substance-related topics and issues would be useful as a first point of call, as Brosnan & Adams (2020) found online resources were the most commonly selected resources for autistic adults seeking support with problem drinking.

Advantages of this format for autistic individuals include increased flexibility and accessibility, greater immediacy (not having to go through intermediaries), ability to communicate from their own homes, and communicating through the written word (Sehlin et al., 2018). Furthermore, intervention effectiveness is not diminished as internet-delivered interventions have been shown to have high treatment credibility and good clinical feasibility for autistic audiences (Backman et al., 2018). In fact, interventions and support delivered online can be just as or even more beneficial than traditional face to face methods. For example, Roberts et al. (2019) found that an online sleep behaviour education program for parents of autistic children was just as effective as when the program was delivered face-to-face. Additionally, parents who took part in the online version of the program also showed more decreases in parental fatigue than the face-to-face group, which could be due to a reduction in travel time and the convenience of having the program online.

While online resources and interventions may not replace face-to-face methods altogether, they appear to be useful for this population and can be a beneficial supplement to the more traditional methods. Additionally, parents of autistic children report that the internet is one of their main sources of information and support in relation to autism (Hall et al., 2016). However, concerns are raised over the quality of the information they might find and interestingly, some disadvantaged parents prefer not to engage with more rigorous and quality resources as they are viewed as being too complicated or confusing to be helpful (Hall et al., 2016). This highlights the beneficial impact a quality and accessible online resource on substance use and abuse for autistic individuals and their families may be.

The medium of delivery should also be considered in the recruitment of autistic adults for research projects in this area. Clarke et al. (2016), reported difficulty in traditional interviewing with autistic adults about substance use, due to the verbal format of the interview and the challenges participants faced in voicing their experiences in this format. They recommended the use of alternative, perhaps online, qualitative interview techniques. In support of this, challenges with the traditional interview format for autistic participants has been found in other research areas (e.g. McDougall et al., 2018). For example, the use of an online qualitative survey has been used successfully in gaining the perspectives of autistic participants (Camm-Crosbie et al., 2019).

6.0. The current project

The review of the literature highlights that despite the growing acknowledgement of substance use and abuse problems among autistic communities, there has been little research in the area of support for this group. Of particular concern, is the lack of any practical support or information specifically designed for autistic audiences. The literature review has highlighted potential strategies preferred by autistic individuals, which could be utilised when creating accessible information on this topic for autistic individuals.

Although the literature review has highlighted potential strategies preferred by autistic populations (such as online media), there is no information on whether such strategies would be preferable for information on the topic of substance use and abuse. As such, the purpose of the PhD project is to address this area. This was achieved via a single research aim:

- To develop an educational resource on substance-related topics designed specifically for and informed by autistic adults

To achieve this aim, several research objectives were created and are as follows:

- To gather information on the presentation of information autistic adults prefer to engage with
- To gather information on the substance use-related content that would be of interest for autistic adults
- To gather information on the experiences and feedback of the resource titled, “alcohol and drug information for autistic adults (ADIFA) from autistic adults and parents of autistic adults.

Chapter Two: Holistic methodology of the PhD Project

Overview

As discussed in Chapter One, the overall aim of the PhD project was to address the lack of tailored support or information for autistic adults on alcohol and drug use and related problems.

The aim of Chapter Two is to detail the methodology used in the project for Stage One and the methodological considerations more generally. In order to achieve this, discussions around the approach, theories, participants and philosophical position are presented. The chapter then concludes detailing the design of the research projects to be conducted.

1.0. Approach

1.1. Knowledge to practice gap

The focus of the current project is the development and production of a pragmatic educational resource to be used by autistic adults. As highlighted in Chapter One, autistic adults and their family members have identified the need for researchers to develop more pragmatic resources and interventions (Gotham et al., 2015). However, it is not easy to produce quality research focused on pragmatic outcomes, as this type of research presents its own challenges and complications. In fact, a gap between knowledge and practice has been identified across different projects and disciplines (Lipschitz et al., 2019; Doumas et al., 2019; Sanetti & Collier-Meek, 2019). For example, in their study developing an implementation plan, Kennedy et al. (2020), summarised the knowledge to practice dilemma they faced; research had demonstrated the therapeutic potential of exercise for people with cancer, but an effective process to connect patients to effective programs was missing. Similarly, research has indicated that there is a lack of educational information for autistic adults on substance topics, however, autistic adults are only provided with standard resources not tailored or reflective of their needs. This highlights the importance in the development of effective processes and resources or interventions appropriate for the intended users. In order to bridge the knowledge to practice gap and develop an appropriate and usable resource, each decision involved in the methodology needed to reflect and address this problem.

1.2. Pragmatic Approach

One of the first considerations needed was in relation to the research paradigm or philosophical position. As detailed by Saunders et al. (2015), in their conceptualisation of research methodology, the philosophical position or paradigm forms the foundation of the research project and details the set of beliefs the researcher and research project employs. The traditional paradigms can be considered as opposite ends of a continuum, with positivism at one end and interpretivism at the other end (Heeks et al., 2019). They are often described as opposing views. Positivism proposes that "reality" exists externally and independently of people, which can be measured objectively and can produce generalisations; Interpretivism proposes that "reality" does not exist externally but is socially constructed and given meaning by people (Heeks et al., 2019).

Each position can usually be summarised by the type of measures used, with positivist projects usually encompassing quantitative measure and interpretivist projects employing qualitative measures. However, neither of these positions fully address the practical focus of the current project. A strictly positivist position would not be adequate in incorporating the perspectives and viewpoints of autistic adults, whereas, a strictly interpretivist position would not fully allow generalisability of perspectives to inform the specific development of the resource. To develop an appropriate and informed resource, a combination of the two positions was required.

Pragmatism is a philosophical paradigm that can be viewed as a compromise between positivism and interpretivism. Pragmatism is concerned with the saliency of thoughts, words and situations to address and solve problems (Kaushik & Walsh, 2019). As its name suggests, this paradigm is pragmatic in nature and is concerned with using knowledge actively and with purpose, whether that be through a function or application, to describe the world in an action-oriented manner, or in the discovery between action and knowledge itself (da Silva et al., 2018). The pragmatism paradigm originated in the 1900s, primarily from the work of James (1907). In more contemporary literature, the pragmatic paradigm has been used successfully in projects where the focus was on an actionable production. For example, pragmatism paradigm has been successfully employed in the contexts of patient-oriented research (Allemang et al., 2021), social work research (Kaushik & Walsh, 2019) and education research (Panerai et al., 2019). Furthermore, pragmatic research does not rely on an "either, or" approach to the research measures. Pragmatic research is often mixed methods and can combine elements from both qualitative and quantitative measures (Yvonne Feilzer, 2010). Adopting a pragmatic paradigm was deemed as appropriate for the current project because the aim of the current project (to develop an educational resource) required the gathering of actionable knowledge, that could be applied to said development. Additionally, the ability to incorporate a mixed methods design would provide the development with actionable research from autistic adults' perspectives that could be generalised and applied to the resource.

1.3. Implementational Science

One of the core principles of the current project is the practical application of its findings and implementation of knowledge into a fully formed and functional educational resource. As such, the approach and methods across the different stages of the project had to appropriately address and incorporate this principle. One way to do this was through the considering various frameworks or models that can be utilised to support the implementation of the project.

Implementation science was borne to address how research can be created and used to achieve more evidence-based practices (Bauer & Kirchner, 2020). In recent years, more focus has been brought to the theoretical bases to implementation and the strategies and frameworks used to achieve implementation. Nilsen (2015) discussed the different theoretical models and frameworks in this field and created a classification of five groups: process models, determinant frameworks, classic theories, implementation theories, and evaluation frameworks. In broad terms, process models are concerned with describing and/or guiding the process of translating research into practice; determinant frameworks, classical theories, and implementation theories, all focus on understanding or explaining what influences the outcomes of implementation; evaluation frameworks provide a structure for evaluating implementation endeavours (Nilsen, 2015).

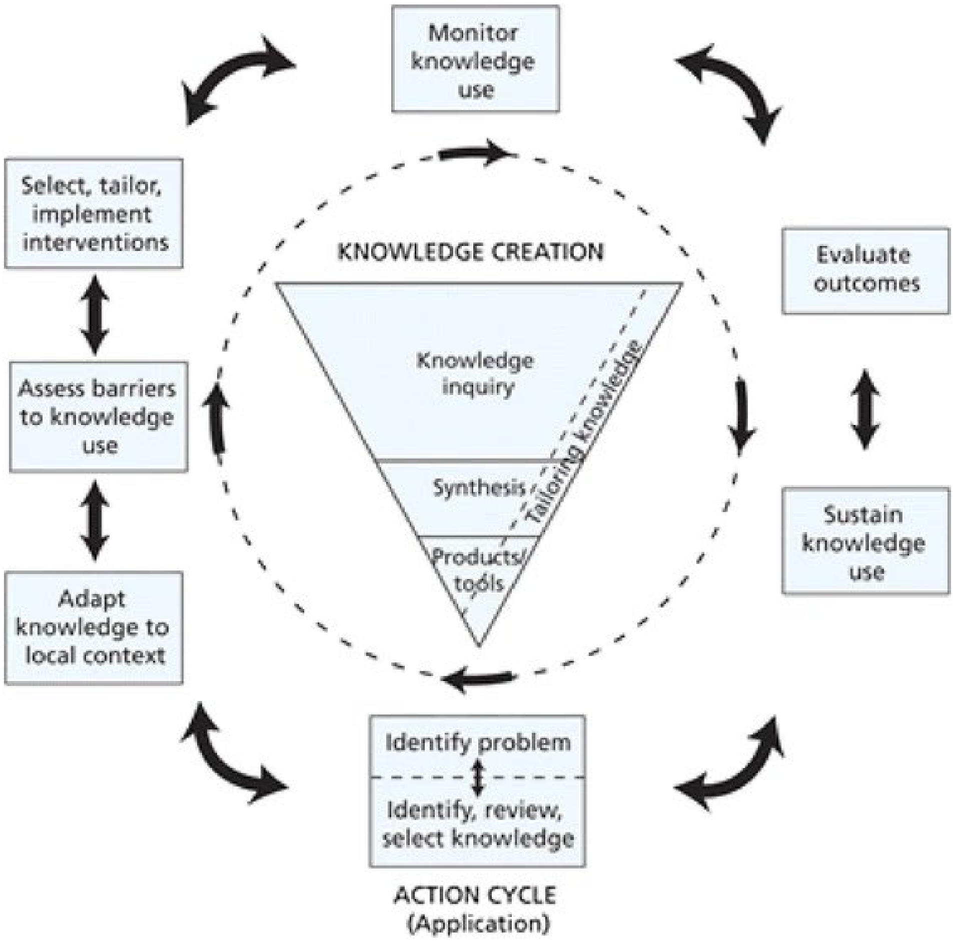
The current project lends itself to adoption through a process model. This is because the main outcome is the development of a fully formed educational resource that has been guided by the translation of the knowledge gained and findings produced in the research projects conducted in the relevant stages.

1.4. Knowledge to Action Framework

One such process model is the knowledge to action framework also known as the KTA framework (Graham et al., 2006). The KTA framework was developed to address the confusing and numerous implementation concepts and terminology by creating a conceptual framework that can be used/consulted to successfully translate knowledge into sustainable, evidence-based interventions. The KTA framework is encompassed by two distinct, but connected components: knowledge creation and action cycle (displayed in figure 1). Each of these components contain several phases that overlap. The phases can be iterative as each phase of the components can inform the other, can be completed

separately or simultaneously, and do not require the use of every phase. As the original authors state, the phases can be "dynamic…can influence each other" (p. 20; Graham et al., 2006).

Figure 1) The Knowledge to Action Framework



From Graham et al. 2006. Lost in knowledge translation: time for a map? *The Journal of Continuing Education in the Health Professions*, 26, p. 19.

The knowledge creation component is concerned with the production and synthesis of knowledge, becoming more refined, summarised and user-friendly as it moves through the different phases. The three phases are knowledge inquiry (obtaining knowledge from primary studies), knowledge synthesis (collection and interpretation of results from primary sources within a more holistic context), and knowledge creation (tools/products that present synthesised materials into user-friendly formats tailored to meet the end user's information needs).

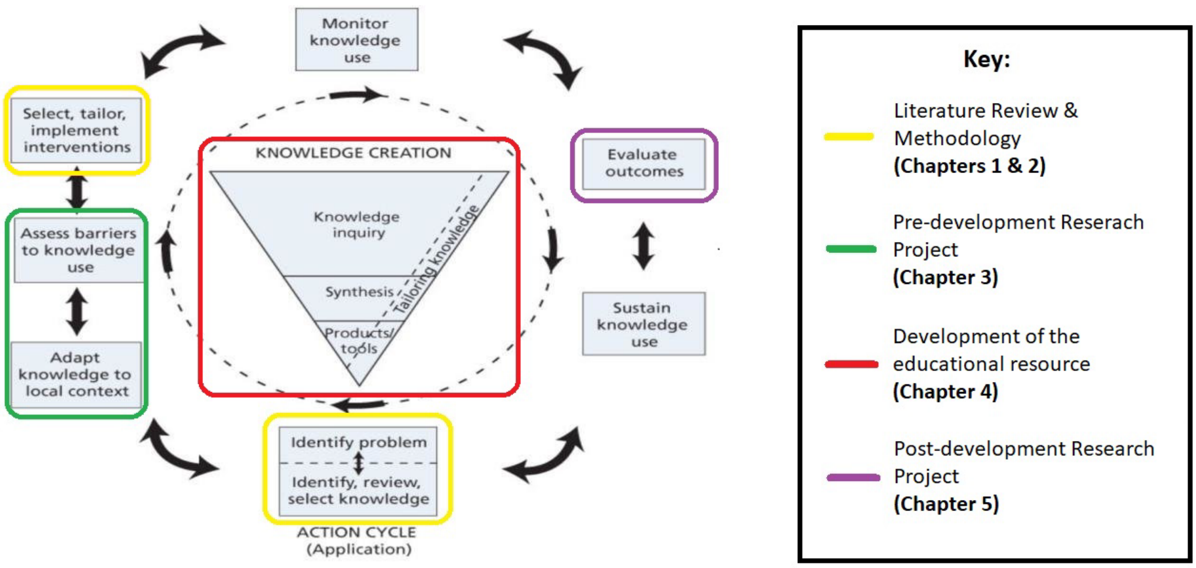
The seven phases in the action cycle outline processes and activities, which are needed for successful implementation of knowledge into applied practice (for reference to the current project, see figure 2). Identification of the problem is the typical starting point for implementation and involves reviewing what is known about the problem/area and whether there is a gap that needs to be addressed. Two closely related and crucial phases are adaption of knowledge to local context and assessment of barriers/facilitators to knowledge use. These phases involve knowing the audience—exploring their perspectives and insights into a particular area of knowledge—and what factors can inhibit engagement with such knowledge. Of particular importance for these phases are the perspectives of the audiences or “stakeholders” who will be the recipients for the implementation of the particular knowledge. Another phase is to select, tailor, and implement an intervention to deliver the implemented knowledge.

The intervention itself is not limited by a particular medium or mode and can take the form such as: educational (passive or active strategies), organisational or patient directed. Once the intervention has been delivered, the use of knowledge can be monitored through qualitative or quantitative measures in order to determine whether the intervention has been successful in regards to the target audience. The final two phases refer to evaluating the knowledge implementation strategy used itself and assessing how or if the knowledge imparted is sustained over a period of time.

1.5. Application of KTA framework within the PhD project

The KTA framework can be applied and considered in all stages of the PhD project. The application of the FTA framework and its relation to each Chapter and stage is detailed in figure 2.

Figure 2) The Knowledge to Action framework and its implementation within the PhD project



In regards to the knowledge creation component of the KTA framework, it can be applied to the current project in regards to the development and dissemination of the educational resource for autistic adults on the topic of alcohol/drugs. The content for the resource is supplied from primary sources (knowledge inquiry), evaluated and combined to create a holistic resource (knowledge synthesis), and finally composed into a tailored and user-friendly resource for the use of autistic adults (knowledge tools/products).

The phases in the action cycle are used to help achieve the knowledge creation component. The different aspects of the action cycle can be applied in order to provide the current project with an over-arching structure, in order to best achieve the aim of developing an educational resource for autistic communities. The literature review in Chapter One was used to evaluate the area of alcohol/drugs topics in autistic populations and identified the lack of support and information on this topic for this population and identified the gap for the PhD project to explore (identify problem – identify, review, select knowledge). The purpose of Chapter Three is to understand from autistic adults' perspectives the focus and presentation of content for the proposed resource (adapt knowledge to local content) and what would help to engage with such a resource (access barriers to knowledge use). Chapter Four is concerned with the development of said resource, implementing the results of the previous chapter (select, tailor, implement interventions). The purpose of chapter five is to evaluate the resource by engaging with the target population, autistic adults (evaluate outcomes).

The KTA framework is an established and highly cited conceptual framework (Field et al., 2014). While the framework has been used widely, one study that uses this framework is particularly relevant as it contains several similarities to the current project. Soloman et al. (2018), looked at the development of an online, educational resource to act as a rehabilitation guide for people living with HIV. The study employed a three-stage participatory process; stage one involved perspectives from clinicians and people with HIV for recommendations on how to best adapt content for people with HIV; stage two consisted of the adaptation to the online resource based on the results from the previous stage; stage three involved a comprehensive review of the newly adapted resource by people with HIV and clinicians (Soloman et al, 2018).

The authors used the framework to help guide the process for gathering data and in their analyses. They found that participants were predominately positive of the resource. They were able to provide the resource with information and experiences that they, as the indented user, would find useful and engaging. In fact, the authors noted that several participants were either currently using or had plans to use the resource developed. One participant had used the resource to find employment, another used it to select an appropriate therapist, and several other participants had shared the resource within their communities (Soloman et al., 2018). This demonstrates how the KTA framework can successfully help develop resources. The authors also noted that the KTA framework was a useful way for them as a researcher to conceptualise the steps involved in the stages of development (Soloman et al., 2018).

While the target population and topic of the resource may be different, the structure outlined by Soloman et al. (2018), is similar to the process outline in the current project. More specifically, both projects begin with gaining the perspectives of the intended users' pre-development, using the findings to develop the resource, followed by gaining the feedback and evaluations of the resource post-development from the community intended for its use. The successful use of the KTA framework in a research study with a similar approach—in addition to the study reporting favourable experiences with its use in delivering a tailored, practical resource—lend credence to the application of the KTA framework for the current project. Consideration of the implementation and application throughout the development of an educational resource is crucial to its success. The KTA framework provides a practical guide to achieve this implementation.

2.0. Educational approach for the resource

In order to provide the most appropriate resource for the intended audience, the educational approach needs to be considered. One such approach that could be utilised is a psychoeducation design.

2.1. Definition of psychoeducation

Psychoeducation is a well-established approach dating back to the 1980s when it was initially introduced as an intervention for individuals with schizophrenia and their families. Anderson et al. (1980) argued individuals with schizophrenia are vulnerable to overstimulating environments and prone to relapse and as such, required a targeted approach incorporating information about the condition. This was thought important in equipping such individuals and their families with the knowledge to neutralise the precipitators of relapse and reduce the negative stigma around the condition. The components of this approach are as follows: briefing the individual on their condition, problem-solving training, communication and self-assertiveness training, and involvement of family members in the treatment process (Anderson et al., 1980). The definition and use of the psychoeducation approach have expanded since the 1980s, and whilst no universal definition exists, psychoeducation generally refers to the act of imparting knowledge to individuals about a particular condition enabling them to acquire competencies to manage a condition (Bonsack et al., 2015). This can take the form of simply imparting facts and information for the individual or a more intense process aimed at facilitating psychological change for the individual through absorption of the information and application to themselves and their lives (Gordon et al., 2015). Additionally, there are two different approaches to psychoeducation; active and passive. Active psychoeducation incorporates the present involvement of a therapist or "coach" with the individual and/or their family during the process, whereas, passive psychoeducation requires the self-assimilation of materials provided to the individual and/or their family (Sarkhel et al., 2020).

2.2. Tailored delivery of psychoeducational information

Much like the definition, there is no standard, universal medium of psychoeducation. The delivery can vary between conditions and purpose, ranging from group to individual, face-to-face through to a smart-phone application (e.g. Hidalgo-Mazzei et al., 2015; Donker et al., 2009). This flexibility in delivery offers the opportunity for psychoeducational materials and interventions to be tailored or developed specifically in mind of their audience and their potential needs, creating the most appropriate and accessible resource necessary. Despite this, research on psychoeducation and autism is limited. Most research studies focus on the parents of autistic individuals, sometimes with their young autistic children (e.g. Palmer et al., 2020; Patra et al., 2015). However, the few studies that did look at the experiences of the autistic individual, were positive. For example, one group-based psychoeducation programme on enhancing self-awareness of autism found that participants aged 9-

14 years old had more general knowledge on autism, greater awareness of their unique strengths and difficulties, and did not negatively impact their self-confidence (Gordon et al., 2015). Similarly, an educational intervention created for autistic adolescents and young adults (aged 16-25) to educate them about autism, resulted in a significant improvement of knowledge from pre-intervention to post-intervention (Backman et al., 2018). Furthermore, the psychoeducational programme was internet-based and delivered entirely online. This mode of delivery was found to be highly accessible (Backman et al., 2018). This suggests that not only can psychoeducation be a useful and effective resource for autistic individuals, but can also allow for greater accessibility through the flexibility of delivery.

While active psychoeducation may be considered more beneficial in regards to behaviour change (Tang et al., 2018), passive psychoeducation is by no means ineffectual. In fact, passive psychoeducation can have a modest effect on behaviour or attitude change (Donker et al., 2009), and can greatly increase subject knowledge (Bridges et al., 2015). Furthermore, passive psychoeducation materials are immensely practical, as they can be easily disseminated, require little cost, and have the potential to reach a much greater audience than active psychoeducation (Donker et al., 2009). As such, passive psychoeducation can provide a useful starting point for individuals and families who wish to seek help or who wish to expand their knowledge of a particular topic. Furthermore, this passive resource would be important as a form of self-help or self-advocacy, as many autistic individuals indicate a preference for tackling issues on their own and that they should have access to the necessary resources to do so (Kronenberg et al., 2015). This is particularly important for sensitive topics (such as substance use) as their wishes and desire to live how they want may differ from their parents or families wishes (Young et al., 2020). Given that there is no tailored information for autistic individuals on the topic of substance use and abuse and their preferences for online material, the development and dissemination of a passive psychoeducational resource could be a useful, first step in providing support and information for autistic individuals on this issue.

Psychoeducational practice for autistic individuals with co-occurring ADHD was recently discussed within a wider framework by a multidisciplinary group of clinical and academic professions with extensive experience within this field (Young et al., 2020). The expert consensus reported the benefit of using psychoeducational interventions and resources in improving the experiences of and long-term outcomes for this population, and suggested the use of psychoeducation as an important precursor to other interventions, both medical and therapeutic (Young et al., 2020). In support of this, Vasa et al., (2016) recommended psychoeducational of symptomology as an important first step and precursor to other treatments of anxiety in the autistic youth. This highlights the importance of psychoeducation as a first step towards treatment for a variety of different issues. Additionally, the topics of the psychoeducational should be relative to the audience, with psychoeducation for young people and adults addressing additional topics of sexual education, pregnancy, and alcohol and illicit drug use and consequences (Young et al., 2020). The issue of audience has also been discussed in other psychoeducational programmes. For example, in a recent feasibility study for a parental support programme, despite parents reporting positive views on the programme, the materials and the format, thematic analysis identified that some parents felt parts of the information taught did not apply to their autistic child (Palmer at al., 2020). This is due to the heterogenous nature of autism, and as such, a one-fit all approach isn't applicable. This supports the notion that for a psychoeducational intervention or resource to be successful, focus on the perspectives of the intended audience should be taken into consideration throughout the creation, development, and evaluation of the resource/intervention.

To date, there are no studies explicitly asking autistic adults and their family members on their preferences for psychoeducational resources. Studies have looked at feedback from autistic family members on a particular psychoeducational resource or intervention, but not asked for their general preferences in engaging with such material or the content prior to the resource/intervention being created (e.g. Palmer et al., 2020). Additionally, these studies are usually directed towards parents of young autistic children, meaning the perspective of autistic adults is neglected. This highlights the need for more research to explicitly look into the preferences of autistic families, particularly autistic adults, on psychoeducational resources and interventions at different stages of the process of development.

2.3. Psychoeducation & brief interventions

An alternative approach that could be chosen for the current resource is a brief intervention design. Brief intervention refers to an intervention or technique that aims to change an unhealthy or risky behaviour (such as alcohol consumption) in a structured and client-centred way (Mattoo et al., 2018). Specifically in substance-related behaviours, brief interventions are based on harm reduction, aiming to reduce an individuals' substance consumption to safe levels (Mattoo et al., 2018). Interestingly, brief interventions may contain psychoeducational aspects, but the primary focus is inciting or enabling behavioural change from its audience (e.g., Vasko et al., 2019). The length of the intervention depends on the design (e.g., single or multiple sessions) and it can be delivered in person or through online methods (e.g., Copeland et al., 2017). In their study comparing an online brief intervention for cannabis use with a more, extended, feedback-oriented intervention, Copeland et al. (2017) found that in the short term, brief interventions were just as effective as longer, more reciprocal interventions at reducing cannabis use and related problems.

As both psychoeducational and brief intervention approaches can accommodate preferences for online delivery, more considerations need to be made to select the most appropriate approach. Firstly, the literature discussed in Chapter One highlighted that the resource should primarily be focused on imparting knowledge as there is a lack of general information tailored for autistic adults. The purpose of the resource is not focused on behavioural change but on increasing autistic communities' knowledge on substance use topics. This lends itself more to a psychoeducational approach, as the primary goal of psychoeducation is on knowledge and information dissemination (Gordon et al., 2015). Whereas, as mentioned in studies on their use, brief interventions focus more on behavioural changes, such as reducing substance use (e.g., Copeland et al., 2017). Secondly, the literature in Chapter One clearly emphasised the importance of autonomy and independence in accessing and utilising the resource (Sehlin et al., 2018). This aim is more aligned with to a psychoeducational approach, as this approach can be delivered actively, such as by a therapist or "coach", or independently, in which the materials/resource can be self-administered and accessed independently by the individuals themselves (Sarkhel et al., 2020). Whereas, even online delivered brief interventions are typically delivered by a healthcare professional or professional in that particular area (Mattoo et al., 2018). As such, the current resource will employ a psychoeducational approach, as the focus is on the information/knowledge provided, can be accessed without the use of an active "coach" or professional, and can be implemented through an online, internet-based delivery.

3.0. Participant Inclusion

3.1. Reflexivity: Perspective of a non-disabled, neurotypical researcher

As highlighted in my introduction chapter, I am a non-disabled, neurotypical researcher. I am not autistic, yet I am conducting a research project on addressing the needs of autistic people. Additionally, I have never had a substance-related problem, yet I aim to develop an educational resource on substance-related problems. This presents its own challenges and difficulties. This is because I do not have any "lived experience" of autism or substance-related problems. Lived experiences have been found to be a benefit when incorporated throughout the research process (Mellifont, 2019). While the perspectives of non-disabled researchers are valid in conducting research communities they are not a part of, as Sheldon (2017) states:

*"They cannot and must not be offered in lieu of people with disabilities being able to conduct their research and define their own questions." (*Sheldon, 2017:*985)*

In order to develop an appropriate and successful psychoeducational resource for autistic adults, consideration in my interactions with the community is crucial. In their research Ostrove et al. (2019), interviewed disabled people exploring the qualities they used to described effective non-disabled "allies". The themes conceptualised for non-disabled researchers to embody were trustworthiness in their understanding of their disability identity, effective communication. willingness to learn, and the ability to make personal connections (Ostrove et al., 2019). In accordance with this guidance, the medium of participation and the incorporation of autistic communities within the current project need to reflect their needs.

3.2. Autistic Adult Centred Research

One of the core principles of the current project is the emphasis on the perspectives and engagement of autistic communities. One way this can be achieved is through the mode of delivery. Recruitment of autistic adults can be hindered if the mode of delivery selected is not preferred or favoured by the autistic individual. For example, Clarke et al. (2016), reported difficulty in conducting traditional, in person interviews with autistic adults. This was due to the verbal format of the interview and the challenges this posed to participants in articulating their experiences within such a format. This has been replicated by others meaning additional challenges in recruitment may be present if solely face-to-face methods are employed. As the current project attempts to address the needs of autistic communities, their preferences and needs involving participation should be acknowledged and incorporated. For example, autistic adults themselves stated their wish for being able to communicate through the written word instead of spoken, meaning flexibility in approach is needed (Nicolaidis et al., 2015).

A second issue for consideration is whether the methodology is appropriate for the intended age group of the population being recruited. The methodology typically used in research exploring autism in childhood, may not translate to studies with autistic adults. For example, in studies with autistic children, parents or guardians are often used to act as a proxy for their children, however, using a proxy for adults creates significant ethical concerns, questions the validity of the research being conducted, and disenfranchises those autistic adults (McDonald & Raymaker, 2013). Instead, parents of autistic adults should not be included as a proxy for their child, but for their own unique perspectives and experiences. This is because parents can provide a unique perspective as they have often had to face battles to access support for their autistic child, in addition to having to navigate support and information independently (Crane et al., 2015; Carlsson et al., 2016). Furthermore, research has suggested family members are important in autistic adults' social networks and sources of support (van Asselt-Goverts et al., 2015; Marsack & Samuel, 2017). The current study will benefit from the inclusion of parents of autistic adults; however, their experiences and perspectives should be treated as their own and not on behalf of their autistic child.

The disenfranchisement felt by autistic individuals around their involvement in research has led to calls for more inclusive and more considered methodological choices (Chown et al., 2017). For example, autistic researchers and scientists are expressing their experiences and challenges within their chosen fields, and suggesting frameworks and practices that can better support autistic people. For example, a pragmatic framework was developed from the experiences of autistic scientists on providing inclusive support for autistic and neurodivergent geoscientist students (Kingsbury et al., 2020). This consideration is not just for scientists and researchers but also for the recruitment and involvement of autistic adults outside of academia. A recent review highlighted empowerment in research as crucial to autistic communities and a central part in the motto "nothing about us without us" (Cascio et al., 2021). The authors argued that this can be achieved by giving autistic research participants options in how to be involved (such as different formats in participation and choices through informed consent) and helping to shape the processes and contexts of research projects (such as enabling autistic co-researchers).

As interest in research regarding autistic adults increases, guidelines on the involvement of autistic adults in research is sorely needed. In response to this need, Nicolaidis et al (2019), conducted an institutional ethnography of their participatory projects involving autistic adults in order to create practice-informed guidelines/recommendations for including autistic adults as co-researchers, research participants, or both. This ethnography resulted in seven guidelines to promote the successful inclusion of autistic adult co-researcher, and six guidelines for inclusion of autistic adults as research participants.

In order for the inclusion of autistic communities to be successful, consideration needed to be made on the extent of their involvement. Participatory research (also known as action research), is a methodological principle concerned with the extent of connection between the researcher and the relevant communities they wish to engage with (den Houting et al., 2021). It refers to the extent the views of the community are incorporated into the research design, process and implementation. Arnstein’s ladder of participation (1969) is a metaphor that helps illustrate the stages of participant engagement, with the ladder representing the stages of “power” starting from no power (e.g., having a theory applied to your community), to moderate power (e.g., participation and consultation of your community), to complete power (e.g., community co-researcher). In time, this metaphor has been adapted (e.g., Hurlbert & Gupta, 2015) and the stages of the ladder challenged (e.g., Tritter & McCallum, 2006), yet it still remains a useful metaphor in understanding community engagement across disciplines (Slotterback & Lauria, 2019).

In terms of research with autistic communities, participatory research has been identified as an important and valid methodological approach (Fletcher-Watson et al., 2018).

For the current project, the experiences and perspectives of the autistic community will come from autistic participants and not co-researchers. This is for several pragmatic reasons: firstly, while the research suggests substance use and addiction are an issue for autistic communities, there is a lack of perspectives from autistic communities themselves on whether a tailored educational resource is needed; secondly, as an unknown, neurotypical researcher, I have limited connections with the autistic community; thirdly, I am not able to offer any funding for potential co-researchers, meaning they would not be compensated financially for their work. As such, the focus of the current project is to engage autistic communities as participants. While the positive aspects of all forms of participatory research are in autistic contexts, it remains relatively uncommon or misunderstood (den Houting et al., 2021). This suggests that implementation of guidance or frameworks for good practice are needed in order to achieve meaningful and respectful participation.

3.3. Guidelines specific to autistic adults as research participants

The guidelines discussed were developed by Nicolaidis et al., (2019), from their experiences conducting participatory research with autistic participants. The first guideline for the successful inclusion of autistic adults as research participants is to avoid the risk of undue influence and exploitation while maximising autonomy and inclusion. Of particular note regarding this guideline is the attainment of informed consent. The authors emphasis not to make assumptions on assessments needed to obtain informed consent, specifically that a diagnosis of autism is not conducive with an assessment for decisional capacity. These decisions should not be automatic or default but should be considered depending on different factors relating to the study (e.g., level of risk and complexity), the participant (e.g., communication skills and co-occurring conditions), and the consent process itself (e.g., accessibility of materials). Completing research under assumptions about decisional capacity and autism risk offending, alienating and disengaging autistic adults from participation in such research studies.

The second guideline is to make the consent process as accessible as possible. This can take the form of adaptions to the content of the consent form or the medium of delivery. For example, adapting the type of language used (making it simpler and more concrete), adding images, or providing audio, text-to-speech versions are all useful in increasing accessibility. Additionally, the adjustments needed may be based on the factors of the sample targeted for participation. Adapting the medium for completing the consent form is also useful, particularly in providing a way to complete the form online.

The next guideline refers to the mode of participation, with suggestions to offer multiple modes of participation in order to maximise inclusion of autistic participant with differing strengths, preferences and needs. In regards to qualitative measures, suggestions are made for providing participants with both synchronous and asynchronous options, and oral or written options. By offering variety in the mode of participation—particularly with the option for oral or written preferences—this could help ease the difficulties some autistic adults experience in qualitative methods and support inclusion in and engagement with the research project.

The fourth guideline concerns quantitative methods, recommending not to make assumptions that survey instruments validated with general populations, caregivers, or child are valid for the use with autistic adults. The need for adaptions should be considered, and if modified, the instrument should re-test its psychometric properties. Suggested changes might be to adjust the language, either through the adoption of a preface, substitution of difficult vocabulary or terms, or adding graphics to help clarify complex problematic response answers.

The next guideline relates to qualitative methods, emphasising the creation of accessible interview guides. This relates to the content of the questions (avoiding abstract in favour of concrete questions), the delivery of such questions (providing participants an option to review the questions in advance) and clarity in what is required (including a preface on the process of the interview). By incorporating such recommendations, it may help to ease feelings of unknown some participants may be experiencing and aid understanding of any expectations.

The final guideline is to only use proxy reporters if direct participation is not possible, even with accommodations and supports. The authors state there should be a clear distinction between a supported participant (autistic individual who completes the study with help from a supporter) and a proxy (supporter completes the study with minimal input from the autistic individual). Additionally, supporters should be given the opportunity to express their own perspectives separately from the individual they are supporting, and proxies should be given a separate survey or questions from other participants. As mentioned previously, unnecessary use of a proxy who speaks for an autistic adult can be detrimental to both the research study and the autistic individual.

To summarise, the perspectives and inclusion of autistic adults themselves is fundamental to the success of the current project. Recruitment of autistic adults may face additional challenges, meaning that in order to successfully recruit participants from this population, all methodological approaches and designs should be conscious of potential challenges and give great consideration to the guidelines highlighted in this section.

4.0. Current project's design

4.1. Qualitative Design

As the focus is pragmatic, in both approach and purpose, the methodological design used in the proposed studies needed to be addressed. The design needed to allow for the information gathered from autistic adults and parents of autistic adults to be interpretated and implemented practically into the development of the psychoeducational resource. In order to achieve this, a qualitative descriptive design was selected. This design allows the participants to express their experiences, preferences and needs in their own words, which can be interpretated pragmatically, for the development and improvement of the psychoeducational resource.

Qualitative descriptive methods have been described as a "level 1 research endeavour" (Brink and Wood, 2001; p. 85) that lack the depth and complexities of the more established qualitative methods (Pasque et al., 2012). However, this characterisation risks undermining the practical and flexible nature of this method. Qualitative description provides insights from the individuals themselves experiencing the phenomenon that ventures to stay true to their words and are often used in consultation for the development of relevant interventions or resources. Additionally, as Kahlke (2014) remarks, rigorous adherence to prescribed and "approved" methodologies relies on the assumption that there can be an original, correct or true methodology, which is undoubtably false. In fact, all methodologies are subject to theological divisions, debates and shifts and researchers should not be pressured to select a particular methodology at the expense of the aims and objectives of the research being conducted.

While qualitative description is popular within and most often associated with nursing and midwifery fields, it has been successfully implemented in other disciplines. For example, one study used a qualitative descriptive approach was used to explore the experiences and information needs of families with children with Down syndrome in regards to their communication development (Melvin et al., 2019). Another study used a qualitative description method to explore how the self-care of patients with chronic obstructive pulmonary disease can be influenced by group education (Mousing & Lomborg, 2012). Burnette et al. (2019), employed a qualitative descriptive approach to examine the coping strategies used by cancer survivors for depressive symptoms. Studies such as these highlights how qualitative description can be appropriately utilised in a variety of different contexts and disciplines. Additionally, in all of the studies mentioned (Melvin et al., 2019; Mousing & Lomborg, 2012; Burnette et al., 2019), the findings were used practically to either help inform the development of, implications for, or additional strategies to compliment resources or interventions. This further supports qualitative description as an appropriate and suitable method for studies with a focus on practical applications of their findings.

5.0. Summary of the methodology

The central methodological issue to address in the development of the current project was the practicalities behind the translation of knowledge into practice. This was achieved through the selection of a paradigm (pragmatic paradigm), the incorporation of an implementational framework (KTA), the selection of an appropriate educational definition of the resource (psychoeducation) clarification of the extent of participant inclusion (autistic adults and parents of autistic adults), and the selection of an over-arching design (qualitative descriptive design).

The next step for the current project is a pre-development research study, in which the preferences for the resource are gathered.

Chapter Three: Findings from Stage One on Informing the Development of an Educational Resource

Introduction

The purpose of this chapter is to gather information from autistic adults and parents of autistic adults, with the aim of implementing their suggestions into the development of a psychoeducational resource. This was achieved through a qualitative survey-interview and analysed using content analysis. This chapter describes the methodology used in the study, and the two stages of analysis, which are split into part A and part B.

Methods

Study Objectives and Design

The objectives of the current study were as follows:

- To gather information on the presentation of information autistic adults prefer to engage with
- To gather information on the substance use-related content that would be of interest for autistic adults would be

In order to achieve this, a qualitative design was employed. Data was collected through structured interviews, which could be delivered in a variety of different ways depending on the preferences of the participant. The interview questions could be completed through instant messenger (i.e., Microsoft Teams, Skype, WhatsApp), by email, or through an online qualitative survey. The decision to provide a variety of different ways to participate, particularly through the provisions of both traditional audio mediums (i.e., online audio messengers like Microsoft Teams) and written mediums (email, survey, text-based online messengers), was made to accommodate for the preferences of autistic adults. As discussed in Chapter Two, accommodations such as providing the participant different choices in how to participate can help to make a research project more accessible for autistic participants and increase the sample size.

As the interview could be delivered in both traditional audio formats as well as written formats, the questions needed to accommodate this flexibility. Fundamentally, the questions used were the same (see Appendix 1). As the questions were developed for use in an online qualitative survey, consideration for content that would be appropriate for this medium was needed. From their experiences conducting qualitative surveys online, Braun et al., (2021), described several principles for good survey design. They proposed that qualitative survey questions should be clearly stated and contain concrete meaning. Using this guidance, the questions were developed to be easy to be clear and contained further information or clarification should the participant require it (e.g., examples of the topics or answers: see Appendix 1).

Participants

The project aimed to recruit autistic adults for participation. This included autistic adults who also had co-occurring ADHD or a mild learning disability. All genders and ages (aged 18 or over) were welcome to participate. The inclusion and exclusion criteria for the project are displayed below.

Inclusion criteria:

- Autistic adults aged 18 or over
- Autistic adults with ADHD, a *mild* learning disability or without either
- Individuals who choose to take part and opt in
- Adults who can read and understand the consent form, information sheet and survey/interview questions
- Adults who live in the UK

Exclusion criteria:

- Children, adolescents and anyone under the age of 18 regardless of whether they are autistic or not
- Neurotypical adults
- Autistic adults with a moderate to severe learning disability
- Those who lack the capacity to choose to take part and opt in
- Adults who cannot read at a sufficient level to understand the relevant information
- Adults who live outside of the UK

Autistic adults did not have to have an official diagnosis of autism. This was for two reasons. Firstly, as the main method of participation was through online mediums, screening for diagnosis would be difficult to achieve, particularly for the online qualitative survey. Secondly, the need for an official, medical diagnosis of autism would not align with the aims of the project. This is because the aim of the project was to identify areas that could be implemented in the development of an online educational resource for autistic adults. The resource itself would not require a diagnosis of autism to access it and is designed for all autistic adults to use, including those who may self-identify as autistic. Therefore, screening was not a prerequisite for participation.

Participation included autistic adults with co-occurring conditions, namely ADHD and mild learning disabilities. As discussed in Chapter One, autistic adults with ADHD have been identified as being at an increased risk of substance use and related problems. Additionally, autistic adults with a mild learning disability may not be at an increased risk of substance use and related problems but may require additional support for substance-related problems. As the educational resource was developed for all autistic adults, perspectives of those with co-occurring ADHD and/or mild learning disability would be invaluable in developing a resource that can cater to autistic adults as a whole.

Participants were a volunteer sample and did not receive any form of reimbursement. Participants were recruited via autism-related charities and organisations with each acting as a "gatekeeper" for the autistic populations. This meant that charities and organisations approached for promotion of recruitment material were each consulted by the researcher to discuss whether they thought the study will be appropriate for their members/audience. The recruitment media was distributed on behalf of the researcher by the relevant charitable organisation and depended on the discretion of the organisation. Of the organisations approached, only a few charities declined to promote the project. The reasoning behind their decision was that they were a small organisation and/or had a policy not to promote any research projects as they received too many requests.

The largest charity to take part in promotion of the project was the research charity, “Autistica”. In order to take part, an additional ethics process had to be undertaken and reviewed by the charity itself. The project was accepted and promotion took the form of an invitational email containing the details of the project sent on behalf of the researcher to members of the “Autistica Network”. This network is comprised of autistic people and family members of autistic people, who have indicated an interest in research on autism-related topics and agreed to be notified of potential research projects.

Procedure

Potential participants were first contacted through recruitment material (an invitational email or notice) sent on behalf of the researcher by an autism-focused charity or organisation. The invitational email contained the details of the project, including the rationale of the project, the modes of participation, the participant information sheet (Appendix 2), and the contact details of the principal researcher. If the individual was interested in participation, the recruitment material informed them of the different modes of delivery they could select to participate (instant messenger, email, or online survey) based on their preferences. The procedure for the interview differed on which mode of participation was selected by the participant.

For both the instant messenger interviews (both audio or text-based) and the email interviews, the participant first needed to contact the principal researcher through the details provided in the recruitment material to convey their preferences.

For the instant messenger interview, the researcher and participant had to agree on the time and date the interview was to occur and which messenger application to use. The participant could select a video call or audio call (i.e., Microsoft Teams) or a text-based messenger (i.e., WhatsApp). Once the time, date and medium were agreed upon, the participant was sent a consent form to sign and send back (Appendix 3). The researcher must have received a completed consent form before the interview could take place. However, as noted in the descriptive analysis of demographic questions section (pages 69-70), none of the participants selected an instant messenger interview. If a participant had selected this mode of delivery, the interview would be synchronous in nature and would have taken place on the agreed time and date for approximately 30 minutes. Once completed, the participant would have been thanked for their time and reminded of how they could get in contact with the researcher should they need to (e.g., if they wished to withdraw their data).

For the email interview, once the participant had contacted the researcher and stated their preference for this mode of delivery, the researcher emailed them the consent form (Appendix 3). The email interview was asynchronous, participants were not required to agree a time and date for the interview and could complete it in their own time. Once the consent form was signed and emailed back to the researcher, the participants then received an email that contained the interview questions in full. The questions were sent in full, instead of a certain number per email, as this would encourage completion of all questions and reduce the risk of participants not responding. Participants were encouraged to consider the questions and answer at their own pace. Once all questions contained in the email were answered and returned, participants could receive another email with questions formed around their previous answers. This was designed to encourage deeper understanding specific to each individual as these questions will not be formed before the interview takes place and will differ between participants. Once these questions had been answered and returned, one final email was sent informing participants that the study was completed, thanking them for their participation, and informing them on how they could get in contact with the researcher should they need to (e.g., if they wished to withdraw their data).

If the participants were interested in the online qualitative survey, they first needed to click on the link provided in the recruitment material, which took them to the “Online Surveys” site that hosted the survey. Participants were presented with a screen detailing the study and providing a link to the participant information sheet. As in the recruitment material, participants were encouraged to read the sheet and take the time to consider whether or not to take part (recommendation of 24 hours). If they decided to continue, participants were then presented with a screen containing the consent form (Appendix 4). If participants wished to continue with the survey, they had to agree in full to the consent form. If they wished to consent, they checked the “I Agree” button at the bottom of the screen, which would then take them to the survey’s questions. If they did not consent and checked the “I Disagree” button, they were returned to the introduction screen of the survey. The survey’s questions consisted mainly of free-text boxes for participants to write their responses, with some questions containing multiple choice tick box answers. The survey contained 12 questions in total and were fundamentally the same questions asked in the other modes of delivery (see Appendix 1). The survey was designed to take approximately 10 minutes to complete.

The start time and date, as well as the completion time and date, were taken from the survey site (see Appendix 5 for a full table of the times and dates). However, it is difficult to ascertain how long it took for participants to complete the survey, as the times and date only relate to the start and completion of the survey, and not the time spent by participants on the survey. Additionally, the survey contained a "complete later" option. This is evident when looking at the range of times, with the shortest time of 4 minutes to complete and the longest time of three days, 17 hours and 44 minutes to complete. The average completion time of respondents who completed the survey on the same day was 22 minutes.

Once each question was answered, the participants were presented with the final end screen. This screen informed participants that the study was completed, thanked them for their participation, provided a unique participant code, and information on how they could get in contact with the researcher should they need to (e.g., if they wished to withdraw their data).

Ethical Approval and Considerations

Ethical approval for the current study was gained from the Ethics Committee of Manchester Metropolitan University (Appendix 6).

Informed Consent

One of the participant groups approached for the study was autistic adults with a co-occurring learning disability. This potentially raised issues regarding informed consent and capacity. However, of this population, only adults with mild learning disabilities were targeted for participation, and this was specifically mentioned in the recruitment material and participant information sheet.

As the study was promoted online via relevant charity sites and organisations, it was not practical to assess the capacity of participants with a learning disability. However, online organisations and charities approached for promotion of recruitment material each consulted with the researcher to discuss whether they thought the study was appropriate for their members. For example, if upon discussions with a particular charity, the charity stated that they work more with autistic adults with severe learning disabilities, the project would not be promoted through such charities. This was done to ensure that the appropriate groups of adults were exposed to the promotions for the study.

Additionally, simply not allowing those with a learning disability, or having particular parameters around autistic adults in general, presents its own set of ethical issues. Adults have the right to determine for themselves whether they wish to take part in research, and they should not be excluded because they are autistic or have a learning disability. Additionally, participation required a certain level of cognition to be able to read and understand the materials. As long as the adults were able to read and understand the information provided (information sheet, consent form, questions), and fulfil the inclusion criteria they were allowed to participate.

All participant had to sign a consent form if they wished to participate. For individuals wishing to take part by email or instant messenger, they were sent a consent form to sign and return (Appendix 3). For the online qualitative survey, the consent form required participants to indicate their agreement through a check box (Appendix 4).

Right to Withdraw

Participants were made aware that they could withdraw their data at any time and without requiring a reason, before the completion date of the study (30/06/2020). Participants who completed the study via the online qualitative survey were automatically given a unique participant number upon completion. If they wished to withdraw their data, they would use the contact details provided on the recruitment material, information sheet and first page of the survey to contact the research, relate their unique number and ask for their data to be withdrawn. Participants who took part via email or instant messenger simply used the details already provided to contact the researcher and inform them of their withdrawal. Once the request was made, all data relating to the respective participant was destroyed.

Confidentiality and Anonymity

A number of considerations were made to ensure confidentiality and anonymity of the participants and their data. Recruitment adverts were sent on behalf of the researcher by related charities. The research did not have direct access to any databases or details. Participants needed to make first contact if they wished to find out more or participate. Data collected via the online qualitative survey was anonymous in nature, as participants were asked not to provide any contact details (e.g., name, email address) and were automatically assigned a participant number upon completion of the survey. For email and instant messenger interviews, email addresses and any phone/application details were destroyed upon completion of the PhD. Participants were also given pseudonyms, with any quote included in the final report only being identifiable by the researcher and the participant themselves. All data was kept in a security protected computer that was only accessible by the researcher.

Consideration of Distress

Although the current study was considered low risk—as questions pertaining to personal experiences of drugs and/or alcohol use and/or disorders were not included—efforts were made to ensure participants had access to appropriate care should they become distressed. This was done by providing participants with contact details of relevant services (e.g. NHS, National Autistic Society) and the researcher flagging any potentially vulnerable person (anonymously) with their supervisors.

Analytic Approach

The analytical approach chosen was qualitative content analysis. Qualitative content analysis is flexible in its design and procedure (Elo & Kyngäs, 2008), meaning that this approach is suitable for use within the current project.

According to Hsieh & Shannon, (2005), qualitative content analysis can embody three distinct approaches: conventional, directed, or summative. The conventional approach is usually employed where there is little previous research and is inductive in nature, meaning the categories created from the data and are not preconceived. The directional approach is the opposite, in which categories are derived from previous theory and are deductive. The summative approach involves first identification and quantification of certain words or context within the data. This is then used as a basis for a more latent analysis, in which the focus shifts to interpreting the meaning and context of the words or content (Hsieh & Shannon, 2005).

Qualitative content analysis has been successfully used to analyse interview data. For example, Burnette et al. (2019), used qualitative content analysis to analyse interviews from cancer survivors on coping with depressive symptoms. This was a successful approach as it allowed the analysis to be data-driven and stay true to the perspectives voiced by the participants. This resulted in a greater insight on the topic and the development of practical, clinical suggestions.

The current project employed a summative qualitative content analysis approach, as this provided the analysis with a clear structure for developing pragmatic areas that could be implemented in the development of the educational resource. Additionally, this approach allowed for the implications identified to be data-driven and led by the perspectives of autistic adults themselves.

Results

A.0. Summary of Demographics and Summative Analysis of Data

A.1. Descriptive Analysis of Demographic Questions

The participants for the current study consisted of autistic adults, including those with co-occurring ADHD. The current study contained three demographic questions, age, gender and presence of particular co-occurring conditions (ADHD and Learning disabilities). Furthermore, participants had a choice of how they wished to participate in the study, through an online survey, by email or by instant messenger. The descriptive analysis for these demographic questions and choice of participation was compiled into a table (see Table 1 below).

Table 1) Table 1 depicts the descriptive statistics for the three demographic questions, age, gender and co-occurring conditions, in addition to the choice of delivery respondents used to participate in the study.

Age (years)	**Gender (number of participants)**	**Co-occurring Conditions (number of participants)**	**Choice of Delivery (number of participants)**
Mean – 42	Male – 19	Autism – 47	Online Survey – 57
Range – 49	Female – 39	Autism & ADHD – 12	Through Email – 2
Total Responses – 57	Total Responses – 58	Total Responses – 59	Total Responses – 59

The sample size of the current study was 59 participants, who either identified as autistic (47 participants) or autistic with ADHD (12 participants). This was considered to be a good sample considering the difficulties previous research has had in recruiting autistic adult participants for qualitative studies (e.g., Clarke et al., 2016; McDougall et al., 2018). This sample was also comfortably within the expected range of up to 100 participants recommended by Braun & Clarke (2021) for qualitative questions included in online studies. Additionally, the current study included autistic participants with co-occurring conditions, specifically ADHD and learning disabilities. None of the respondents identified as having a co-occurring learning disability but 12 participants identified co-occurring ADHD. This is important because research suggests autistic individuals with co-occurring ADHD may be at an additional risk of substance related problems (e.g., Butwicka et al., 2017), however, previous studies usually focus one group or the other and not the perspectives of both (e.g., Clarke et al., 2016).

The youngest participant was 22 years old, and the oldest was 71 years old, resulting in an age range of 49. There were two participants who chose not to indicate their age. The mean age for the 57 participants who did respond was 42 years. The majority of the participants chose to complete the study's questions through the survey (57 participants) compared to the 2 participants who chose to participate through email. Additionally, the majority of participants identified themselves as female (39 participants), whereas, there were 19 respondents who identified as male. This is typically unusual in autistic studies, as respondents are typically skewed toward male participants and male perspectives (Beggiato et al., 2017). One individual did not wish to state their gender.

A.2. Descriptive analysis of questions

The study contained six closed questions. Three of these questions had predetermined, categorical answers for participants to choose from (e.g., Do you prefer to access information and support online or in person?). The other three were free-text responses in which the question was determined to be fairly closed (e.g., who would you feel comfortable talking about drugs and/or alcohol?), with each of these questions followed by a free-text open-ended question asking for more information about their choice (e.g., In what ways, if any, does this person/source help you to feel comfortable talking about this topic?). These follow up, open-ended questions are *not* included in the descriptive analysis below, as they form part of the qualitative content analysis to follow. The descriptive results for each of the six questions are displayed in the following table (Table 2).

Table 2) Table 2 displays the responses to the closed questions, by number of participants who chose each response and percentage of frequency against the total number of respondents.

Question	Frequency of Responses Chosen by participants (and % of total)	Total Number of Respondents
Do you prefer to access information and support online or in person?	In Person – 10 (17%) Online – 42 (71%) Other – 7 (12%)	59
What format would you prefer? (Multiple options available)	Bullet point of facts – 47 (80%) Pictures & diagrams – 42 (71%) Facts & figures – 42 (71%) Video content – 26 (44%) Leaflet – 25 (42%) Blogs – 10 (17%) Other – 4 (7%)	59
Have you ever accessed educational material (online or otherwise) on alcohol and/or drug information and/or support?	Yes – 46 (78%) No – 13 (22%)	59
What kind of material was it?	Online – 28 (61%) Leaflets – 11 (24%) Other – 10 (22%) Articles & Journals – 5 (11%)	46
Who would you feel comfortable with talking about drugs and/or alcohol?	Professionals – 21 (36%) Family – 13 (22%) Friends – 12 (20%) Anyone – 12 (20%) Other – 10 (17%) Lived experiences – 6 (10%)	59
Where would you go to find more information on or support with drugs and/or alcohol?	Online – 38 (64%) Local services – 22 (37%) Other – 10 (17%)	59

The descriptive analysis of these questions indicated the use of online materials was the most prevalent delivery discussed by the participants across the questions. Specifically, participants preferred to access information and support through online delivery (42 participants, 71% of the group), had previously encountered information or support through online delivery (28 participants, 61% of the group), and would use online delivery to find out more information or support with alcohol and/or drugs (38 participants, 64% of the group).

This finding is not surprising, as it is in line with the wider literature. Autistic individuals have stated the benefits of communicating through and by online delivery, including being able to express their true selves, locate and communicate with similar others, and acting as an avenue for self-advocacy and control (Jordan, 2010; Gillespie-Lynch et al., 2014).

Another key finding from the analysis of these questions was in relation to preferences for formatting. Participants could choose multiple formats that they preferred to engage with, the most prevalent preference was bullet point of facts (80% of respondents), closely followed by facts and figures (71% of respondents), and pictures and diagrams (71% of respondents). This was then followed equally by video content (44% of respondents) and leaflet or leaflet-style (42% of respondents). Lastly were blogs (17% of respondents) and other formats (7% of respondents), which when specified, related to audio content and information of longer length. This suggests that the majority of respondents prefer information to be presented simply, clearly and concisely as those formats that emphasised a summary of information were preferred (e.g., bullet points).

This finding is understanding, as many autistic individuals have lower levels of higher-level linguistic structural language skills than non-autistic individuals—regardless of gender—when measured (Sturrock et al., 2020). This may help to explain why many autistic individuals prefer to engage with more direct, clear formats. Furthermore, presenting information in such a manner as this has been seen to be beneficial within the wider literature. For example, curriculums for autistic students that incorporate direct language and instructions were found to be more educationally beneficial and see sustained longitudinal effects (6-8 months after the intervention) than students who were not exposed to such curriculums (Shillingsburg et al., 2015). This highlights the need for clear, direct formats to be employed if the information contained within the educational resource is to be engaged with and absorbed by autistic audiences.

A.3. Summative qualitative content analysis of questions

The remaining eleven questions were open-ended with free-text responses (for example, “What appeals to you about accessing information this way?”). The data in each of these questions was analysed using qualitative content analysis.

The approach began with an inductive, summative approach, where frequencies for related key words were identified from the data set and categorised under initial meanings (Hsieh & Shannon, 2005). This was conducted by hand, by the researcher, and the results were then complied in a table, with each keyword given a percentage indicating the frequency of appearance (see Table 3 below).

Table 3) Table 3 depicts the key word frequency analysis conducted by the researcher on the qualitative questions, with the frequency displayed as a percentage.

Question	Keywords Identified and the Percentage Present	Number of respondents
What appeals to you about accessing information this way?	Social interaction not required – 32% Ease of access – 30% Autonomy – 30% Process at own pace – 18% Online for information, in person for support – 7%	59
Are there any particular reasons you prefer this(these) formats?	Clarity & simplicity – 36% Easy to read, digest & access – 34% Visual format – 21% Variety – 19% Written format – 13% Loss of concentration & distracting – 13%	49
Can you tell me about your experience with it, including what, if anything was helpful or unhelpful?	Interesting, practical or informative – 23% Neurotypical audiences, not focused on autism – 16% Focus on quitting & bias agendas – 9%	45
In what ways, if any, does this person/source help you to feel comfortable talking about this topic?	Non-judgemental – 27% Understanding – 16% Knowledge & experience – 16% Trust – 15% Confidentiality & anonymity – 15%	57
Can you explain your reasoning behind choosing this(these) sources?	Ease of access & delivery – 15% Trustworthy – 12%	54

	Anonymous & confidential – 10%	
In what ways, if any, would having information on alcohol/drugs help you to access help from alcohol/drug services if you needed it?	Provide practical avenues – 29% Help identify & assess when/if alcohol/drug use is problematic – 25% Specific information relating to autism – 20%	51
What do you think would be particularly helpful or useful in an online resource about drug and alcohol information and support?	Practical support & techniques – 41% The processes of drugs/alcohol – 29% Autism specific information – 25% Perspectives of those with lived experiences – 16% Clarity & usability – 11%	56
Is there anything else that you think is important for me to know about creating an online resource on this topic for those with autism?	Clear focus on autism – 42% Language use – 22% Mindful of stigma & judgement – 10%	50

The key words identified in this summative analysis were varied, but related to one of the categories listed in the table.

One category of key words related to judgement. The analysis identified non-judgemental attitudes as the most prevalent key word used to describe why they would feel comfortable talking with a particular person/source (27% of respondents). Additionally, the key words of stigma and judgement were included by a number of respondents when asked if there was anything not covered by the study's questions that is important. Respondents also included key words on biased agendas and focus toward a particular point of view as unhelpful in previous experiences of educational resources.

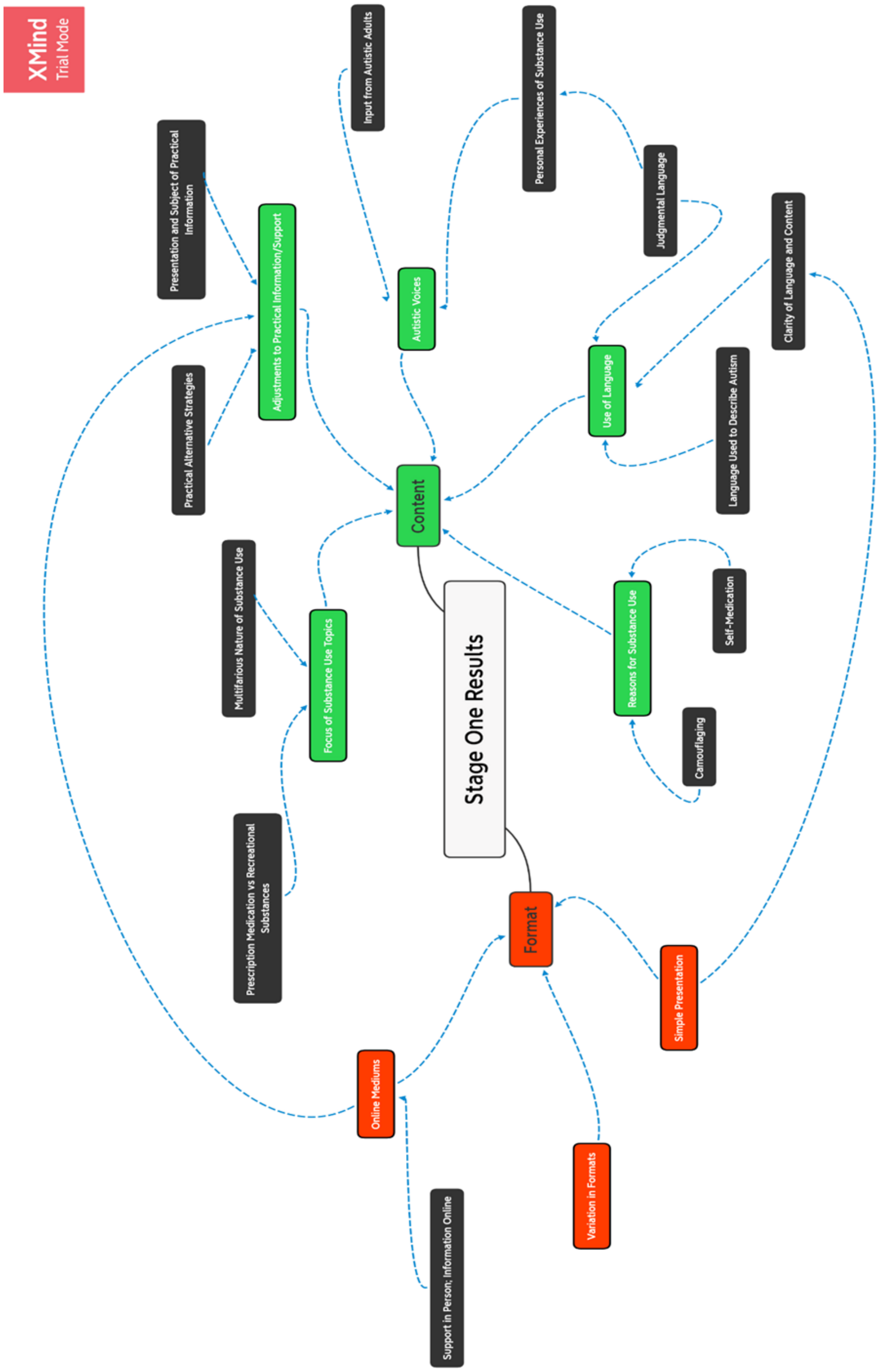
Another category of key words found across the questions was around practical support. Practical support was the most prevalent key word identified by respondents for inclusion in the resource (41% of respondents) and as a helpful aspect of the resource for accessing services (29% of respondents). Additionally, positive previous experiences of educational material on alcohol/drugs identified practical support as a key component (23% of participants).

B.0. Contextual Discussion of Themes from the Qualitative Questions

The purpose of the following analysis was to further explore the categories of key-words identified via the summative analysis compiled in Table 3. This further analysis was conducted in order to gain a better understanding of the categories produced, with the aim of producing actional themes that could be implemented in the following development stage (in Chapter Four).

The topics were grouped together by content into 6 distinct overarching topics. Each overarching theme contained at least one sub-theme. The themes were compiled into a diagram to display the interconnecting nature of each theme and their relation to one another (see Diagram 1). Each of the 6 overarching themes and their respective subthemes are explored below.

Diagram 1) Diagram 1 displays the themes discussed in the qualitative analysis and their relation to one another and the descriptive analysis.



B.1. Online Delivery of Information & Support

As indicated through the descriptive analysis, online delivery for resources and support was clearly indicated as a preference for the majority of the respondents. One of the most commonly reported reasoning for this preference is the ability to easily and instantaneously access it.

“Can access it anytime”

“Ease of access with no need to travel”

“Ease of access”

“Easy to access from phone without having to go into a library or bookshop”

“I don’t have to […] go anywhere”

The findings in the present study suggest that one of the benefits of online resources is that there are no delays in accessing them and they can be easily and independently accessed. These findings are concurrent with previous research. For example, research has shown that, in particular, online-based interventions and educational materials are highly accessible for autistic individuals, as they are flexible, allow participation in a comfortable environment, and utilise written communications (Backman et al., 2018; Sehlin et al., 2018).

The ability to instantly access resources and support is important to the success of such resources. This is because a lack of instantaneous and/or easily accessible support has been identified as an issue for autistic adults in the wider literature. For example, in a qualitative study, Crane et al. (2019), found that autistic adults reported a lack of support—in relation to both autism and mental health issues—with support only being offered at crisis point, by which point it may have been too late. Additionally, when support or services were available, the support was not immediate, with autistic adults reporting considerable delays before the services could be accessed. A lack of local, easily accessible support/services can act as a barrier to engagement with support and services for those who feel uncomfortable or disinclined to travel/use public transport or if the distance is too great for them to access the support and get back again (Camm-Crosbie et al., 2019). As such, for the proposed resource to be of use for autistic audiences, instantaneously accessible delivery (such as online) should be employed.

B.2. Support in Person

While participants identified a clear preference for information and support to be provided through online delivery, this was not universal as 10 respondents preferred in person support/information. In fact, in contrast to the majority of other participants, these participants preferred or embraced social interaction in relation to accessing information and/or support.

“I prefer the human interaction; it appears we are veering always more towards digital interaction these days.”

“I learn from others […] I find online information to be very hard to keep my attention on.”

“I prefer to have one on one time with the person to enable me to build a trusting relationship with them…[online] I don’t connect the way I would do face to face.”

This is interesting as previous research tends to focus more on the social difficulties expressed by many autistic adults and preferences for online or written delivery (e.g., Sehlin et al., 2018). However, less focus has been taken to consider autistic adults who prefer to receive support and/or information in person and face-to-face.

However, within the current study, the preferences for in person information and support seems to favour this delivery more in relation to accessing support.

“I prefer to find information online and support in person.”

“I prefer to access information online and support in person. I like the time to read and process information before I then seek support from a person, ideally face to face and in person.”

Additionally, respondents also noted that while they preferred to access support in person, they still faced certain autism-specific challenges.

"I would expect the support that actually creates change to be in person. Most of my problems come down to difficulties with connecting with other people, and in my experience, solutions come from finding ways to connect and communicate with people face to face."

This is interesting as it indicates a willingness to put themselves through potential discomfort in order to access a service that they would find beneficial. This could be applied to the development of the educational resource through the provision of detailed pragmatic information involving in-person services, such as descriptions of how to get to the service or what an appointment might be like. As the proposed resource will be developed as an educational resource, to act as a first point of call for autistic audiences wishing to find more information on the topic of alcohol and drugs, an online delivery would still achieve this best. Additionally, the online resource could contain practical information on what in person support is offered and how it could be managed.

B.3. Adjustments to Practical Information

Another contextual aspect that should be considered in developing a successful resource is the inclusion of support information and links. One of the most widely stated topics for inclusion by respondents was for an emphasis on practical information and support. However, in order for this information to appeal specifically to autistic adults, respondents indicated that it cannot be generic.

"There's plenty of general info already, but ASD (autism spectrum disorder) specific less so."

"Don't just duplicate existing online resources. It has to be Autism specific, or at least oriented."

"Honest, researched, individuated information from reliable, trustworthy sources - one size does not fit all."

Respondents clearly state the need for the information to be specifically adapted for autistic audiences in order to be successful. Autism, by nature, is multifaceted. One autistic individual will not be the same as another and as some respondents stated, for any potential resource to be successful, it has to accommodate for this variation.

"As an autistic person from an educational background, it would be useful to have a resource which presents the same information in a range of styles/formats, to accommodate the different learning styles people have."

"Careful with referencing social norms in examples or using unrealistic examples or insensitive examples NOT babying autistic people with oversimplification, instead realising the change in format is just because the brain is processing info different from non-autistics, and remembering we are adults."

"Be very clear. Don't assume prior experience with these things or desire to use them. I find it irritating when things I have to read assume, I want things that I don't, especially when they frame them as universal experiences. I know that it's usually to make people feel more normal and comfortable, but it is not helpful for me!"

As indicated above, the proposed resource should provide information and support in a variety of different ways, being mindful that information/support currently provided may not be suitable or will discourage autistic adults from engaging with the resource (e.g., referencing "common" experiences may make autistic adults feel excluded). As in one of the examples above mentions, the resource needs to embrace the variety of autism and not condescend or patronise. This is crucial for the resource as a whole but also specifically relating to practical information and support.

This need has been identified recently in relation to autism and mental wellbeing. Maddox et al. (2020), conducted a qualitative study exploring how community mental health services could be adapted and improved for autistic individuals, from the perspectives of clinicians in this area and autistic individuals who have had experience with mental healthcare. They found that autistic individuals identified a need for community education on mental health and autism, as many autistic individuals did not seek support services due to a lack of awareness of available help. (Maddox et al., 2020). For example, autistic adults were not aware of the options of how to access services and did not think to call a community mental health centre – as one individual stated, this option was “not on their radar” (Maddox et al., 2020). This highlights the importance of providing educational resources for autistic adults in general and specifically, the inclusion of detailed, practical information.

B.3.1. Practical Alternative Strategies

One way in which the practical information and support can be adapted for autistic audiences is in relation to their motivations for substance use. Within the present study, respondents stated the importance of not just including information on why autistic adults might engage with substances, but practical alternatives individuals can use instead.

“Taking drugs and /or alcohol could be an impulsive way of pushing social norms away, or a way of feeling more connected with society. I feel that it's really helpful to be offered alternative choices to consider.”

“What could we do instead when we feel really impulsive and reckless? What are any alternatives? Proper tangible alternatives, not just 'be mindful'.”

“Offering other methods by which people can manage feelings, sense of loss of control, anxiety, depression, awkwardness.”

“I'd like to see alternate, healthier ways of getting a buzz, such as rock climbing or dancing. A comparison chart perhaps of the positive effects of drugs and alcohol alongside other healthier ways of experiencing similar effects.”

In order to better support autistic adults, the practical information provided needs to include alternative strategies and techniques for managing social situations and psychological distress. However, the practical alternatives should not be haphazardly selected. Alternative strategies must be credible and appropriate for the intended audience. Currently, there is no research on practical alternatives for substance use specifically for autistic adults, and as such, identification and recommendation of particular strategies could be difficult to incorporate. For the resource to remain credible and trustworthy, these strategies must have been identified by related professionals, sufficiently referenced in the wider academic literature, or recommended by credible autistic organisations and communities.

B.3.2 Presentation and subject of practical information/support

Another related adjustment for consideration is the presentation and nature of the resource itself and how the practical information and support is accessed (e.g., is it a link to another website, or a phone number).

Within the present study, respondents overwhelmingly stated a preference for delivery in which no social interaction was required. This is mirrored in the wider literature, with a substantial number of autistic individuals preferring to access information within written formats and without face-to-face interactions (Nicolaidis et al., 2015). This needs to be considered in relation to the practical information and support included in the potential resource. For example, as autistic adults may use alcohol to manage social interactions, providing alternative practical strategies that are based around social interactions would be redundant. This issue has been identified more generally by the respondents within the current study (full quotes located in Appendix 7).

"Reasonable adjustments to reaching out and how to put some structure to your life to manage e.g., Wellbeing strategies, how to make a Network of support, Sensory, Executive functioning, Links to autism."

"Information presented for autistic people would be helpful. Services rarely have accessibility guides explaining what to expect when you attend - people, rooms, how waiting works etc."

"How to request Reasonable adjustments to reaching out to services (1:1 instead of groups, text instead of phone calls, having key person) ... Steps like a visual structure or schedule of what you can do to manage reaching out or stopping etc."

"Factual information about impact, ways to access services that are not automatically 'come in and be assessed', information about how interventions can be tailored."

"Video of people who have accessed support or people who offer the support so you know who you will be talking to ahead of time."

The respondents within the current study identified the need for tailoring the practical information with autism-specific considerations. This is a particularly important topic, as the specific adjustments identified are not currently offered within mainstream resources on alcohol and drug topics. The ability to include such topics would not only aid engagement with autistic audiences but would be offering something unique. The central way in which this could be achieved would be that practical information and support should not just *inform* about the practicalities but *explain*. For example, it should explain if support can be accessed in multiple ways, if it's only face-to-face, what does this look like and how can this be managed for autistic adults.

One way in which this could be achieved is through digital storytelling. Digital storytelling is an educational technique in which elements such as images, videos, sounds and texts are combined to produce a short story depicting a particular topic (Peñalba et al., 2020). These stories can be produced to narrate a particular person or groups experiences or to educate on a particular topic, and have been used successfully in a variety of different disciplines such as healthcare (Guse et al., 2013) and religious studies (Hess, 2014). This educational technique could be adapted and utilised in displaying certain practical information to be included in the resource. For example, digital storytelling could be used to show autistic adults the processes of getting help for alcohol and/or drug related problems, and provide a real-world, visual representation of what that process may look like. However, this technique would have to be used carefully so as to not potentially aggravate any sensory issues. For example, the digital story may not contain any audio (or have a clear option to turn it off), or be told solely in an image and text format instead of as a video. This could be one way in which practical information could be displayed. This would be an appropriate strategy for autistic adults, as the descriptive analysis showed many autistic adults indicated a preference for written and pictorial information compared to video or audio mediums. Providing pragmatic, written and/or pictorial, step-by-step guidance could help to present certain practical information (e.g., topic like where to get help for substance-related problems) in an appropriate and accessible medium for autistic adults. This would help to provide more detailed practical information—which has been identified as important by autistic adults themselves—in a format autistic adults stated a preference for.

By explaining the practical information and support in relation to autism-specific needs and by including suitable, alternative strategies for managing such needs, the resource will be more serviceable and practical for autistic audiences especially compared with existing resources.

B.4. Autism-Specific Motivations for Substance Use

In order to better adapt the educational resource for autistic audiences, a clear focus should be taken on the topics chosen for inclusion in any resource. The respondents stated that focus should be made to include why autistic people might wish to engage with alcohol and drugs.

B.4.1. The 'Self-medication' Hypothesis

The self-medication hypothesis (Khantzian, 1985), is a popular theory employed within substance use fields in order to help explain the motivations behind their use (e.g., Hawn, Bountress et al., 2020; Hawn, Cusack et al., 2020; McHugh & McBride, 2020; Waddell et al., 2021). This theory proposes that individuals engage with substances in order to alleviate and moderate negative psychological distress (Khantzian, 1985). Within the wider context of literature, there have been few studies on the application of this theory for autistic adults, but those that have suggest self-medication might be a potential motivation for autistic people engaging with substances (e.g., Ressel et al., 2020). Within the present study, respondents stressed an acknowledgement of using substances in such a way and the importance of including this as a topic in any potential resource designed for autistic adults.

"People use for a reason - often to suppress a nagging sensory issue or mental health issues."

"A lot of autistic people self-medicate with cannabis products, including legal CBD but also currently illegal products, and mushrooms."

"I think the correlation between autistic individuals and drug/alcohol usage as a coping mechanism for social situations and/or sensory overload is an important topic and should form a basis for part of the information."

"It should understand autistic adults are at high risk of self-medicating with alcohol and drugs."

"Access would be facilitated by information about how common it is for people with ASD (autism spectrum disorder) to reply on alcohol/drugs as a means of self-soothing."

Whether the respondents are speaking from their own personal experiences or their observations in general, there is a clear acknowledgement in the role of self-medication in autistic adults engaging with alcohol and/or drugs. This is interesting as it could help to illuminate why autistic adults may be at a higher risk of substance-related problems when compared to the general population. The participants' responses on the motivations behind self-medication relate to presentations of autism or autism-specific experiences, such as sensory issues, self-soothing, and difficulties with social situations. As opposed to other mental health motivations usually associated with the self-medication hypothesis (e.g., anxiety, depression, PTSD), autism is not a condition that is manageable through medical interventions or psychiatric interventions, it is a life-long condition that does not need to be cured but is a fundamental aspect of the individual. The motivations expressed by respondents (e.g., sensory issues, etc.) are present throughout the individual's life, meaning the potential to develop the use of substances to self-medicate is also present throughout their life.

Although research on substances as self-medication for autistic individuals is scarce, there is support from previous literature for autistic adults to use alcohol and/or drugs for these purposes. For example, in qualitative interviews with autistic adults with experiences of alcohol or drug related problems, Clarke et al. (2016), found that autistic adults used their substance of choice to self-medicate feelings of anxiety, depression, sleep difficulties and ADHD traits. Autistic adults spoke of substances addressing an emotional or cognitive mechanism of their psychological distress, for example, by shifting their cognitive appraisals, such as using alcohol to reduce negative self-appraisals (Clarke et al., 2016). Furthermore, wider research on ADHD has found that one of the motivations for substance use in individuals with ADHD is to self-medicate the symptomology of their condition (Odell et al., 2017; Liebrenz et al., 2014). These studies highlight self-medication for psychological distress as an important factor aspect of substance use for autistic adults, particularly those with co-occurring ADHD. However, while some respondents did specifically mention self-medication in response to mental health issues (for which the theory was originally devised), respondents seemed to specify that the negative distress the substances were being used to alleviate are issues specifically relating to autism, particularly relating to social situations. This was also found by Clarke et al. (2016), in their study, whereby participants indicated the use of substances to facilitate social interaction. This use was described by the authors as distinct from self-medication, suggesting use for social facilitation was more of a proactive approach by the individuals, whereas, self-medication was more a reactive response. However, it was noted that these motivations were interrelated (Clarke et al., 2016). Use of substances for this purpose has been noted more widely within the literature on autism and is conceptualised as the idea of 'camouflaging'.

B.4.2. Substances used as 'Camouflaging' in social situations

An emerging area of interest in research on autism is the idea of camouflaging. This idea is defined as the use of strategies by autistic people to minimise the visibility of their autism during social situations and interactions (Lai et al., 2011). These strategies can be deliberate or unconscious and are employed in order to "mask" autistic characteristics and help the user to appear non-autistic (Hull et al., 2017). This relates to the idea of self-medicating, as some respondents within the current study specifically mentioned employing substances (particularly alcohol) as a strategy to manage social situations.

"People with autism and / or ADHD can be impulsive. Taking drugs and /or alcohol could be an impulsive way of pushing social norms away, or a way of feeling more connected with society."

"I am interested in how my drug use/ and current alcohol use, is related to my ASD. It feels to me as if drugs used to, and alcohol still does, make me feel less autistic in social situations. It might help others find better methods of coping socially."

"An explanation of how drugs and alcohol can mask symptoms, make you feel accepted by some groups of people, but also excluded from other groups of people… We are vulnerable adults, and we may not understand the world, so taking something which makes us experience the world in a different way can make us more vulnerable."

"[in relation to what topics should be included] knowing how autism might lead to needing alcohol or drugs for example I drink to do better in social situations."

Whether deliberate or impulsive, respondents clearly stated the use of alcohol and drugs as a camouflaging strategy for managing social situations. There has been little to no previous research on camouflaging strategies and substance use in autistic populations, but there is tentative support for its use. For example, some autistic adults have indicated using alcohol to camouflage their autism in order to "fit in" in social situations, such as in feigning an interest in conversation topics they had no interested in (Bargiela et al., 2016; Clarke et al., 2016). Furthermore, Kronenberg et al. (2015) found that autistic individuals may use substances (particularly alcohol) in order to help manage their autistic symptoms in social situations, making them feel more relaxed, focused and less agitated. The current study supports this idea, as some respondents explicitly mention this as a reason for use, supporting the notion that any resource on substance use and related problems should include this topic.

The inclusion of such topics would be useful and relates more generally to how alcohol (and drugs) may be assessed. Although under-researched and discussed in Chapter One, research is conflicted on the extent of alcohol and drugs use related problems for autistic individuals, i.e., autism itself is a risk factor for substance-related problems (Butwicka et al., 2017), risk of substance-related problems is dependent on the substance used and whether the individual had ADHD (Mulligan et al., 2014), individuals with autistic traits were less likely to report drinking to intoxication but had a greater risk for alcohol dependency (de Alwis et al., 2014). A recent study on the prevalence of “risk drinking” in autistic adolescents and young adults found a lower prevalence of risk drinking for autistic participants (Kaltenegger et al., 2021). However, these findings may be in part due to the instruments used, namely the Alcohol Use Disorders Identification Test (AUDIT; Babor et al., 2001) and the researcher’s own devised questions. These instruments may not be appropriate for capturing drinking behaviour within autistic populations, as the instruments focus on feeling “drunk” and consumption of units of alcohol or abstract questioning (such as, “How often during the last year have you failed to do what was normally expected from you because of your drinking?”). The variance in prevalence of alcohol and drug related problems may be influenced by inappropriate measures to capture such behaviour. This highlights the importance of including topics on self-medication and camouflaging using substances for a successful resource for autistic adults. By including these topics, it will help autistic individuals to know more specifically about their relationship with alcohol and drugs, and help to identify when it may be problematic in a more appropriate way. For example, instead of simply talking about excessive drinking in units, the resource could talk about when drinking for social facilitation may become problematic (i.e. do you feel like you need a drink when engaging in all social interactions?).

The inclusion of these topics within an educational resource does raise ethical considerations. More specifically, whether discussions on this topic are promoting (whether intentional or not) the use of such camouflaging techniques. However, autistic adults have clearly indicated a desire for inclusion of these autism-specific topics within the resource. Additionally, the resource is targeted at autistic adults, and therefore, denying access to such topics raises its own concerns around censorship of information. In order to best circumvent this, discussion of these topics should consider the language used, choosing to use impartial, non-judgemental language. Additionally, camouflaging techniques should not be included as a practical strategy but solely to inform about motivations for alcohol and/or drug use in autistic adults. Finally, information presented should be transparent, include references, and ultimately be reviewed and approved by both substance use professionals and various autistic audiences.

As respondents stated within the present study, motivations for substance use are a key area of interest. In order to successfully appeal to autistic adults, resources developed on alcohol and drug topics should include motivations for use; specifically, how for autistic individuals, the notion of self-medication and camouflaging are intrinsically linked to substance use.

B.5. Autistic Voices

B.5.1. Input from Autistic adults

Another way in which any potential resource can be adjusted for autistic audiences is the inclusion of autistic voices. The methodological approach of the current study focused on the importance of autistic voices and perspectives, however, respondents stated that consultation of autistic voices may not be enough to encourage proper engagement with a resource or service.

“If the material is aimed at people with autism, it should be designed by people with autism, or at least involving them closely.”

“It has to be written, coded, developed and spread by autistic people, for autistic people.”

“You need close input of people with autism - and not just the results of a questionnaire.”

Responses such as these highlight the importance of incorporating autistic perspectives throughout the process of development of any resource aimed at these audiences. This includes incorporating autistic people or their experiences within the resource itself.

“To have access to online phone or video counselling with people who understand autistic traits to talk about personal situations and experiences. I'm more inclined to listen to someone who is an autism specialist.”

“[In response to supporting autistic adults using substances] The person just needs to be able to communicate with autistic people.”

“Reading experiences of autistic people would be interesting.”

Responses such as these emphasises the involvement of autistic people and perspectives should not be tokenistic, but instead should form an integral aspect of any resource or support developed for these audiences. This is important as it is autistic adults themselves directly stating the benefit of including autistic perspectives within educational material on substance-related resources intended for use by their communities.

Incorporating autistic voices has been implemented within the wider literature, particularly in regards to conducting literature itself. Recent research has identified a need for autistic individuals to be more involved and included within research projects exploring topics relating to autism (Pellicano, 2020). This can be achieved through participatory or emancipatory research projects. Participatory research refers to research where one or more of the researchers is autistic, whereas, research projects conducted solely by autistic researchers is considered emancipatory research (Martin, 2015). Participatory or emancipatory research has been suggested to be better placed to support the needs of autistic individuals and have positive implications for the autistic individual as well as the other researchers involved with the project (Martin, 2015; Pellicano, 2020). In order to help researchers to create more inclusive research, Chown et al. (2017), developed a four-part framework for participatory or emancipatory research.

While the current study is not participatory or emancipatory, the principle aim for the current study is reflected within the final part of the framework identified by Chown et al. (2017), namely, that the research outcomes are focused on improving the lives of autistic people. In order to achieve this aim, the perspectives voiced by participants in the current study indicate that more involvement of autistic people is needed than simply participating in the current study. This could be achieved through incorporating autistic people or their experiences within the resource itself, using their own words. This can also be related to the wider push for more inclusion of specific groups in order for research to better support such groups. This is because as mentioned by autistic people and their family members in the wider literature, involving autistic individuals is important as they are the best source to consult for issues relating to themselves (Gotham et al, 2015). Incorporation of autistic perspectives would increase the authenticity of the resource from the perspectives of its intended audience.

B.5.2. Personal Experiences of substance use

In addition to incorporating the voices of autistic adults, respondents in the current study identified the importance of including the experiences of substance use and related problems from the individuals themselves who have used/had problems with such substances.

“I think it would be useful to have testimonies from people who've used the drugs, to hear what they say about how it feels and what the effects are.”

“More understanding from the perspective of the user. Most resources do not acknowledge what is attractive about drugs nor how they really make you feel.”

“Testimonials - I want to hear the voices of the people who've used it. It's important to know that I'm not alone.”

“I think it needs to be written by people with lived experience and also professional and academic knowledge.”

Incorporating the viewpoints of individuals who have experience or struggled with substances has been used in resources on such topics. For example, Treloar et al. (2019) conducted a mixed-methods evaluation of a website that presents personal experiences of drug use and related problems using their own words. They found that individuals who visited the website expressed a greater, more holistic understanding of drug related issues and decreased expressions of stigma towards such individuals. Furthermore, a more recent evaluation on a similar site but on the topic of drug overdoses, has been considered as a valuable source of information by related health sectors as an avenue for tackling drug use related stigma (Farrugia et al., 2021). This highlights the importance of including personal experiences in the proposed resource as a means for increasing knowledge on the subject (which is the purpose of the educational resource) and decreasing the associated stigma.

Additionally, many programmes for substance use related problems are social or include social aspects with others who experience or are experiencing such problems (such as mutual aid groups like

Alcoholics Anonymous). The idea of sharing the perspectives of these individuals with one another gives individuals a sense of solidarity, and a feeling that they are not alone. This has been mirrored by some participants in the current study.

"AA makes me feel very comfortable because people there share openly about their drinking (and how they got sober), and there is no pressure to share…We realise we are not alone, and there is a way out."

"I want to hear the voices of the people who've used it. It's important to know that I'm not alone."

"I feel that only people in AA have the understanding that makes me want to talk about drinking. There are so many experiences that only alcoholics have and other people just don't get it."

Responses such as these highlight the benefits including personal experiences can have for autistic adults who may be experiencing similar feelings of including such perspectives in the development of a successful resource on this topic. This is interesting as these responses highlight that while some autistic adults may experience challenges with social situations, the desire and need for a sense of community and solidarity are important. In order to better support autistic adults, the sense of community and solidarity need to be fostered somehow within the support or information provided. Inclusion of personal accounts from autistic adults on their experiences of alcohol, drugs and/or addiction could be a strategy to foster a sense of solidarity without the need for social interaction or in-person discussion. Although the current study did not ask for personal experiences, the few who did include their experiences highlight just how valuable their inclusion in the proposed resource would be (full quotation contained in Appendix 7).

"I smoke Cannabis because it provides me with a slightly disconnected feeling from the outside world which does not seem to have a place for me where I do not stick out or screw things up … I frequently find myself working with some of the rougher elements of society who find me an irresistible target for bullying … I just wish that my conditions could have been recognised and at least addressed

to some extent when I was younger, so many of my life choices would have been different and cannabis use would probably never even have been considered."

The experiences of such individuals are vital, as they can provide discussions on topics related to autism (bullying, employment, late diagnosis) and substance use (self-medication) in an authentic way that would not be achievable from a non-autistic individual who has not experienced such problems. These experiences provide an invaluable relation between the topic of alcohol and drugs and the autistic audience the resource is designed for.

B.6. Use of language

One of the most crucial aspects to consider when developing the educational resource is the language that will be utilised. Respondents identified a variety of different ways in which the choice of language can act as an impediment to engaging with a resource or support.

B.6.1. Language used to describe Autism

One issue relating to language use, is the words used to describe autism and autistic people. Respondents identified a clear need for the correct terminology to be used.

"I am an autistic person. Not with it. Nor do I have it. Any info source should choose its language carefully."

*"A resource using Person First Language (& puzzle piece images!) would not be shared between autistic people, because there should be Nothing About Us Without Us…An online resource should use the words "autistic people" instead of "people with autism"/"people who have autism"…Autistic people *are* autistic. So, they are "being autistic" and not "having autism"."*

"People first language i.e., autistic people would indicate an understanding that unlike people with alcohol dependency or drug problems, being autistic is not something that is acquired."

The use of person-first language (a recognition of the person first before their condition; i.e., with autism) has traditionally been used in relation to autistic individuals. However, many now consider this language to be insensitive to autistic people as autism is intrinsically related to their perceptions of the world, and cannot be separated from their sense of identity. Within the wider literature the autistic community is challenging the dominant assumption that autism is a disorder, which needs to be eradicated, prevented, treated or cured (Nicolaidis, 2012; den Houting, 2019). Incorrect terminology risks disengagement from autistic audiences. This is important as the recruitment material used in the current project used person-first language (e.g., see Appendix 2). This highlights the significance of inclusion of autistic perspectives throughout the development (both pre- and post—development) of the educational resource, as inclusion of incorrect terminology could have been inadvertently employed. In order to prevent this, special consideration should be made by utilising multiple sources on the correct terminology that should be used within the proposed resource. Additionally, piloting the resource with a group of autistic adults could be a useful preventative strategy.

B.6.2. Judgemental Language

One theme that reoccurred throughout the data set related to perceived judgement and stigma. Participants stated the importance of the tone of material and not coming across non-judgemental and impartial if the potential educational resource was to be successful (full quotations located in Appendix 7).

“What would be most important is the presentation of facts and reasoning. It should be supportive and not judgemental… It must at all costs be based on evidence and facts, not opinion and morals.”

“Do not preach! Inform! No tales of terror like the cancer adverts do.”

“[in relation to self-medicating with substances] Please do not default on saying this is 'bad'. I'm not suggesting you promote it, but [individuals] should not be subjected to shaming tactics, however subtle.”

“I think that the most important thing would be to not ask people to give up drinking or even cut down … they need unconditional positive regard, acceptance and to be given hope.”

“Real answers, not just 'don't do drugs kids'.”

“The language should be non-judgemental and offer comfort to the client.”

“The information should be clear. Based on proven research. No alarmism. It should be non-judgemental.”

These responses indicate that autistic adults have previously experienced judgemental language on substance-related education. In addition to this, the most prevalent reasoning for the source they feel comfortable talking with about alcohol and drugs was because they were viewed as non-judgemental.

“They’re trained to discuss things in a non-judgemental way and to have open minds.”

“Non-judgmental and willing to listen or debate.”

“I would hope that they wouldn’t judge me or abuse my trust.”

“A feeling of trust and lack of judgement.”

“If talking to professionals…Their experience and understanding and lack of judgement are also helpful.”

The fear of judgement and perceived stigma felt is a common theme identified by individuals who have some level of experience with alcohol and drug use and conditions.

For example, one systematic review of all representative population-based studies on stigma and substance use conditions found that public perceptions and attitudes towards those with such conditions tend to be negative and severe, with such attitudes shared worldwide (Schomerus et al., 2011). In fact, those with substance use conditions may be one of the most stigmatised groups, as Harnish et al., (2016), found individuals with substance use and mental health conditions experience significantly more stigma for their substance use problems than their mental health conditions. This experience of perceived judgement and stigma was reported by respondents in the current study. Respondents identified this perceived stigma and judgement as a negative impact on engaging with or reaching out to support services.

"There is such a stigma around alcohol/drugs, and as someone who works in a local authority in a relatively small city, I certainly wouldn't be comfortable accessing a public support service that maybe attended by some of the clients that I support, or even some of the colleagues that I work with."

"I have often been afraid of the idea of going to alcoholics anonymous as I feel I wouldn't fit the stereotype of an addict...maybe get rid of the stigma and the preconceptions."

"In over twenty years of cannabis use, I have never admitted to any health professional that I use it because I feel there would be a stigma if it appeared on my records."

These responses highlight the detrimental impact stigma and judgement can have on autistic adults. They specifically stated how the negative preconceptions of others about substance-related problems and behaviours would actively shape their decision on whether they would seek support or further information on substance-related issues. This highlights the importance of including non-judgemental language and content in order to provide support or information for autistic communities on this topic.

The respondents within the current study are not the only ones who experience such an issue. One of the most prominently cited impacts for the individual within the wider literature is that stigma acts as a barrier or deterrent in engaging with and seeking treatment (Barry et al., 2014). For example, Becker et al. (2015), found that individuals with drug/alcohol use problems specifically describe the experience of stigma as being directly related to seeking and engaging with help for their problem.

The impacts on the individual experiencing addiction-related stigma are significant and multifaceted and stigmatising views are not limited to the general public. These negative perceptions can also extend to some members of the medical community. For example, medical students and healthcare professionals have also indicated high levels of addiction-related stigma (Haroun El Rasheed et al., 2016). Additionally, an impact on healthcare can be felt as the stigmatising views held by healthcare professionals can contribute to suboptimal care for those with an addiction (Boekel et al., 2013). This was also present within the current project. One respondent recounted their experiences of trying to seek help for their alcohol-related problems and the judgement they felt they received in return.

"There were times, after particularly bad benders, when I did reach out for help, but no one knew about alcoholism, no one wanted to talk about alcoholism. I was just told to take anti-depressants (which is a bad combination with alcohol) and to not talk about how I felt. After I'd gone to AA, I told my GP who shouted at me that I absolutely had to take Librium and told me off for 'leading everyone a merry dance'."

This experience of being judged by a trained medical professional and dismissed with unnecessary drugs for depression and anxiety (Librium), highlight the negative impact some autistic adults face for simple trying to discuss alcohol and drug related issues.

In order to prevent the proposed resource from unintentionally engaging in stigmatising views, careful consideration needs to be made to the choice of language. The resource should be impartial, and as such, the use of language should reflect that. Content and practical information should be provided without using language which may imply any sort of morality or judgement. Evaluation of the resource should include those with personal experience of such issues to help indicate whether any unintentional bias is present.

B.6.3. Clarity of language and content

Another aspect for consideration in the use of language indicated by respondents was that surrounding its clarity (full quotations located in Appendix 7).

"Autistic people benefit from information, from things being very clear and explicit, and from knowing what is and isn't normal."

"The language being autistic friendly, so direct and literal, concise, use visual aids, any steps broken down."

"Simple language that can be understood by anyone."

"AA is really good, but the language of the meetings, programme, and literature is really antiquated … language can be a barrier for people with autism and/or learning disability."

"Ensuring it was up to date and not cringey ... some sites I've seen are really trying too hard to be 'down with the kids', with all the faux graffiti type 'street' aesthetic and the young people I work with find that sort of thing quite off putting."

"Information needs to be stripped down to what I need to know. Too much writing, font style, layout can be an immediate put off."

Responses such as these highlight that for a resource to be successful, implementation of simple and clear language is paramount. Respondents indicated the use of complex information or aesthetically displeasing formatting as a potential barrier to use of the resource. This is further supported by preferences of format discussed in the descriptive analysis. The descriptive analysis highlighted the benefits of clear, concise and direct summative information, which has been seen in the wider literature (Shillingsburg et al., 2015). Additionally, this clarity and simplicity of information would also help the resource appeal to individuals with learning difficulties or disabilities. Wider research has identified the use of clear, direct language as crucial adaptation to facilitate engagement with individuals with a learning disability. For example, a recent literature review found that using accessible, easy to read information was important in best meeting the needs for people with learning disabilities (Chinn & Homeyard, 2017). Additionally, they found that this type of accessible information could be helpful in advancing engagement of a diverse groups of people with learning disabilities. However, resources should be careful when considering ‘easy read’ types of information. For example, Buell et al. (2019), found that individuals who were exposed to simplified language resulted in significantly greater comprehension than those exposed to ‘typical’ language, however, none of the other aspects of the easy read format presented in the study produced significant results. Furthermore, Hurtado et al. (2014) found that presenting information in easy read formats did not significantly make the information easier to understand. Additionally, there is little consensus on the best way to construct an easy read format (Chinn, 2019). This suggests caution should be taken if the resource is to employ an easy read format, however, what is clear is the benefits of simplified language for both autistic adults and people with a learning disability.

As such, the proposed resource should incorporate these findings by using a mixture of written, pictorial (and to a lesser extent, audio) formats in order to break up information and provide more clarity for the audience. Additionally, the resource should employ language that is simple and easy to follow.

B.7. Inclusion of Additional Specific Substance-Based Topics

B.7.1. Multifarious nature of Substance Use

In addition to the multifaceted nature of autism, the experiences and uses of alcohol and drugs are not universal and can vary from person to person. The complexity of this issue was highlighted by some respondents.

"I don't know because people using substances of all kinds can be anything from dying to sensible users. It's hard to signpost everyone to the right place for where they are."

"I also think that there is a lot of ignorance about what alcoholism really looks like. We're not all street drunks. Many of us were functioning drunks with jobs, families, etc. The really bad effect of alcohol is what it does even between drinking sessions: the feelings of anxiety, depression, low self-worth, that are the direct effects of excessive alcohol on the brain over long periods. Also, some people are a lot more sensitive to this than others."

"I do not seek help for alcohol / substance misuse personally. However, this information is always useful as alcohol and recreational drugs seem to be a big part of our culture. The more knowledge on this, the better. I'm aware that it is useful to seek information from more reliable sources / many sources. However, I'm also aware that much information is contested regarding this subject."

This issue can lead to confusion on alcohol and drug topics, as well as, an undermining of the credibility of such resources if information is not consistent. As such, the proposed resource needs acknowledge this variety and to explain it when discussing the relevant information. This could link with the inclusion of personal experiences of alcohol and drugs, as including these personal stories will highlight that while problems relating to alcohol and drugs may be shared, the experiences are distinct from one another.

B.7.2. Prescription medication vs recreational substances

One topic that some respondents indicated was the interpretation of what constituted alcohol and drug topics. Specifically, several respondents highlighted that drugs were not only recreational but medical too (full quotations located in Appendix 7).

“I think you need to clarify whether it's addiction you are focussing on. Or whether there would be information on how to manage taking prescription drugs which aim to support aspects of life with autism.”

“I use Solpadine SOLUBLE daily as this seems to help calm my nervous system in a milder way and help keep my stomach working. Would be nice to know how this works?”

“I am not interested in alcohol or recreational drugs as these aren't my problems but I am interested in the side effects of prescription drugs given to me to help with chronic depression and anxiety exacerbated by autism.”

“Make sure there are distinctions made in that drug addiction doesn't just mean illegal drugs - it can refer to things like painkillers and other medications. I've struggled for years with painkiller addiction and haven't been able to find any help.”

This is interesting as many autistic individuals have co-occurring conditions, such as ADHD, anxiety and depression (e.g., Hollingdale et al., 2020; Hollocks et al., 2019). Each one of these conditions have medications associated with them, that can be prescribed by medical professionals. This may have implications for the development of the resource, specifically on whether to include such medications in the informative literature or focus solely on recreational use and illegal substances. As co-occurring conditions are common for autistic individuals, it may be important to incorporate informative topics on their use, side-effects, and potential for developing issues with, in order to provide a more adapted and holistic resource for autistic audiences. If this information is to be included within the resource, the resource would first need to be reviewed by healthcare professionals.

Discussion

Positive Aspects of the Current Study

The methodological approach to the current project was novel and in contrast to the typical qualitative techniques used in previous qualitative research with autistic participants. For example, Clarke et al. (2016), reported difficulty in traditional interviewing with autistic adults about substance use, due to the verbal format of the interview and the challenges participants faced in voicing their experiences in this format. They recommended the use of alternative, perhaps online, qualitative interview techniques. Recent studies have started to implement these recommendations within their research. For example, similar to the current project, Camm-Crosbie et al. (2019) used a mixed method, qualitative leaning, design distributed to participants through the internet in the style of an online survey. This was found to be successful within their sample, as was the similar method used in the current project.

The current project is novel and useful in a number of different ways, one of which is the focus on practical support for autistic adults. In a recent qualitative study, Crane et al. (2018) conducted interviews with autistic adults and found a general lack of post-diagnostic support for autistic people. This was particularly profound for support for autistic adults, as one respondent highlighted,

"I found an [autism] group meeting, and I walked in and it was little kids with their parents all having cups of coffee in a play centre…I'm 46, I don't want to go on a climbing frame with 4-year-olds." (p. 3767: Crane et al., 2018).

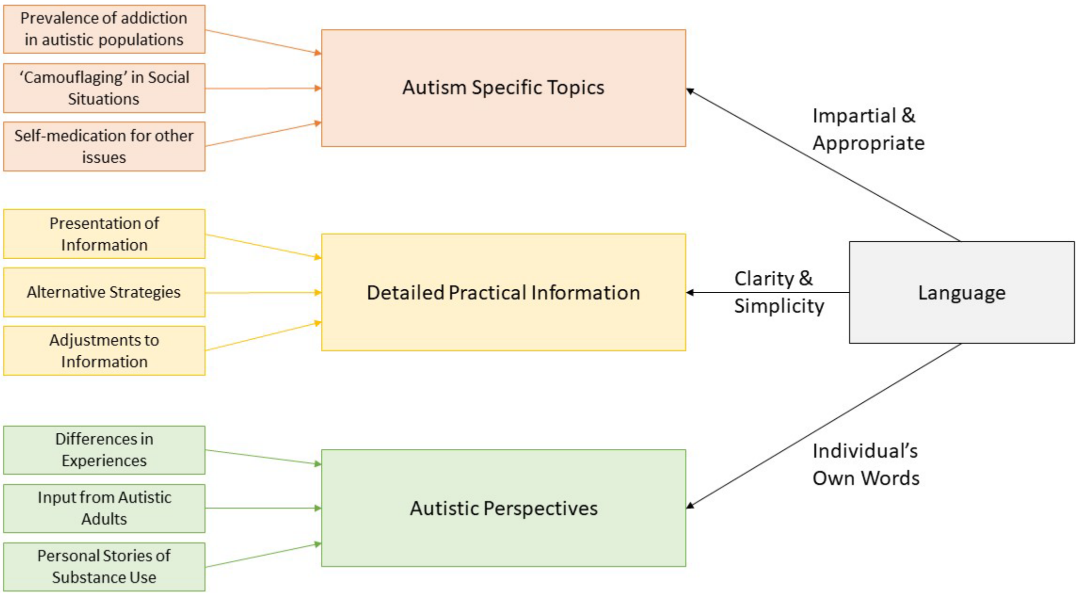
Instead, they voiced their preferences for more practical advice and support, relating to topics such as employment, benefits, education, housing, and healthcare. Research such as this emphasise the importance of providing practical support and educational resources specifically for autistic adults, which is the main purpose for the current project. Additionally, professionals acknowledged the lack of support post-diagnosis, stating that although they would like to provide more support, they were unable to due to service demand and external pressures on their professional time (Crane et al., 2018). This highlights the benefits of economical and passive avenues of support and information for autistic individuals to better support them on certain topics while not causing additional demands on health-related services. This further supports the aims and economical nature of the research project in general.

Applications for Resource Development

The findings from the current study have resulted in the identification of a number of areas that can be utilised in the development of the educational resource on the topic of substances for autistic audiences. In terms of how the resource should be delivered, the findings from the current study clearly support the use of online, internet-based delivery. As the primary purpose of the resource is to inform and not to act as an active intervention, utilising an online delivery will provide audiences with independent and immediate access to such a resource. In relation to the formatting of the online educational resource, the findings indicate a preference for simplicity and ease of navigation. This means the resource should avoid unnecessary complexity, by displaying information in a clear and concise written manner, using a variety of different supplementary formats to support this (such as images, diagrams, and to a lesser extent, audio).

In terms of the context for the resource, the implications for the resource have been compressed and simplified into diagram 2 below, which is to be referred to throughout the development of the educational resource.

Diagram 2) Diagram 2 displays the implications for the resource identified in the current study's findings to be considered in the next stage of the PhD, the developmental of the resource itself.



The findings from the current study have identified three key areas that should form the basis for the development of the educational resource. These key areas have been identified by autistic adults themselves within the current study and will be crucial in separating this resource from other resources on alcohol and drug topics. This is because no other current resource on this topic contains the voices and perspectives of autistic adults who have had experience with alcohol and/or drugs. Similarly, no other current resource includes topics specific to autism, namely the reasoning behind why autistic individuals may engage with alcohol and/or drugs, and whether they are at an increased risk of related problems. While many other resources contain practical information on alcohol and drug information and support, it is limited. It does not take into account the difficulties autistic adults may face (such as social and sensory difficulties) and therefore does not provide adequate detail (such as alternative ways to engage with support, the processes for getting support and whether support can be adapted for their needs).

The key areas represented in Diagram 2 are interlinked as each component does not act in isolation. For example, autistic perspectives could include experiences on why they began using alcohol/drugs (autism specific topics) or on their experiences on treatment and substance-related services (detailed practical information). For the resource to be successful and best meet the needs of the targeted audience, there will need to be an incorporation and unification of all three key areas identified.

In addition to the three key areas, Diagram 2 displays an important additional factor. This factor relates to the language used in the resource. This is crucial to the success of the resource as the resource will primarily be text-based. The findings from the current study highlight the importance language can have in relation to all three of the key themes identified and how, if mishandled, can discourage autistic adults from engaging with the content. In order to achieve this, the language used should be clear, precise and avoid complex jargon, particularly in regards to detailing the practical information. The language used to voice autistic perspectives and experiences should be their own in order to ensure the resource is credible and authentic. When discussing the autism-specific topics (as well as discussions of autism in general) appropriate terminology should be used, with special care to exclude person-first language (i.e., with autism) when discussing autistic individuals. Additionally, discussion of these topics should be impartial and non-judgemental. The findings from the current study clearly stated that the resource should be impartial and there should be no hidden agenda (whether deliberate or not). The discussion of alcohol and drug topics should neither endorse nor condemn their use.

In summary, the educational resource should be developed to be delivered online. The formatting should be primarily written—with support from other formats (images, diagrams, audio)—which should be displayed clearly and simply with easy navigation of the resource. The content of the resource should be centred around three key areas; detailed practical information, autism specific topics, and autistic perspectives. Additionally, the content of the resource should make special consideration to the language used, specifically focusing on clear, precise, non-judgemental, and authentic language.

Chapter Four: Development of the Online Educational Resource

Overview

The aim of this chapter is to detail the development of the online resource designed for autistic adults on the topics of alcohol and drugs. This is achieved through detailing the application of the findings from Chapter Three and how they were incorporated into the development of the educational resource. This chapter is separated into several different aspects of the development: design principles, content, language, and presentation.

1.0. Design Principles

Many health educational websites use design principles to act as a foundation for the development of the educational resource. Arguably the largest health education website in the UK is the NHS website (https://www.nhs.uk/). The NHS website has published what they refer to as the "design principles" that are used in the development of any digital aspect of the NHS (NHS, 2023). Similar principles, with slight differences in terminology, were also detailed by another UK educational website (though not strictly health based) the government website, GOV.UK (https://www.gov.uk/). These principles are detailed in table 1.

Table 1) Table one details the design principles published by the educational websites, NHS and GOV.UK.

Principle	Description
1. Put people at the heart / Start with user needs (NHS / GOV.UK)	Information and support should be created specifically in mind of the user/audience
2. Design for outcome / Build design services, not websites (NHS / GOV.UK)	A specific outcome or service should inform each part of the development
3. Be inclusive / This is for everyone (NHS / GOV.UK)	Inclusive and accessible for everyone and not just for a select few
4. Design for context / Understand context (NHS / GOV.UK)	Design with the entire user journey in mind, consider how each aspect fits together to build the bigger picture
5. Design for trust (NHS)	Information created should be reliable and any information supplied by the user should be confidential
6. Test your Assumptions / Design with data (NHS / GOV.UK)	Test the design with real people. Work with researchers and experts to produce credible findings to support the design or point out what needs improving
7. Make, learn, iterate / Iterate, then iterate again (NHS / GOV.UK)	Start small before iterating more widely. Test designs repeatedly (alpha versions, beta versions etc.)
8. Do the hard work to make it simple (NHS & GOV.UK)	Some site journeys can be complex. Take the time to think through the process and not make things more complex than they need to be
9. Make things open (NHS & GOV.UK)	Share the work, be accountable, and be transparent in the designs
10. Do less (GOV.UK)	Only do what can be achievable. Utilise principles from designs that have been proven to work
11. Be consistent, not uniform (GOV.UK)	Use the same language and design patterns wherever possible. Consistency results in familiarity

Taken from their respective websites: https://service-manual.nhs.uk/design-system/design-principles & https://www.gov.uk/guidance/government-design-principles

The principles described by the NHS and GOV.UK are largely in keeping with the ethos of the current resource. Namely, that the resource is focused on the intended audience and that testing is needed to ensure the suitability of the resource. While it is interesting to note the development principles behind some of the biggest UK educational websites, the principles themselves are not very pragmatic. They refer to how design should be approached and do not necessarily provide usable tactics to implement into the development of an online educational resource.

Ho et al., (2004) were interested in exploring the implementation of research specifically to online health resources. They looked at research discussing the development of online health resources and documented the potential issues implementation into online mediums faced and the practical tactics that can help circumvent these issues. Their results are presented in table 2.

Table 2) Table two depicts the categories, issues and tactics researchers face when developing online health materials. Aspects that are relevant to the current resource's development are highlighted in red and *italicised*.

Category	Issues	Tactics
Organisational factors	Institutional policies Effect on organisation	Top management support and leadership Participative decision making
Financial issues	*Financing* Profitability *Sustainability* Professional compensation	Accurate and timely communication *Investment by organisations and governments* *Professional incentives and rewards*
Legal issues	*Liability* *Copyright infringement* Jurisdiction Electronic signature	Interjurisdiction reciprocity agreements Registration process for out-of-jurisdiction practitioners
Ethical issues	Interregional variability in political, economic, and health care contexts Patient consent Confidentiality	Full control over data provided Informed consent Information about privacy and confidentiality standards
Professional issues	Regional differences in standards of practice, certification, and licensure Lack of standards in communication and documentation of care within and between professions across settings Professional access rights Interference with patient-physician encounter	National licensure systems Multidisciplinary development Inclusion of IT into professionals' role Integrated clinical workstations
User factors	Authentication *Access* *Understanding* *Interface design* Workflow Cultural impediments to acceptance Cultural variation in languages	*Practitioner and patient-centred design principles* Pre-process resources to standardise presentation to the user Training Virtual reality

Logistical issues	*System performance, portability, and compatibility* Data archival and retrieval standards *Multiplication of users' interfaces and software* *Installation, maintenance, and user support*	*Accommodates multiple platforms (e.g., PC, phone)* *Tools working around the clock, recovery, procedures, redundant hardware* Integrated health IT systems Health information-sharing consortiums
Cognitive issues	*Lack of a general metaknowledge to structure internet resources* Validity of medical concept representation *Avoid "overlearning"*	*Meaningful organisation of the medical domain* Ergonomics *Tailored information* Learning by doing with simulators Diagnostic support systems
Content issues	*Author credentials and responsibility* *Reliability* *Accuracy*	Quality seal of approval standards *Knowledge must be documented; date of publication, releases, authors, sources, references* *Peer-review system* Repurposing data by sharing

Taken from Ho et al. 2004. Technology-enabled knowledge translation: frameworks to promote research and practice. *Journal of Continuing Education in the Health Professions*, *24*(2), 90–99. https://doi-org.mmu.idm.oclc.org/10.1002/chp.1340240206

The guidance created by Ho et al., (2004), covers a variety of different areas that may be involved in developing online educational resources. However, it is important to note that these guidelines were created for the creation of e-health materials, which is a broad category referring to any type of online health material. Therefore, depending on what the resource is, not every category, issue and tactic will apply to its development and maintenance. For example, ethical issues around confidentiality of personal data are not appropriate for the development of the current resource, as the resource is purely educational, it does not require any personal data to be entered at any point of engaging with it. Of the categories, issues and tactics deemed relevant to the current resource's development are discussed.

Financial Considerations

The only financing costs are for domain registration (the website address) and the website hosting/ platform (in this case “Ionos” was used). Through a successful application to Manchester Metropolitan University, a funding award was given to the researcher. This funding award covered the full costs of the development of the educational resource and provided the resource to be hosted online for a full year. In order for the resource to remain online and be sustainable over time other avenues of support are needed. Once the resource has been evaluated, if the results are favourable, the resource could be funded by a relevant charity organisation (e.g., National Autistic Society, Autistica, etc.). The website could be hosted on the organisations pre-existing websites domains, meaning costs would be minimal.

Legal Considerations

The researcher is liable for the content of the resource. As the resource is educational and does not require any payment or personal details to be provided, legal liability issues are minimal. However, one issue that may arise is copyright infringement. Careful consideration of images and diagrams is required in order to avoid complications. Images and diagrams were created by the researcher themselves, bought from credible sources (e.g., Shutterstock Images), or accompanied with full references and rights to the full author.

User Considerations

In order for the resource to be easily accessible by the intended user, consideration to the online journey of the user was needed. Utilising the findings from Chapter Three and implementing them throughout the development ensured the resource was developed with consideration of the intended audience. Additionally, theories and research on design implementation (e.g., cognitive load theory) ensured the choices made in the development were supported by credible external research.

Logistical Considerations

As the resource is hosted online, it needs to be instantly accessible and work seamlessly on all devices. The website is hosted by the company “Ionos”, which was selected as a credible and reliable website hosting business. They ensure the website is hosted around the clock, and provide easy access with trained staff to fix any issues around accessing the website. When developing the resource, “Ionos” provide the design capabilities to assess the functionality and presentation of the resource across different devices (desktop/laptop, tablet, android phone & apple phones). They provide the ability to make specialised changes to ensure the content will work across the different devices.

Cognitive Considerations

As the resource is intended to be used by all autistic adults, regardless of their experiences and knowledge (or lack of experiences or knowledge) on alcohol and drugs, the resource needs to provide an entry point accessible to all autistic adults. For the sections relating specifically to autistic topics of drug and alcohol topics to be effective, a general understanding of the topics should precede each of these sections. For example, “how common is addiction for autistic people?” needs to be preceded with the information on what an addiction is and how common it is for non-autistic people.

“Overlearning” of information may present a problem. This is when too much information on a particular topic is provided or the information covered is not novel and can be found in other educational resources. Providing too much information can be just as ineffective as not providing enough information (Zhang et al., 2021). To combat this, consideration to the length of each section and selecting the key information is needed. By including topics specific to autism and presenting the information in an accessible way for autistic people should ensure the resource is distinctive from other alcohol/drug educational resources.

Content Considerations

The final points for consideration relate to whether the content and information is credible, reliable, and responsible. Transparency and openness are crucial components in determining the credibility of scientific research (Adewumi et al., 2021; Ihle et al., 2017). In order for a health information initiative (such as an online resource) to be credible and trustworthy, the same principles apply (Vukovic et al., 2018). Who the resource was developed by and why needed to be clearly signposted in the resource. Additionally, how, where and why the information was sourced needed to be clearly stated. Incorporating this information is a credible way to increase the transparency and openness of any health educational resource (Vukovic et al., 2018).

1.1. Application to Current Resource (ADIFA)

By considering both the theoretical principles and the pragmatic design issues that may occur ensure that the implementation of the resource specifically for online mediums is successfully achieved. The points of consideration detailed provide a useful guidance on the certain aspects for the development of the resource. However, these principles may *describe* the development choices considered, but do not detail how the principles were *interpretated* specifically into the development of an online educational resource.

This chapter details the development choices made when creating the resource, the reasoning behind these choices and how they were implemented within the resource (including examples). This is important as the results from Chapter Three provided original and previously unexplored considerations from autistic adults themselves. As such, sufficient detail is needed to explain how these results were incorporated, particularly in regards to design choices on the content, language, and presentation of the resource.

2.0. Content of the Resource

2.1. Sourcing the Information

The information used in resource was sourced from three primary places: published peer-reviewed research, published books, and relevant charity and government websites.

The research and books selected were sourced from the literature review used for Chapter One of the PhD project. This research was important in creating information for the resource that was targeted and related specifically to autistic adults, as the research contained in Chapter One focused on these issues. Key pieces of research were selected in order to achieve this aim without overloading the resource with information.

In order to supplement the practical information, the resource needed information from relevant charity and government websites. The websites used were all UK based and provided guidance and/or treatments for drug and alcohol issues. A full list of the sites used can be found under the references and resources page of the website https://www.adifa.co.uk/page-4, but for example, they include the NHS, FRANK and Autistica. These websites were sourced using search engines (e.g., Google, DuckDuckGo), with the results filtered by locations (i.e., the UK). Researcher's discretion was used to assess whether the websites were credible, and all the websites cited were well established and well-known (e.g., the NHS).

2.2. Categorising information

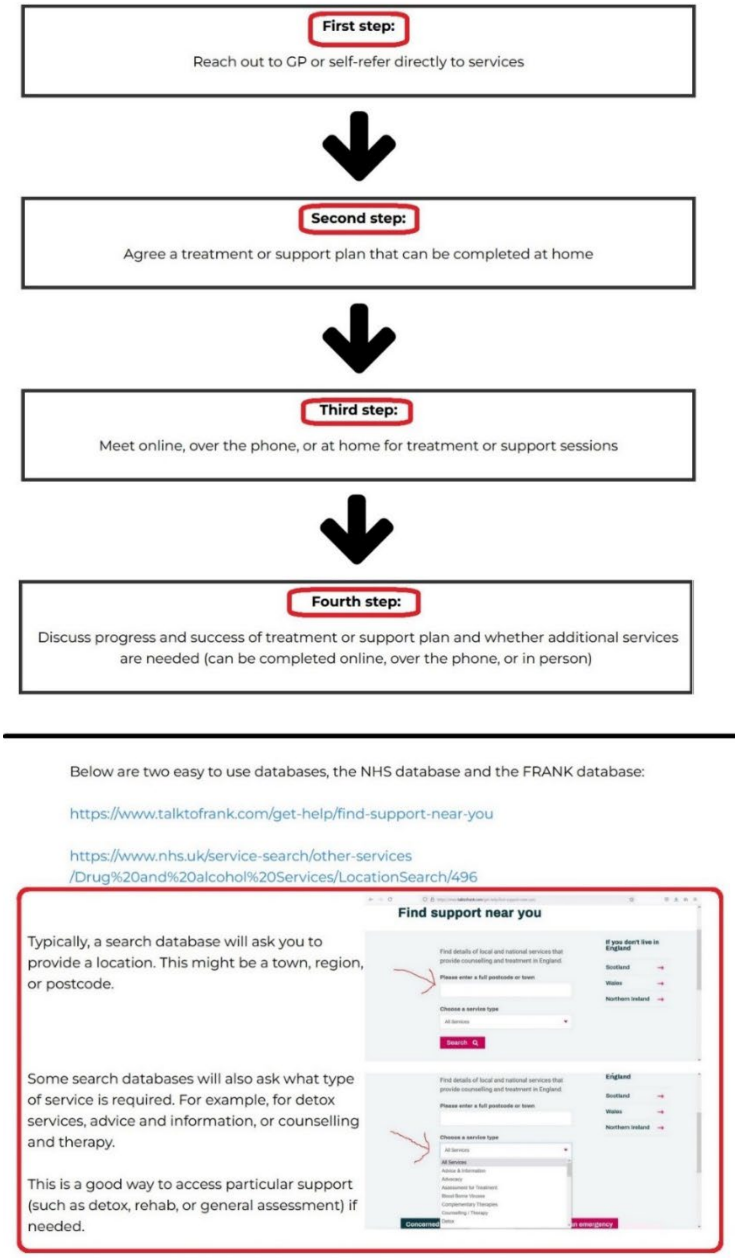
The information contained in the resource was categorised primarily into two defined categories; conceptual information and practical information.

Conceptual information refers to information on alcohol and drug topics, such as what they are and how they work. This information is not necessarily for the individual to act on, but more to inform them and increase their knowledge on alcohol and drug related topics. Whereas, the practical information contained detailed information relating more towards various forms of support and treatment that the individual could use (e.g., assessing use, where to get treatment). The primary aim of this type of information was to increase the individuals' knowledge but also provide them with detailed, practical resources and steps should they require support in real-life.

The information was split into these two general categories as in the previous qualitative study, autistic adults asked for the inclusion of detailed, practical information. This was because many felt educational material did not contain enough detail when discussing practical information. For example, limited types of contact details were provided (like a phone number) instead of a description of all the ways contact can be made with a particular source.

To accommodate for this need, the practical information contained in the resource detailed multiple avenues of contact, more detail on how treatments can be adjusted, and descriptions of relevant processes step-by-step.

Example 1) This demonstrates how practical information was categorised and displayed in the educational resource



First step:

Reach out to GP or self-refer directly to services

Second step:

Agree a treatment or support plan that can be completed at home

Third step:

Meet online, over the phone, or at home for treatment or support sessions

Fourth step:

Discuss progress and success of treatment or support plan and whether additional services are needed (can be completed online, over the phone, or in person)

Below are two easy to use databases, the NHS database and the FRANK database:

https://www.talktofrank.com/get-help/find-support-near-you

https://www.nhs.uk/service-search/other-services
/Drug%20and%20alcohol%20Services/LocationSearch/496

Typically, a search database will ask you to provide a location. This might be a town, region, or postcode.

Some search databases will also ask what type of service is required. For example, for detox services, advice and information, or counselling and therapy.

This is a good way to access particular support (such as detox, rehab, or general assessment) if needed.

Find support near you

Find details of local and national services that provide counselling and treatment in England

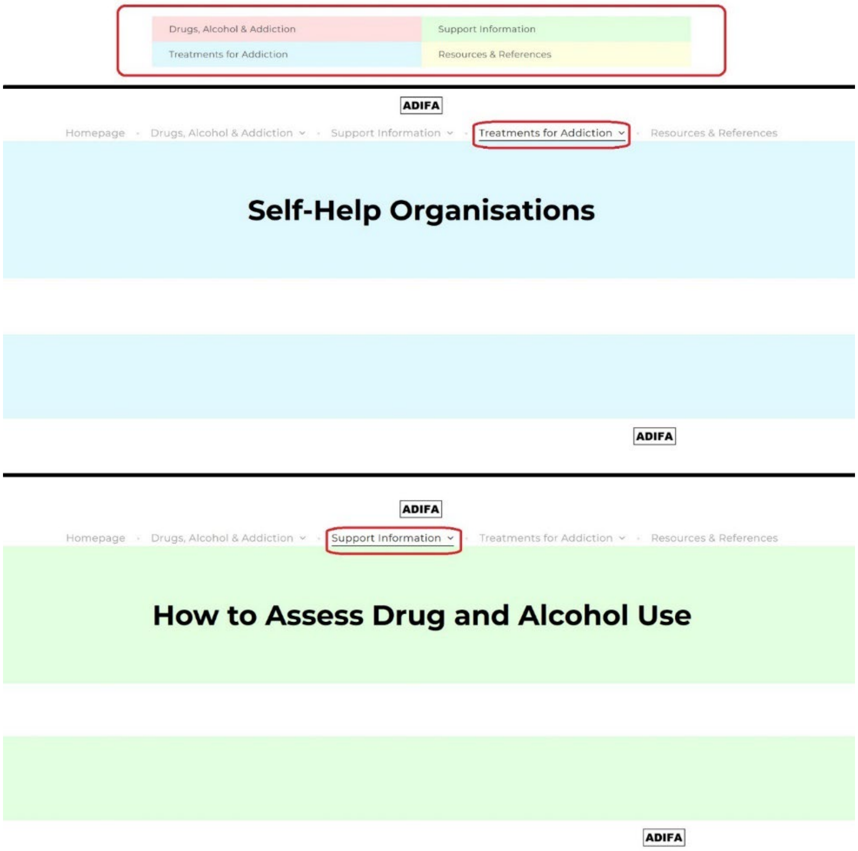
Please enter a full postcode or town

Choose a service type

All Services

In order to better signpost the different sections of the resource, colour bookends were used. This notion is used to help readers quickly and easily delineate the different sections and what section they are currently reading. This is not a technique that has been applied in other educational resources, but as the resource is split into defined categories, this technique was thought to help readers navigate the resource more easily. Additionally, research suggests that to increase the accessibility of a resource, individuals should be able to easily identify what section in the resource they are currently viewing (Chandrananth et al., 2017). Including coloured bookends helps to achieve this by providing an easy, visual cue on each section. The efficacy for utilising this approach will be explored in Chapter Five, when feedback from autistic adults is explored.

Example 2) This example demonstrates the bookending of each section in the resource



2.3. Inclusion of Autism-Specific Information

Throughout the resource, the information contained was focused specifically toward autism and autism-related topics. This was due to the findings from Chapter Three, in which autistic adults voiced a clear need for the resource to relate typical alcohol and drug information to autism and autistic people. Each of the conceptual knowledge sections started by talking about a particular topic of alcohol and drugs generally but finished on how this topic related to autism or autistic people. For example, the section may begin by discussing how common addictions are in the general population and finish with the statistics on how common addictions are specifically for autistic people. This notion can also be found in the practical information sections, such as including a section on social anxiety, a problem often experienced by autistic people.

Example 3) This example demonstrates how autism-specific topics were categorised in the resource

How Common is Addiction?

Establishing how common addiction is can be problematic, particularly for illegal drugs. This is because people may not want to admit to using a drug that is illegal.

The most recent data collected by the office for national statistics estimated that 2.1% of adults are frequent users of drugs, with that number doubling to 4.3% for those aged 16 to 24

How Common is Addiction for Autistic People?

Drug and alcohol addiction is perhaps not something people would think about in regards to autism and autistic people. While this may have been true in the past, more current research and attention has been conducted in this area.

Why do people use alcohol and drugs?

People might use drugs or alcohol for a variety of different reasons, such as to "fit in" with friends, to cope with feelings or mental health problems, or simply because they like the way it makes them feel.

Not everyone who uses drugs or alcohol will become addicted. Many people drink alcohol or use drugs without losing control over their use and are able to stop at any time, whereas for

Why do autistic people use drugs or alcohol?

Autistic people, like non-autistic people, might use drugs and alcohol for a variety of different reasons. However, research in this area had highlighted two potential reasons that may impact drug and alcohol use in particular for autistic people.

3.0. Language Use

3.1. Accessibility of Language

In order to make the resource accessible for autistic adults, careful consideration was given to the language used. The resource prioritised simple, clear language, free from any jargon. This was important as in the findings from Chapter Three, autistic adults specifically asked for simple and clear language to be used. Alcohol and drugs are complex topics and as such careful consideration was needed to simplify the information without diluting its significance.

In order to assess the resources language readability, Flesch-Kincaid tests were conducted (Flesch, 1984). These tests are used to assess the comprehension difficulty of information based on word length, sentence length, and average syllables used. The Flesch-Kincaid Reading Ease Score test uses this information to determine a score. The score runs from 1 – 100, with the higher the score, the easier the information is to read. The Flesch-Kincaid Grade Level test uses the same information but in a different formula, in order to determine the grade level of the text. The grade levels run from 0 – 18, with the lower the grade level, the lower the level of literacy is needed to understand the information. The grades produced are based on school grade level systems in the U.S.A.

Both of the Flesch-Kincaid tests have been extensively used in research to test the readability of particular text-based information. For example, the tests have been used to assess the readability for many health and e-health materials such as for diabetes (Lipari et al., 2020), Parkinson's disease (Fitzsimmons et al., 2010), general hospital information sheets (Williamson & Martin, 2010), patient informed consent forms (Terblanche & Burgess, 2010), and even more recently on patient coronavirus (COVID-19) educational material (Szmuda et al., 2020).

These tests have also been used to evaluate health websites on autism and autistic-related topics. Kollia et al. (2019), used the Flesch-Kincaid reading ease score and the grade level test to assess the readability of 100 websites that specifically related to “autism spectrum disorder”. The websites were selected by entering the term, “autism spectrum disorder” in a search engine and selecting the first 100 websites that met their criteria: an un-sponsored webpage, written in English, and containing a URL that led directly to an article or webpage. The websites were split into two groups dependent on their URL, an “official” URL group (i.e., .org, .gov, .edu), and a non-official URL group (i.e., .ca, .uk, .int, .us). They found that the “official” webpages had on greater readability scores (35.9) than the “non-official” webpages (34.1) They also found that the “official” webpages required lower grade levels (11.9) than the “non-official” webpages (12.8). Despite the intension of the website, the authors argue that on average, information on autism is not accessible for the average reader and may not fulfil the needs of the individual seeking out this information (Kollia et al., 2019). This further highlights the importance in using these tests to determine whether a resource is accessible or not. Additionally, this highlights the need for educational resources to check the accessibility of the language used in the development stages.

These tests have also been used to assess readability of educational material on alcohol and drug topics. For example, Sharma et al. (2018), used both Flesch-Kincaid tests to assess a leaflet they had developed on the consequences of alcohol abuse. They found their leaflet scored 46.6 on reading ease and grade 12 on the grading level (Sharma et al., 2018). Another study looked at drug information created and distributed by a government agency in the Philippines (Fermina & Rachelle, 2020). They found that the information provided on cannabis had greater readability scores and lower grade levels than the information on methamphetamine (reading ease score of 44.5 compared to 36.6; grade level of 9.5 compared to 10.8). This demonstrates that some drugs may be harder to describe in an accessible way than other drugs. In order to accommodate for this, each topic contained in the current resource (ADIFA) will have their readability and grade level tested. Both of these studies (and the study on autism-related health topics) demonstrate how the Flesch-Kincaid tests can provide a credible assessment of the readability of information on topics relating to alcohol, drugs and autism.

As these tests have been used for similar health educational materials, the tests were conducted to assess the readability of the current resource's text-based information. The results for each page of the resource are described in Table 3.

Table 3) Table three details the findings from the Flesch-Kincaid Reading Ease Score and the Flesch-Kincaid Grade Level tests conducted on each of the current resource's webpages.

Resource Page	**Flesch-Kincaid Reading Ease Score (1 – 100)**	**Flesch-Kincaid Grade Level (0 – 18)**
Homepage	61.7	7.2
Drugs, Alcohol & Addiction Header Page	52.5	7.5
How do Drugs and Alcohol Work?	46.6	10.2
What is an "Addiction"?	49.2	10
Why do People use Alcohol or Drugs?	56	9.1
Support Information Header Page	60.7	6.6
Who to Contact for Support with Addiction and How?	64.7	7.1
Where does Support and Treatment Take Place?	60.6	7.5
How to Assess Drug and Alcohol use?	53.9	8.3
Strategies for Social Anxiety	42.5	9.3
Treatments for Addiction Header Page	46.8	8.3
Talking Therapies	59.4	7.5
Medical Treatments	49.5	8.8
Self-Help Organisations	54.4	7.9
References & Resources	30.3	9.7
Average for the Entire Resource	**52.5**	**8.3**

According to the literature, the average adult in the U.S.A. reads at a level of grade 8 (Cotugna et al., 2005), which in the UK would equate to Year 9 (ages 13 – 14). Overall, the educational resource's grade score is in line with the average for adults. The recommendations for medical educational materials are to aim for a grade of 5-6 in order to reach the widest possible audience (Cotugna et al., 2005). However, in practice, this is rarely achieved. For example, the previously mentioned study comparing “official” and “non-official” websites found that the “official” websites required grade levels of 11.9 (Kollia et al., 2019). This means for .gov .org and .edu websites required almost twice the recommended grade level, compared to the current resource which was roughly only two grades higher than recommended. The current resource’s Flesch-Kincaid scores are in line with, or better than the other studies mentioned (e.g., Szmuda et al., 2020). In addition, the current resource’s scores were better than for the resources relating to both autism and alcohol and drug topics (e.g. Kollia et al., 2019; Sharma et al., 2018; Fermina & Rachelle, 2020).

However, this assessment is not infallible, as certain medical or research terms can increase the grade level needed (e.g., “antagonist” drugs), even if the terms are followed by an explanation. This can also help to explain why the references and resources page has the lowest score and one of the highest grade levels, as typically research citations may contain words categorised as complex and hyperlinks may be classed as one long word. To counteract this, in the current resource, if any specialist language was used, it was followed (or preceded) by a simple explanation. For example, the term “receptors” is used in describing how drugs work, which is followed by a simple explanation as “responsible for generating signals within the brain”.

While the average grade score is in line with the average for an adult (albeit in the U.S.A.), assessing the readability from autistic adults will be key in determining whether there are any changes needed (particularly on specific pages). Additionally, conducting the tests on each page of the resource helps to suggest whether certain pages may be more difficult to read than others.

3.2. Appropriate Terminology

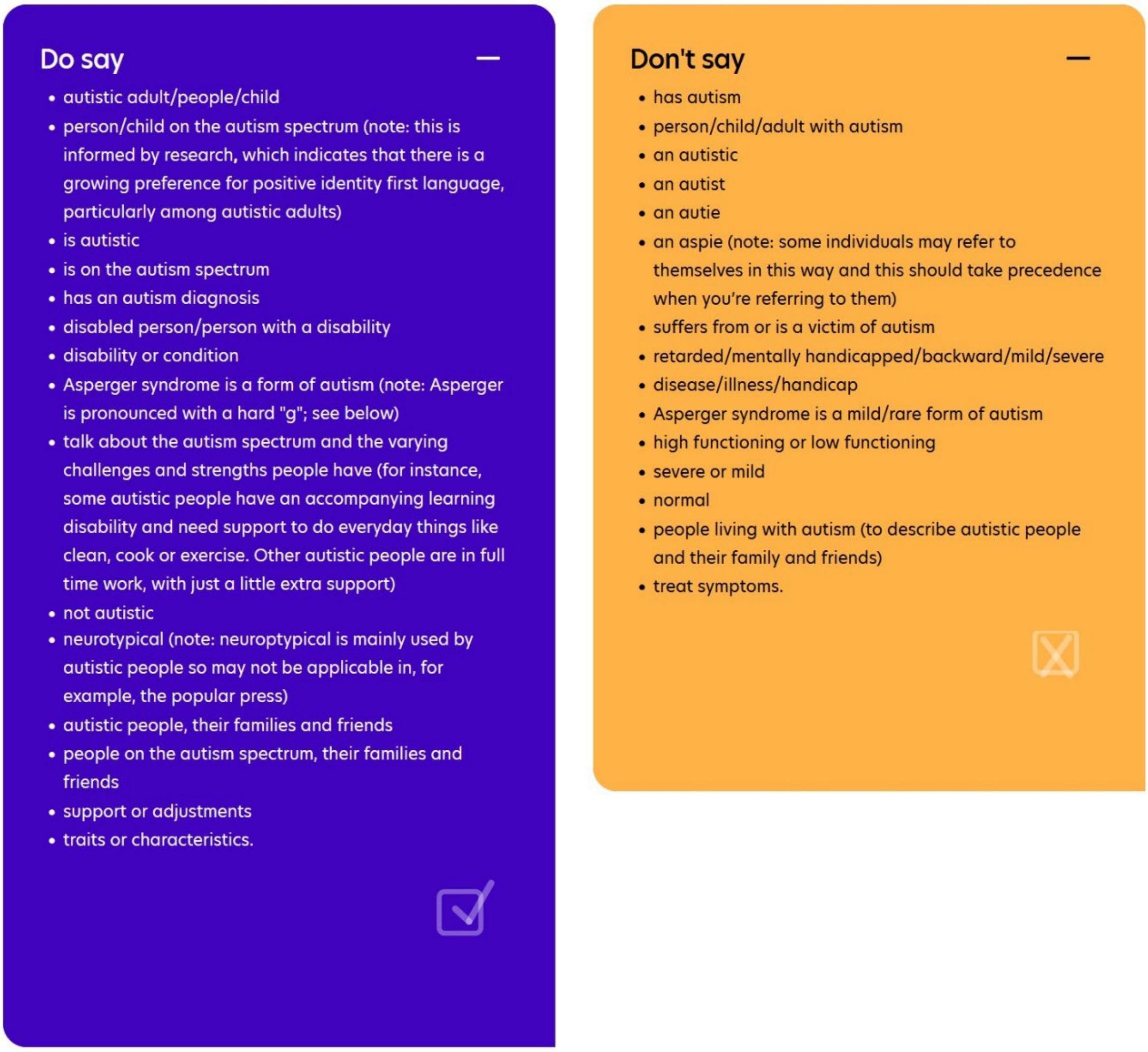
Another aspect of the language used that can make the resource more accessible is the terminology used to describe autism and autistic people. The results from the Chapter Three highlighted the importance of referring to autistic people as such, and avoiding what is known as "person first" language.

Person first language is described as putting the individual before the condition or disability. For example, for addiction, person first language would describe an individual as "someone *with* alcohol or drug problems" (Zgierska et al., 2021). However, many autistic people and their families do not find this type of language appropriate.

In their study on terminology for autism, Kenny et al., (2016) found that autistic people believe that autism is who they are, an integral part of themselves, and that the use of person first language negatively contradicts this. The use of person first language implies that autism is something they have, potentially something that needs fixing, and not who they are. The study also found that at the time, the majority of health professionals preferred to use person-first language, which was in direct contrast with autistic people's preferences (Kenny et al., 2016). This shows the potential disparity that can arise from professionals working with or researching autism and the thoughts and beliefs of autistic people themselves. In order for a resource targeted for autistic adults to be accessible, researchers need to consider the terminology carefully and use terms that autistic people themselves use.

Based on this research, the National Autistic Society (2020) website created guidelines for people to use when referring to autism and autistic people. The guidance provided a useful list of what words were acceptable and what words to avoid. The guidelines are displayed in Image 1.

Image 1) The "Dos" and "Do nots" of writing and referring to autism and autistic people taken from the National Autistic Society's website (https://www.autism.org.uk/what-we-do/help-and-support/how-to-talk-about-autism)



Do say

- autistic adult/people/child
- person/child on the autism spectrum (note: this is informed by research, which indicates that there is a growing preference for positive identity first language, particularly among autistic adults)
- is autistic
- is on the autism spectrum
- has an autism diagnosis
- disabled person/person with a disability
- disability or condition
- Asperger syndrome is a form of autism (note: Asperger is pronounced with a hard "g"; see below)
- talk about the autism spectrum and the varying challenges and strengths people have (for instance, some autistic people have an accompanying learning disability and need support to do everyday things like clean, cook or exercise. Other autistic people are in full time work, with just a little extra support)
- not autistic
- neurotypical (note: neuroptypical is mainly used by autistic people so may not be applicable in, for example, the popular press)
- autistic people, their families and friends
- people on the autism spectrum, their families and friends
- support or adjustments
- traits or characteristics.

☑

Don't say

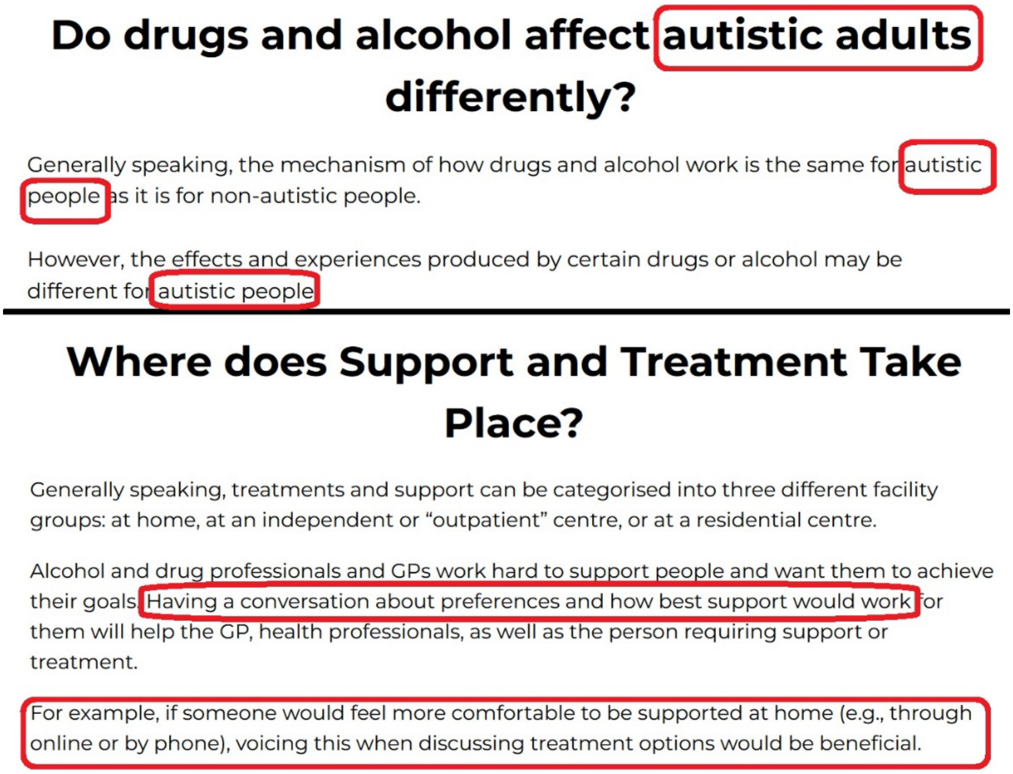
- has autism
- person/child/adult with autism
- an autistic
- an autist
- an autie
- an aspie (note: some individuals may refer to themselves in this way and this should take precedence when you're referring to them)
- suffers from or is a victim of autism
- retarded/mentally handicapped/backward/mild/severe
- disease/illness/handicap
- Asperger syndrome is a mild/rare form of autism
- high functioning or low functioning
- severe or mild
- normal
- people living with autism (to describe autistic people and their family and friends)
- treat symptoms.

☒

The guidelines proposed by the National Autistic Society were applied to the development of the current resource. The resource omits person first language and instead refers to autistic adults as such. This language is consistent across the website, including when discussing research studies that looked at various aspects of autism (as originally, these studies may have used person first language).

Additionally, the sections on practical information refer to how support and treatment services can be *adjusted* to better *support* the needs of the autistic individual.

Example 4) This example demonstrates the terminology used to describe autistic people and autism in the resource



Do drugs and alcohol affect autistic adults differently?

Generally speaking, the mechanism of how drugs and alcohol work is the same for autistic people as it is for non-autistic people.

However, the effects and experiences produced by certain drugs or alcohol may be different for autistic people

Where does Support and Treatment Take Place?

Generally speaking, treatments and support can be categorised into three different facility groups: at home, at an independent or "outpatient" centre, or at a residential centre.

Alcohol and drug professionals and GPs work hard to support people and want them to achieve their goals. Having a conversation about preferences and how best support would work for them will help the GP, health professionals, as well as the person requiring support or treatment.

For example, if someone would feel more comfortable to be supported at home (e.g., through online or by phone), voicing this when discussing treatment options would be beneficial.

3.3. Neutrality and Impartiality

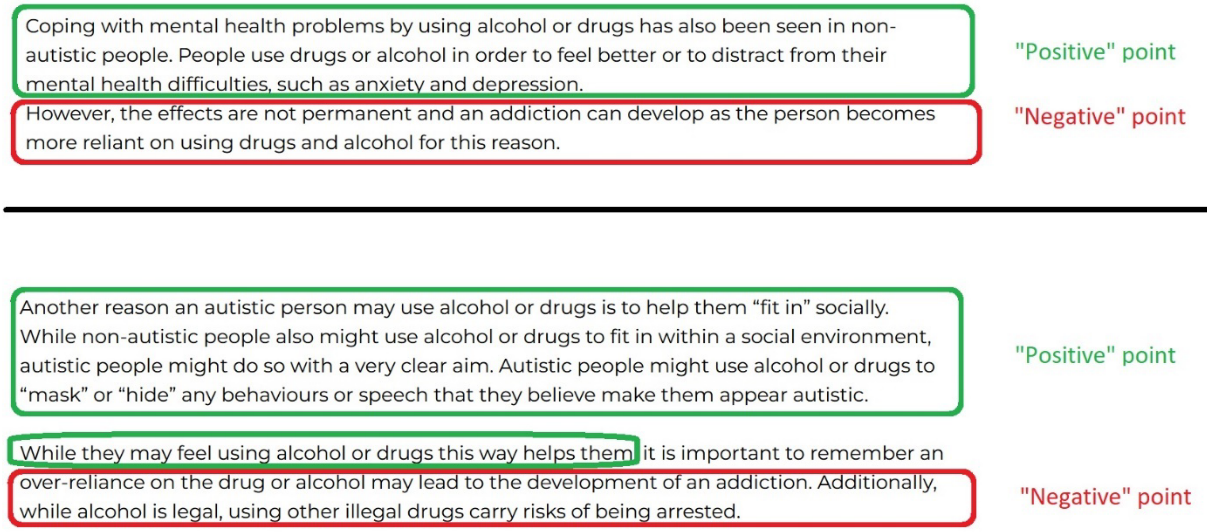
Another point raised by the findings in Chapter Three, was that the resource should be non-judgemental and without bias. Participants stressed the importance of not pushing an agenda, such as encouraging people to quit drug/alcohol use, or presenting information in a "scary" and confrontational way.

Employing the use of “scare tactics” is a common technique used in discussing alcohol and drug topics and education, however, the effectiveness of this approach is still in debate. In their systematic review of scare tactics in alcohol and drug research between 2005-2017, Esrick et al. (2019), found that around half of the research included supported the use of scare tactics, whereas, the other half of the research had mixed findings or did not support its use. This highlights the lack of conclusive evidence on the use of these tactics. Additionally, a lack of conclusive evidence is further supported by the fact that participants varied considerably between each study included in the review, as did the aims of the research and how the “scare tactics” or fear-based messages were employed.

Research suggests that in some instances, using “scare-tactics” or fear can be counter-intuitive. The use of these tactics can instead lead to an increase in stigma and judgement of the individuals who use drugs or alcohol. For example, the UK ran a health campaign called “Heroin screws you up” from 1985-86, which attempted to address the rise in heroin use through a targeted fear campaign. Researchers at the time found that these campaigns were successful in reaching the audience but that the campaign had fostered and reinforced negative attitudes and beliefs about heroin use and individuals who use heroin (Mold, 2021). This is a problem because research has shown that if an individual feels stigmatised, judged or alienated, then they are less likely to engage with support information or services (Branson et al., 2022). As the current resource has been developed for all autistic adults (including those with alcohol or drug problems), presenting information in a confrontational or judgemental way would be detrimental to the intended purpose of the resource.

In the development of the current resource, careful consideration of the language was used, with an emphasis placed on the inclusion of neutral language. While the negative aspects of addiction were discussed, they were not framed in an inflammatory and scary manner that would intentionally put people off using drugs or alcohol. Conversely, the positive aspects of drinking were included (such as fitting in to social situations) but they were not presented in a glorified way to support alcohol or drug use. Neutrality and balance were key. Additionally, sections discussing potential benefits or negatives of alcohol and drugs contained both sides.

Example 5) This example demonstrates how neutrality and balance of information was implemented in the resource



Coping with mental health problems by using alcohol or drugs has also been seen in non-autistic people. People use drugs or alcohol in order to feel better or to distract from their mental health difficulties, such as anxiety and depression.

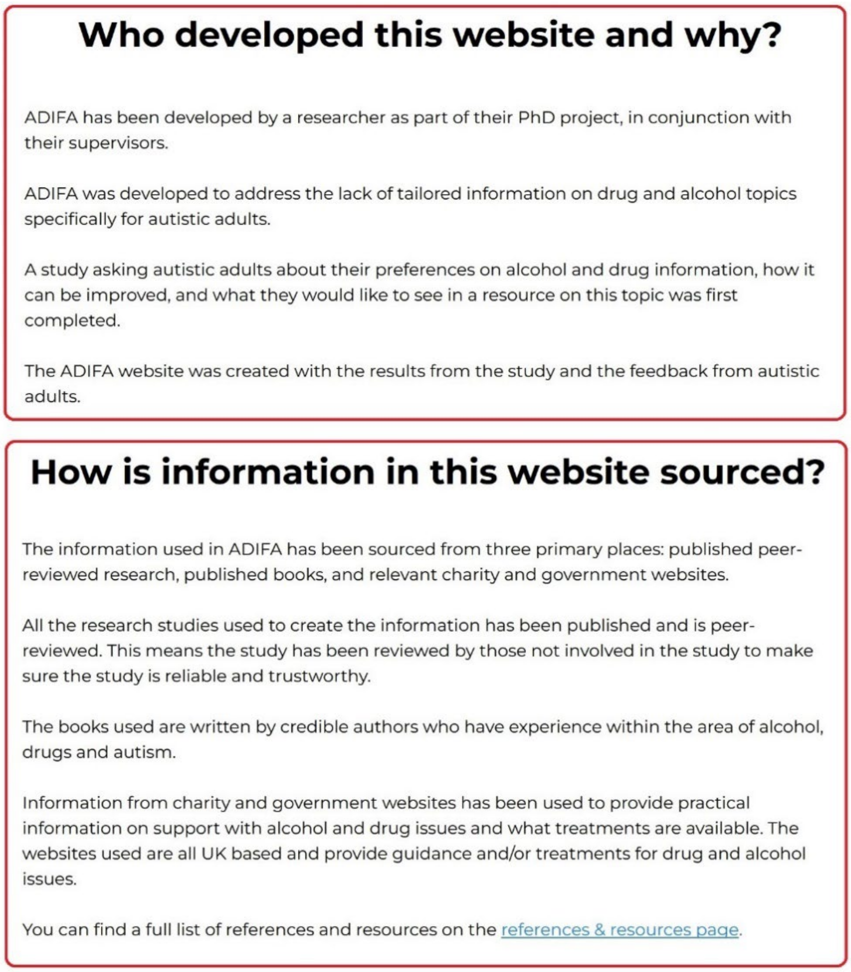
However, the effects are not permanent and an addiction can develop as the person becomes more reliant on using drugs and alcohol for this reason.

Another reason an autistic person may use alcohol or drugs is to help them "fit in" socially. While non-autistic people also might use alcohol or drugs to fit in within a social environment, autistic people might do so with a very clear aim. Autistic people might use alcohol or drugs to "mask" or "hide" any behaviours or speech that they believe make them appear autistic.

While they may feel using alcohol or drugs this way helps them it is important to remember an over-reliance on the drug or alcohol may lead to the development of an addiction. Additionally, while alcohol is legal, using other illegal drugs carry risks of being arrested.

Another way in which the resource could ensure its neutrality was through transparency of information. This included directly stating on the homepage who created the resource, why the resource was created, and how the information was sourced. This was to emphasise that the resource was developed with no agenda for or against alcohol or drug use and provides the individual with tools to assess and consult the sources themselves.

Example 6) This example demonstrates how transparency was implemented in the resource



Who developed this website and why?

ADIFA has been developed by a researcher as part of their PhD project, in conjunction with their supervisors.

ADIFA was developed to address the lack of tailored information on drug and alcohol topics specifically for autistic adults.

A study asking autistic adults about their preferences on alcohol and drug information, how it can be improved, and what they would like to see in a resource on this topic was first completed.

The ADIFA website was created with the results from the study and the feedback from autistic adults.

How is information in this website sourced?

The information used in ADIFA has been sourced from three primary places: published peer-reviewed research, published books, and relevant charity and government websites.

All the research studies used to create the information has been published and is peer-reviewed. This means the study has been reviewed by those not involved in the study to make sure the study is reliable and trustworthy.

The books used are written by credible authors who have experience within the area of alcohol, drugs and autism.

Information from charity and government websites has been used to provide practical information on support with alcohol and drug issues and what treatments are available. The websites used are all UK based and provide guidance and/or treatments for drug and alcohol issues.

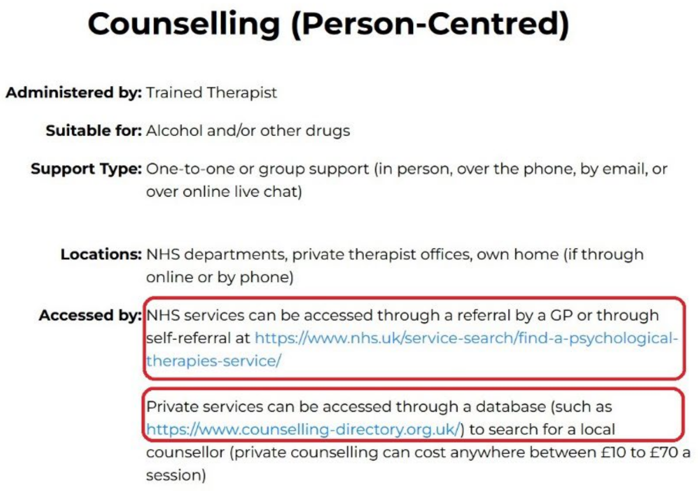
You can find a full list of references and resources on the references & resources page.

This transparency of sources was further achieved by achieving hyperlinks to the sources themselves. Whenever third part information was included (such as drinking diary examples), hyperlinks were provided for the individual to gain direct access to the information’s source.

Example 7) This example demonstrates the use of hyperlinks in the resource for any external sources

However, it can be tricky to know how many units of alcohol are in a drink. Diagrams have been created to easily show how many units are in each drink, such as the one created by Cancer research UK.

Alcohol Unit Diagram. Taken from Cancer Research UK



Counselling (Person-Centred)

Administered by: Trained Therapist

Suitable for: Alcohol and/or other drugs

Support Type: One-to-one or group support (in person, over the phone, by email, or over online live chat)

Locations: NHS departments, private therapist offices, own home (if through online or by phone)

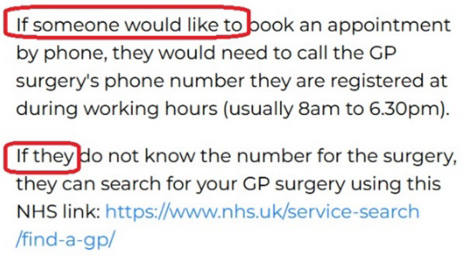
Accessed by: NHS services can be accessed through a referral by a GP or through self-referral at https://www.nhs.uk/service-search/find-a-psychological-therapies-service/

Private services can be accessed through a database (such as https://www.counselling-directory.org.uk/) to search for a local counsellor (private counselling can cost anywhere between £10 to £70 a session)

One final way in which neutrality was achieved was through the use of pronouns. Chandrananth et al. (2017), assembled a guide for researchers aiming to create e-health materials. They used orthopaedics as an example subject area and discussed their experiences of developing e-health materials and the lessons they had learnt through the development. One of their suggestions was the use of second-person pronouns such as “you” to increase the readability of the resource.

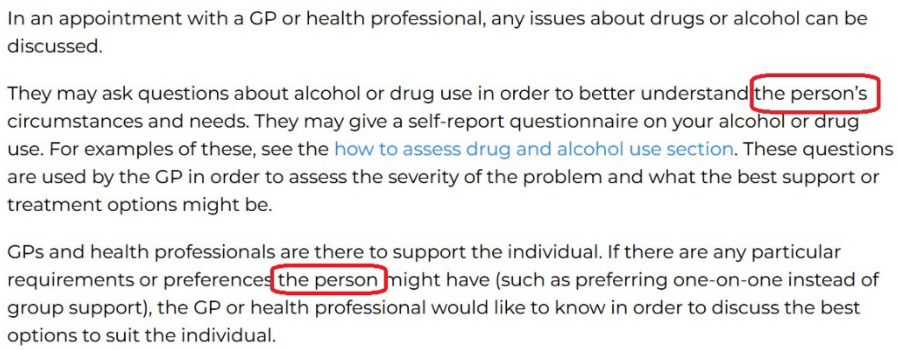
However, using second-personal pronouns in this instance may imply or infer that the reader uses alcohol or drugs or needs treatment or support with alcohol and drug-related problems. The intended audience for the research is for autistic adults, regardless of whether they have ever used alcohol/drugs. Therefore, in order to make the resource accessible to a wider audience—and not to imply any kind of judgement about their use or none use of alcohol/drugs—passive language and third-person pronouns were used. For example, instead of "*you* can get help by…", the resource used language such as "*If an individual* needs help, *they* can get help by…".

Example 8) This example demonstrates the neutral language used in the resource to refer to the reader



If someone would like to book an appointment by phone, they would need to call the GP surgery's phone number they are registered at during working hours (usually 8am to 6.30pm).

If they do not know the number for the surgery, they can search for your GP surgery using this NHS link: https://www.nhs.uk/service-search/find-a-gp/



In an appointment with a GP or health professional, any issues about drugs or alcohol can be discussed.

They may ask questions about alcohol or drug use in order to better understand the person's circumstances and needs. They may give a self-report questionnaire on your alcohol or drug use. For examples of these, see the how to assess drug and alcohol use section. These questions are used by the GP in order to assess the severity of the problem and what the best support or treatment options might be.

GPs and health professionals are there to support the individual. If there are any particular requirements or preferences the person might have (such as preferring one-on-one instead of group support), the GP or health professional would like to know in order to discuss the best options to suit the individual.

4.0. Presentation of the Resource

4.1. Structure of Information

The results from Chapter Three highlighted the importance of simple presentation. Consideration to how the information is structured on the webpage is an important aspect of creating simple and accessible use. Regardless of how engaging or thought-provoking information is, if it is difficult to locate it will be of no use to the intended audience (Chandrananth et al., 2017).

In one of their most cited articles, Nielsen (2006) tracked 232 participants eye-movements when they looked at websites. They found a consistent pattern across the different websites and situations used, namely that participants scanned the information in an “F” shape. This meant that the participants usually focused the most at the top of the webpage before then progressing down the page, mainly focusing on the left side of the page. The most attention is paid to the very top section of the page, particularly if an individual is simply scanning the page.

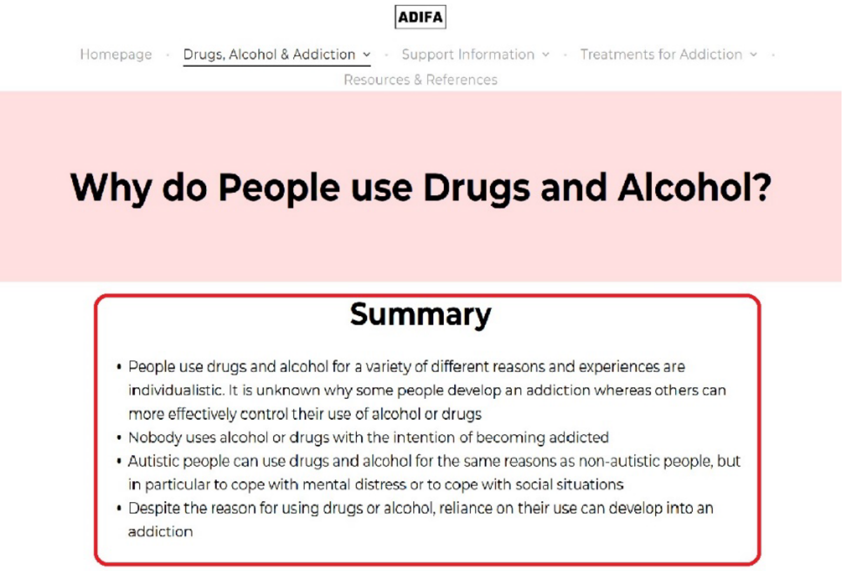
In order to better accommodate for this type of behaviour, the most important information should be located at the top of the webpage. For this reason, the majority of the webpages begin each section with a “summary” of the information contained on the page, located at the very top of the page. By locating this information at the top of the page, individuals who may not be interested in reading the full text can easily and effectively digest the key information (albeit in lesser detail) each page of the resource was trying to convey.

Example 9) This example demonstrates the location for the information deemed most important, the summary information

Where Does Support and Treatment Take Place?

Summary

- Help, support and treatments are chosen to suit the needs and preferences of the individual. They can take place in a variety of different settings depending on the type of treatment required
- Many support and treatment options can be completed at an individual's home. Treatments can be delivered through the internet, by the phone, or at a person's home but it depends on what the service is able to provide
- Some treatment options need to be completed at local centres. For example, many self-help groups prefer to have meetings in person at a local centre (such as a library or community hall)
- Residential treatments occur at specialised clinics or hospitals. They are usually required for people who need specialist supervision and support, such as managing severe withdrawal symptoms



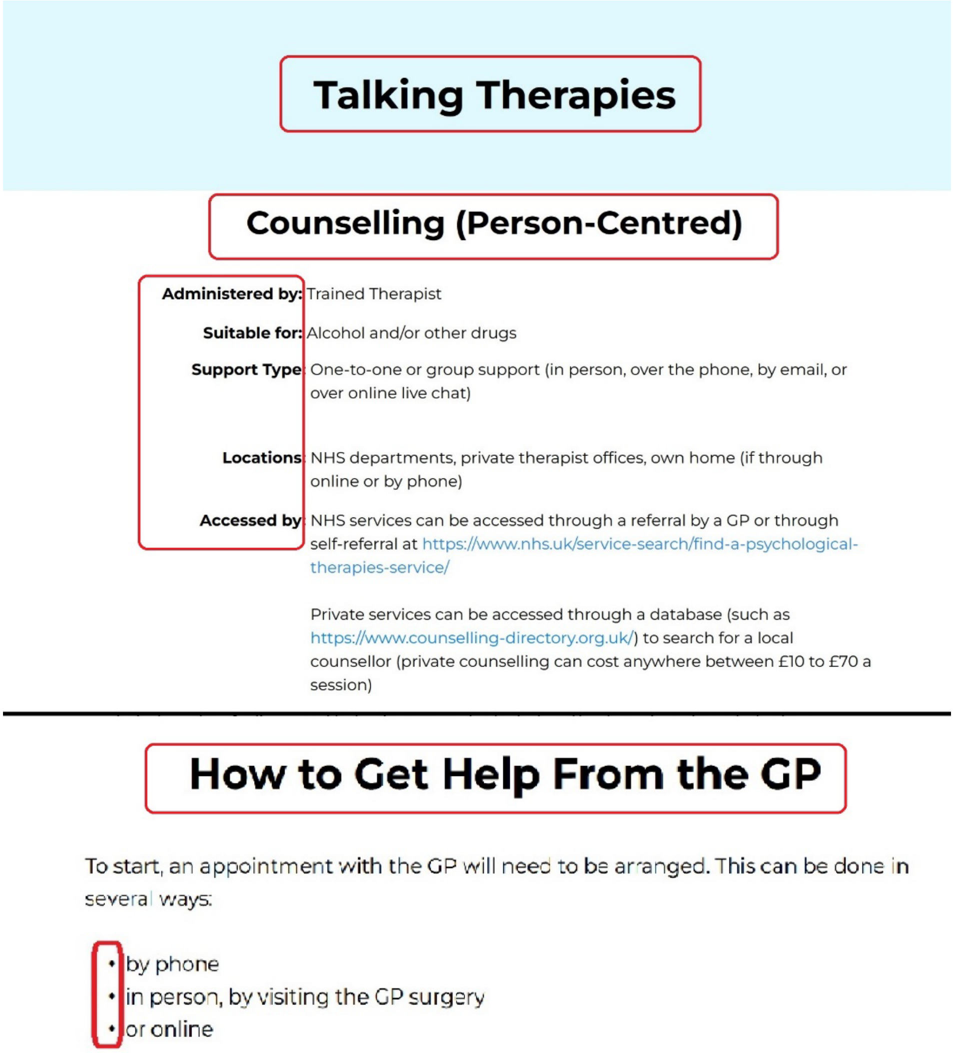
Why do People use Drugs and Alcohol?

Summary

- People use drugs and alcohol for a variety of different reasons and experiences are individualistic. It is unknown why some people develop an addiction whereas others can more effectively control their use of alcohol or drugs
- Nobody uses alcohol or drugs with the intention of becoming addicted
- Autistic people can use drugs and alcohol for the same reasons as non-autistic people, but in particular to cope with mental distress or to cope with social situations
- Despite the reason for using drugs or alcohol, reliance on their use can develop into an addiction

As Nielsen (2006) concluded, while browsing in an "F" pattern is not necessarily detrimental, information can be missed or not fully explored by the individual using the resource. In addition to providing the most salient information at the top of the page, Pernice (2017) proposed other recommendations that can be made in order to remedy or utilise the "F" shape scanning of website browsing habits. The recommendations included in the development of the current resource were the inclusion of headings and subheadings, emphasis of key words and phrases, and the use of bullet points and numbering where appropriate. These recommendations were utilised in order to redirect attention to particularly salient or important information and to help the summarisation of complex information.

Example 10) This example demonstrates the headings and subheadings, emphasised words or phrases, and use of bullet points in the resource



Talking Therapies

Counselling (Person-Centred)

Administered by: Trained Therapist

Suitable for: Alcohol and/or other drugs

Support Type One-to-one or group support (in person, over the phone, by email, or over online live chat)

Locations NHS departments, private therapist offices, own home (if through online or by phone)

Accessed by NHS services can be accessed through a referral by a GP or through self-referral at https://www.nhs.uk/service-search/find-a-psychological-therapies-service/

Private services can be accessed through a database (such as https://www.counselling-directory.org.uk/) to search for a local counsellor (private counselling can cost anywhere between £10 to £70 a session)

How to Get Help From the GP

To start, an appointment with the GP will need to be arranged. This can be done in several ways:

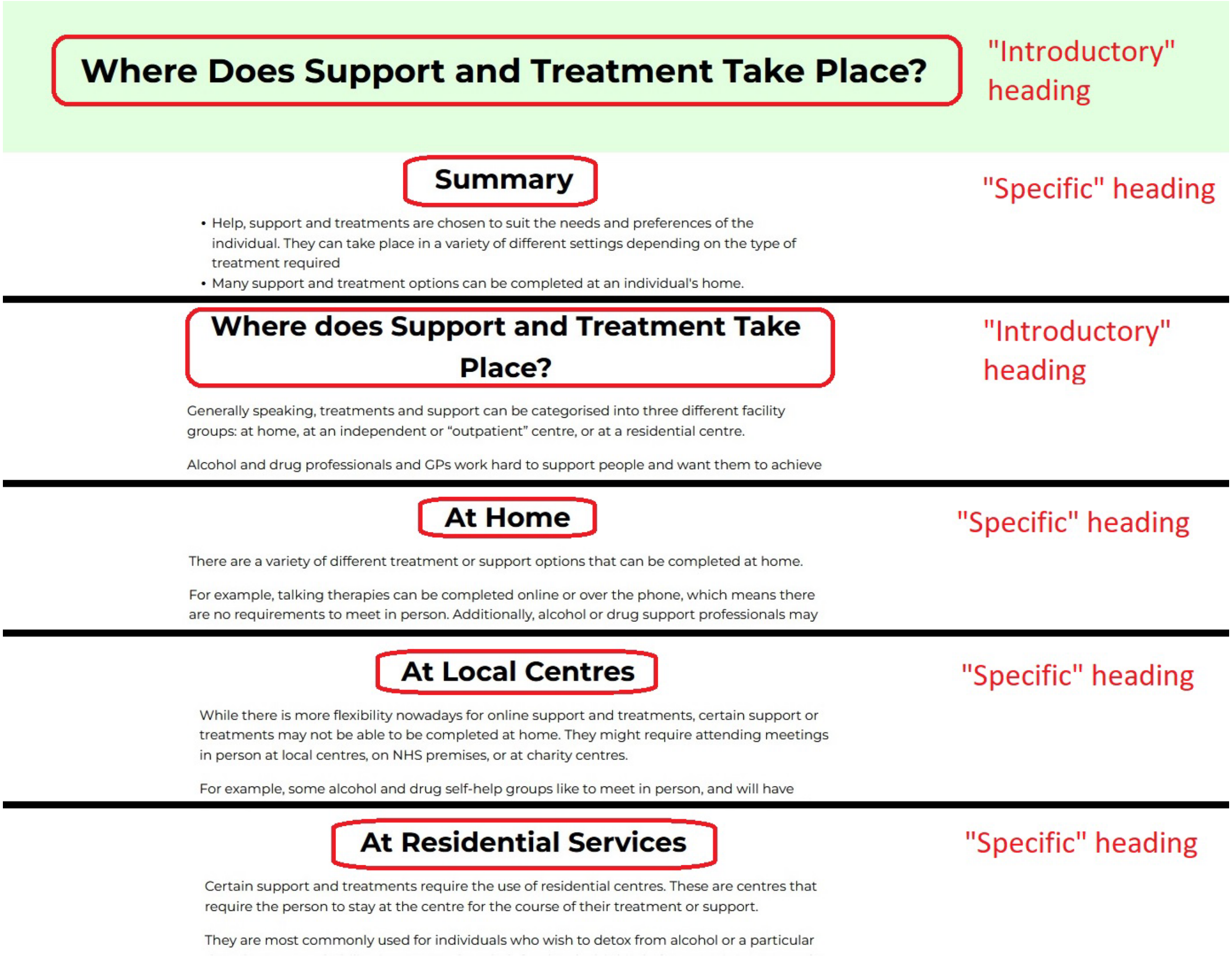
- by phone
- in person, by visiting the GP surgery
- or online

Another recommendation included from Pernice (2017) was that the most important words in the headings and sub-headings were located at the start of each respective heading (such as the first few words). This was employed in the website design for a number of the sub-headings.

However, other headings were longer and were phrased in a question format. Aliu & Chung (2010), compared their educational websites (on plastic surgery) with other educational websites on scores for readability. They used The Flesch-Kincaid formula (the grading system), the simple measure of gobbledygook (estimates the number of years of education needed to understand the information), and the Flesch Reading Ease (which provides a readability score from 0-100). They found that their resources required a greater level of education and were therefore lower in readability than the other websites tested. One of the recommendations they employed to improve this was by phrasing the sub-headings and headings as questions in order to direct attention towards a “chunk” of information at a time (Aliu & Chung, 2010).

Taking into consideration Aliu & Chung’s (2010) research, and Pernice’s (2017) recommendations, a mixture of both question-focused and shorter, key worded headings and sub-headings were used. Question-focused headings were used to introduce certain information, with shorter, key worded headings used for further and more specific information.

Example 11) This example demonstrates the use of specific headings and introductory question-based headings implemented in the resource



Where Does Support and Treatment Take Place?

Summary

- Help, support and treatments are chosen to suit the needs and preferences of the individual. They can take place in a variety of different settings depending on the type of treatment required
- Many support and treatment options can be completed at an individual's home.

Where does Support and Treatment Take Place?

Generally speaking, treatments and support can be categorised into three different facility groups: at home, at an independent or "outpatient" centre, or at a residential centre.

Alcohol and drug professionals and GPs work hard to support people and want them to achieve

At Home

There are a variety of different treatment or support options that can be completed at home.

For example, talking therapies can be completed online or over the phone, which means there are no requirements to meet in person. Additionally, alcohol or drug support professionals may

At Local Centres

While there is more flexibility nowadays for online support and treatments, certain support or treatments may not be able to be completed at home. They might require attending meetings in person at local centres, on NHS premises, or at charity centres.

For example, some alcohol and drug self-help groups like to meet in person, and will have

At Residential Services

Certain support and treatments require the use of residential centres. These are centres that require the person to stay at the centre for the course of their treatment or support.

They are most commonly used for individuals who wish to detox from alcohol or a particular

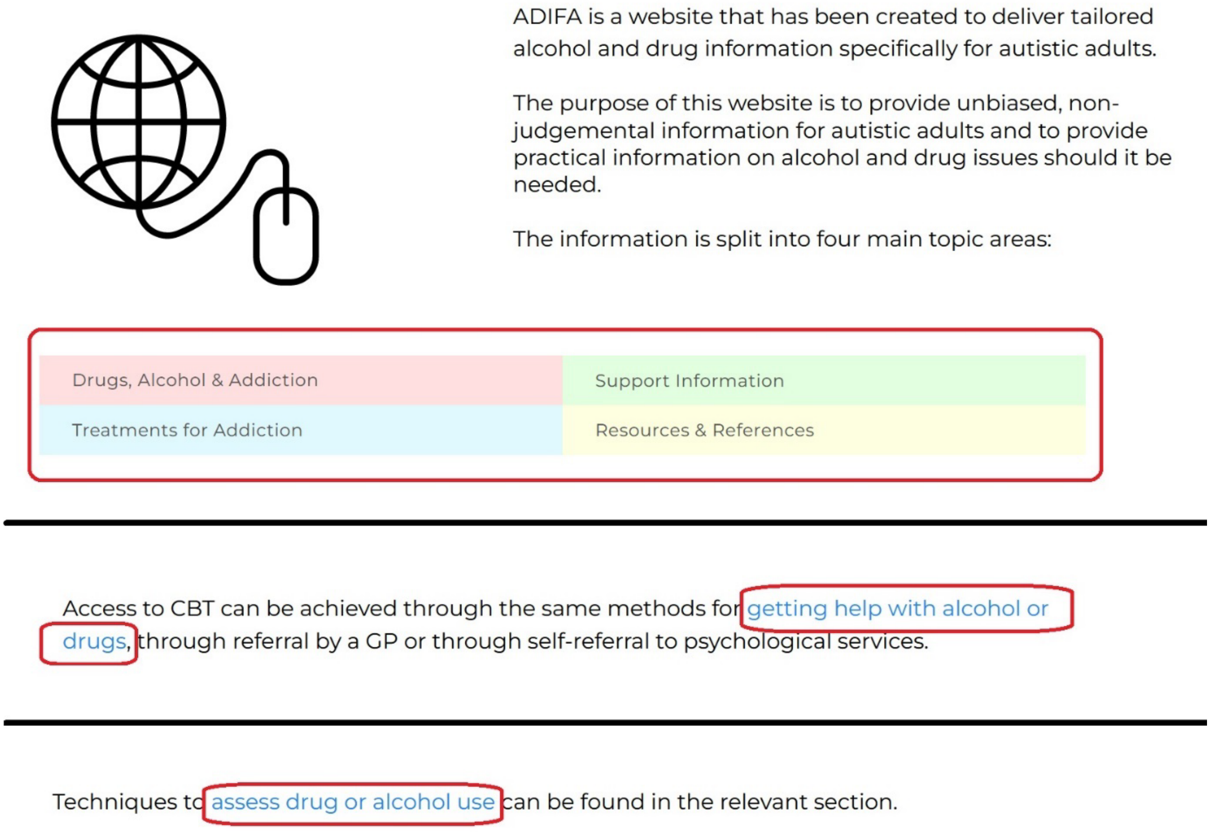
4.2. Navigation of the Resource

In order for the resource to be accessible, consideration to how the website would be navigated was needed. One way in which this was achieved was through the navigation of the menu bar and headings. Arts (2019), created and evaluated an e-health resource for pupils in high school with attentional problems. In their evaluations, they found that the use of clear and simple drop-down menus—that were conveniently displayed—were an effective and user-friendly design aspect (Arts, 2019). Similarly, in their e-health resource on nutrition for rural communities, Atkinson et al., (2009), found that individuals favoured the use of drop-down menus as opposed to menus that required clicking through to view the various sub-headings. As such, to make navigating the resource as simple as possible, information was structured into sections and each section was represented in the menu at the top of the page. If the section contained subsections these were displayed in a simple drop-down menu.

Example 12) This example demonstrates the use of drop-down menus used for the headings and subheadings in the resource

Page links were also created in order to aid navigation. As each many subsections of the resource had information that complemented or overlapped information in other subsections, navigation links were included to help the individual navigate to the complimentary information. For example, a link to the talking therapies page discussing cognitive behavioural therapy is included in the strategies for managing social anxiety, as this type of therapy is also suggested as a treatment option for social anxieties. This is to help reduce unnecessary repetition of information and provides quick access to relevant pages.

Example 13) This example demonstrates the page hyperlinks implemented for the different sections of the resource



ADIFA is a website that has been created to deliver tailored alcohol and drug information specifically for autistic adults.

The purpose of this website is to provide unbiased, non-judgemental information for autistic adults and to provide practical information on alcohol and drug issues should it be needed.

The information is split into four main topic areas:

Drugs, Alcohol & Addiction	Support Information
Treatments for Addiction	Resources & References

Access to CBT can be achieved through the same methods for getting help with alcohol or drugs, through referral by a GP or through self-referral to psychological services.

Techniques to assess drug or alcohol use can be found in the relevant section.

4.3. Use of Images and Diagrams

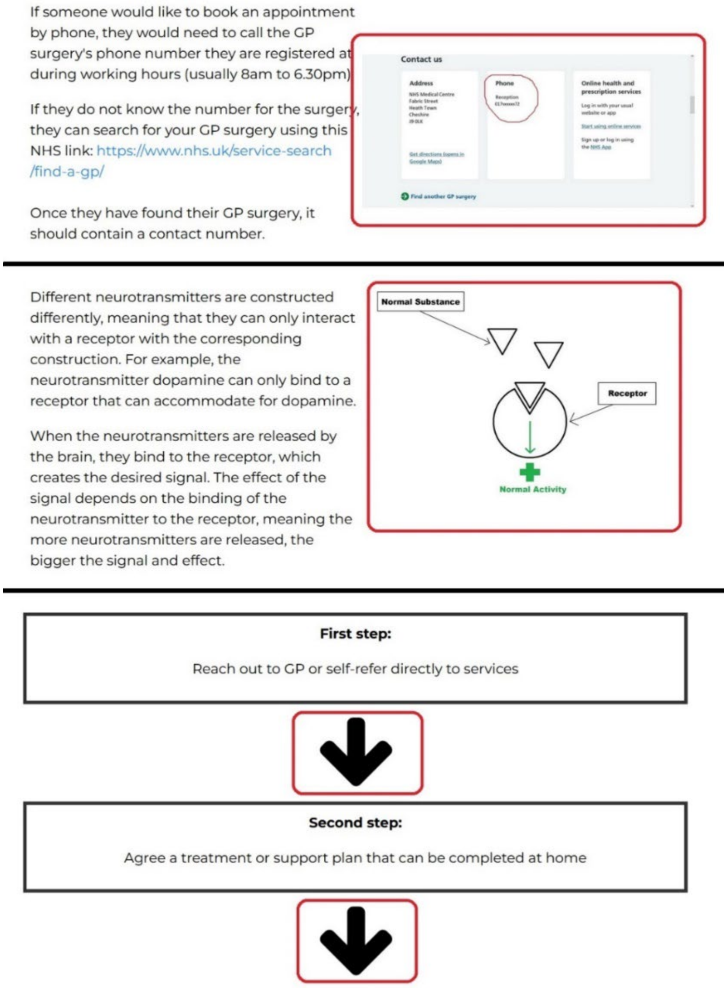
Consideration was given to the use of diagrams and images. Using images and diagrams in e-health resources is commonplace (e.g., Chandrananth et al., 2017). However, in Chapter Three, autistic adults specifically mentioned that images and diagrams should be functional and act to aid the accompanying text. Images and diagrams should not be used simply for aesthetic appeal as this can distract away from the information and in some cases put people off using the resource.

In order to successfully achieve this and integrate diagrams and images in a meaningful way, principles from the cognitive load theory are implemented (Sweller, Ayres et al., 2011; Sweller, van Merriënboer et al., 2019). The cognitive load theory is an instructional theory in which learning activities and materials can be optimised by employing principles based on human cognition. The main principle of this theory is to prevent the overload of working memory capacity. This theory proposes that the use of visualisations (images and diagrams) help to aid the understanding of written text (Castro-Alonso et al., 2021). This is further enhanced through several principles; diagrams and images should be spatially integrated with the text, non-essential information should be excluded from the image/diagram, and the essential information of the image/diagram should be emphasised (Castro-Alonso et al., 2021). One frequently used example is the use of diagrams placed on a different page to the associated explanation. This requires people to retain the information in their working memory whilst also searching for the associated diagram to combine the two. If a diagram integrates both the visual and text elements, the load on the working memory system is substantially reduced.

Research has found empirical support for the implementation of these principles. For example, in their meta-analysis, Schroeder & Cenkci (2018), found that including spatial integration of text and diagrams/images resulted in significantly greater levels of learning and comprehension across multiple educational materials and resources. Additionally, application of the cognitive load principles has been used in a variety of different educational settings. For example, the principles mentioned above (e.g., spatial integration, exclusion of irrelevant information) were successfully used in the incorporation of anatomy diagrams to facilitate medical students understanding of human anatomy (Hadie, 2020).

These principles are present in the current resource. Diagrams and images are presented in relation to the relevant text. The resource does not contain images or diagrams that are functionless or include unnecessary information, but are only used to help clarify the accompanying text. For example, in showing what the GP's webpage would look like if they were trying to book an appointment with their GP online.

Example 14) Example 14 demonstrates the use of diagrams and images implemented in the resource



If someone would like to book an appointment by phone, they would need to call the GP surgery's phone number they are registered at during working hours (usually 8am to 6.30pm).

If they do not know the number for the surgery, they can search for your GP surgery using this NHS link: https://www.nhs.uk/service-search/find-a-gp/

Once they have found their GP surgery, it should contain a contact number.

Different neurotransmitters are constructed differently, meaning that they can only interact with a receptor with the corresponding construction. For example, the neurotransmitter dopamine can only bind to a receptor that can accommodate for dopamine.

When the neurotransmitters are released by the brain, they bind to the receptor, which creates the desired signal. The effect of the signal depends on the binding of the neurotransmitter to the receptor, meaning the more neurotransmitters are released, the bigger the signal and effect.

First step:

Reach out to GP or self-refer directly to services

Second step:

Agree a treatment or support plan that can be completed at home

5.0. Conclusion for Chapter Four

In conclusion, the development of the educational resource (ADIFA: www.adifa.co.uk) was informed by the over-arching implementation framework used in the current project (the Knowledge to Action framework). The results from Chapter Three informed the topics and the presentation to be included in the resource. The pragmatic principles from Ho et al. (2004), were discussed in the relevance to the project and helped to identify any issues that might arise from implementing the research specifically into online mediums. Each design and content decision were detailed and examples taken from the resource were included to demonstrate how they have been applied.

The next stage is the evaluation of the resource. This will form the content for the next chapter, (Chapter Five) in which the experiences and feedback of ADIFA will be gained from autistic adults and parents of autistic adults. These evaluations will help to judge how successful the ADIFA is and what amendments are required.

Chapter Five: A qualitative evaluation of educational website from the perspectives of autistic adults and their families

Introduction

This chapter details the evaluation of ADIFA. This chapter details the methodological approach taken, including who the participants were, what they were expected to do, and the analytical approach of the data created. The chapter is split into three sections: the first describes the aforementioned methodological approach, the second describes the implementational themes generated, and the third describes the reflexive themes generated. The chapter concludes with a summary of the project, including how the implementational themes are incorporated into ADIFA, and how the reflexive themes contribute to the wider literature.

Methods

Study Objective and Design

The purpose of the current project was to address the research objective below:

- To gather information on the experiences and feedback of the resource (ADIFA) from autistic adults and parents of autistic adults.

In order to best address this objective, consideration was needed for the selection of an appropriate methodological design and approach.

The first consideration made was in the design, and whether it should be quantitative, qualitative or mixed methods focused. While the project employs a pragmatic design, and focus has been given to the creation of actionable points, the current project's focus was on exploration of autistic adults' experiences using ADIFA. In order to gain greater information on their experiences and feedback, conversing with participants directly was decided as the best option to achieve this. Therefore, the current project employed a qualitative design, within a larger pragmatic framework.

The project consisted of semi-structured interviews, which could be delivered audibly (i.e., over the phone, or online via Microsoft Teams), or text-based (i.e., via email). The reasoning behind the provision of multiple ways to participate were the same as the project in Chapter Three. Namely, some autistic adults' participation can be hindered by a reductive recruitment approach, and offering multiple options to engage with a research project can help to ameliorate this, particularly for qualitative interviews (Nicolaidis et al., 2019). However, the purpose of the current project was not the same as the project in Chapter Three, and the preference was for a mixture of both text-based and audible interviews. This would allow for a greater exploration of the experiences using ADIFA, as audible interviews are arguably more reciprocal than text-based interviews (Amri et al., 2021).

The questions used in the semi-structured interviews were created to relate to the development of ADIFA (see appendix 8). Questions were centred around content, presentation, and language used in ADIFA. This was to generate actionable feedback, and provided participants a framework in which they could discuss their own experiences if desired.

Description of Participants

The purpose of this chapter was to gain an insight from autistic adults themselves and parents of autistic adults about ADIFA. This was conducted through a semi-structured interview with autistic adults who have had personal experiences with alcohol/drug problems, parents of autistic adults, and autistic adults who haven't had personal experiences with alcohol/drug problems but may have friends or family who have. Participation was open to all genders and ages (provided they were aged 18 or over). The inclusion and exclusion criteria for the project are located below.

Inclusion criteria:

- Adults over the age of 18
- Autistic adults
- Individuals who choose to take part and opt in
- Adults who can read and understand the consent form, information sheet and survey/interview questions
- Adults who live in the UK

Exclusion criteria:

- Adults under the age of 18
- Neurotypical adults
- Individuals who lack the capacity to choose to take part and opt in
- Adults who cannot read and understand the consent form, information sheet and survey/interview questions
- Adults who live outside of the UK

Participants consisted of a volunteer sample. The recruitment strategy stated in Chapter Three was utilised in the current project (the use of relevant autism charities and organisations, who acted as a "gatekeeper" for access to their members). This strategy did not have any reimbursement attached. However, an additional strategy employed was through a specialised network of the Autistica charity, known as the "Autistica Insight Group". This was a paid service in which autistic adults would be contacted for potential participation with a specific aim, in the current projects case, providing feedback on the ADIFA resource.

This strategy was employed as it allowed for specific participants to be recruited, namely, autistic adults who have had personal experiences of alcohol/drug problems. An application to Autistica was made, accepted, and specialised recruitment was utilised (using the specialised parameter of preferences for autistic adults who had personal experiences of alcohol/drug problems). Each participant recruited in this manner was reimbursed £25 for their time. This strategy was successful as it resulted in a sample of autistic adults the majority of whom have had personal experiences of alcohol/drug problems.

Participants could choose the method of participation depending on their preferences. The interview could take place online (through Microsoft Teams), by the phone, or through email. The email interviews were asynchronous, where correspondents were sent between the researcher and the participant. The participants are introduced in table 1 below.

Table 1) This table details the experiences and viewpoints of the various participants

Participant Pseudonym	Description about them
Alex	Alex is an autistic adult who use the "they/them" pronouns. They have not had any personal experience with alcohol/drug problems, but have friends who have.
Abby	Abby is female and self-identifies as autistic and having ADHD. She has an adult son who is autistic. She has previously had problems with alcohol and is now 4 years sober.
Emily	Emily is an autistic female, who has previously had problems with both alcohol and prescription medication. She has two children who are autistic. One of her children (her daughter) has had problems with alcohol when they were a teenager.
Sian	Sian is a female who self-identifies as autistic. She has two children who are autistic. One of her children (her daughter) has previously had problems with marijuana use.
Nicole	Nicole is an autistic female who has previously had experiences with alcohol and drug problems. She is a parent to an autistic adult and her husband has ADHD.
Kyle	Kyle is an autistic male, who has had problems with drugs and alcohol himself, as well as, friends who have also had alcohol and drug problems. He has also had experiences of various behavioural addictions, such as food and porn addiction.
Mary	Mary is a neurotypical female. She has an autistic son. Neither of them has had problems with alcohol or drugs, but her son has social anxiety.
Claudia	Claudia is an autistic female. She has problems with prescription medication, specifically, benzodiazepines. She has been on a detox programme and has cut down on her use.
Jade	Jade is a neurotypical female. She has an autistic son. Her or her son have not had problems with alcohol or drugs but she has known people who have had problems with alcohol. She has previously worked within the NHS as a physiotherapist.
Darren	Darren is a neurotypical male. He has an autistic son. He or his son have not had problems with alcohol or drugs. He works within computer programming and internet design.

The table demonstrates that the majority of participants were autistic (7 of the 10), were a parent to an autistic child (7 of the 10), and were female (7 out of 10). The initial idea was to analyse the groups separately, one to represent autistic adults themselves and one to represent parents of autistic people. However, as the table demonstrates, many participants were both autistic and parents of autistic people, meaning they fulfilled both groups. As such, it was decided to analyse all participants together to produce a representation of the group as a whole.

Procedure

Potential participants were first recruited either through recruitment material sent on behalf of the researcher by relevant charities or organisations, or through the "Autistica Insight Group" process. The researcher was not initially provided any contact details for the participants. If participants wished to take part, they needed to contact the researcher themselves first. For the "Autistica Insight Group" process, the researcher was provided a list of email addresses of individuals who had expressed a wish to take part or find out more information about the project. These details were only provided after Autistica had discussed the project with selective individuals and agreed with them for their email address to be included. The researcher then contacted the potential participants via an email that detailed the project and contained the information sheet (see Appendix 9), consent form (see Appendix 10), and asked them the mode they wished to participate (i.e., by email or through Microsoft Teams). Once the individuals had stated their preference for mode of delivery and completed the consent form, the interviews could be arranged.

For the email interviews, participants were sent the questions in full by email after the consent form had been completed and received by the researcher. Participants were encouraged to take their time and answer the questions to the best of their ability. They were informed to spend some time with ADIFA before completing the questions, but the extent of the time spent on ADIFA was entirely their decision. Once the questions had been completed and returned, the researcher sent a supplementary email with questions created in response to their answers. This gave the researcher the opportunity for clarification or greater exploration of any areas previously discussed. Once these questions were completed and returned, participants were informed of the end of the project, thanked for their time, reminded of contact details for the research, and if recruited via “Autistic Insight Group”, reimbursed for their time.

For the interviews which took place via Microsoft Teams, once their preference for this mode was stated and the consent form completed, a date and time was arranged for the interview. The interview could not take place without a completed and returned consent form. The researcher and participant met on Microsoft Teams on the date and time arranged, which could either be audio only or with the camera on, depending on the participants preferences. Prior to the interview, participants were asked to spend some time with the ADIFA resource. At the beginning of the interview, participants were given 10 minutes to interact with ADIFA. Once complete, the interview could begin. As the interview was online, many respondents stated keeping ADIFA open in their web browser in order to discuss particular pages or sections of the resource. The duration of interviews ranged from 18 minutes to 61 minutes. The average duration of the interviews was 40 minutes. Once the interviews were completed, participants were informed of the end of the project, thanked for their time, reminded of the contact details for the researcher, and if recruited via “Autistic Insight Group”, reimbursed for their time. The data was then transcribed by the researcher and anonymised using pseudonyms.

Ethical Considerations and Approval

Ethical approval for the current study was gained from the Ethics Committee of Manchester Metropolitan University (Appendix 11).

Informed Consent

The intended audience for the educational resource is autistic adults as a whole. Therefore, autistic adults with a learning disability were also welcome to take part in the project. This potentially raised issues regarding informed consent and capacity. However, the project did not seek to specifically recruit participants with a learning disability, but as the educational resource is for all autistic adults, intentionally depriving those with a learning disability from participation would raise its own moral and ethical issues. The website was developed with a certain level of literacy needed to understand it, therefore those with a moderate to severe learning disability would likely not have been inclined to participate in the project, however, those with a mild learning disability may have wished to do so.

As the study was promoted online via relevant charity sites and organisations, it was not practical to assess the capacity of participants with a learning disability. As in the project in Chapter Three, online organisations and charities approached for promotion of recruitment material each be consulted with the researcher to discuss whether they thought the study was appropriate for their members.

The consent form was sent via email to all autistic adults who wished to participate, prior to the completion of the interview questions. The consent form had to be completed in full and returned to the researcher via email prior to the interview. Any participant who had not stated their consent, could not participate in the project.

Right to Withdraw

Participants were made aware that they could withdraw their data at any time and without requiring a reason, before the completion date of the study (30/09/2022). Participants who wished to withdraw their data simply used the details already provided to contact the researcher and inform them of their withdrawal. Once the request was made, all data relating to the respective participant was destroyed.

Confidentiality and Anonymity

A number of considerations were made to ensure confidentiality and anonymity of the participants and their data. Recruitment adverts were sent on behalf of the researcher by related charities. The research did not have direct access to any databases or details. Participants needed to make first contact if they wished to find out more or participate. Any personal data, such as email addresses and any phone/application details, were destroyed upon completion of the PhD. Participants were also given pseudonyms, with any quote included in the final report only being identifiable by the researcher and the participant themselves. All data was kept in a security protected computer that was only accessible by the researcher.

Consideration of Distress

The current study was considered low risk, as although a question pertaining to personal experiences was included, direct exploration and inquisition into participants personal experiences of alcohol/drug problems was not asked and discussions were at the discretion of the participant. Additionally, efforts were made to ensure participants had access to appropriate care should they become distressed. This was done by providing participants with contact details of relevant services (e.g. NHS, National Autistic Society) and the researcher flagging any potentially vulnerable person (anonymously) with their supervisors.

Selection of analytical tool

One of the most important considerations to be made was the selection of an appropriate analytical tool. The previous study in Chapter Three, analysed the data use qualitative content analysis. This proved beneficial as the purpose of that study was to gather information on autistic adults' preferences pre-development of ADIFA, with the production of actionable aspects that could be incorporated into development. However, the current project's objective allowed for more interpretive analysis, as the purpose was to gather the experiences and feedback of using ADIFA.

As such, the analytical approach taken for the interview data was that of reflexive thematic analysis (RTA) as proposed by Braun and Clarke (2006; 2019; 2021). This approach was taken because, although the focus of the project was pragmatic, the involvement of perspectives from autistic adults with substance-related problems allowed for latent meaning to be conceptualised in a wider context. Additionally, this analytical approach respected the view points of the participants, while also acknowledging my reflexive interpretations as the researcher.

The process used to analyse the data followed the six-phase thematic analysis procedure used in Braun & Clarke's (2006) research. This procedure was helpful in outlining the process behind how themes are conceptualised and defined (see table 2).

Table 2) Braun and Clarke's (2006) six-phase procedure and the relation to the current study

Phase	Procedure in the current study
1. Familiarising oneself with the data	Interview data conducted over the phone or Microsoft Teams was transcribed and collated with data conducted by email. Through the interview process, and later through transcription, initial notes were made on thoughts and ideas expressed by participants.
2. Generating initial codes	Features in the data were coded across the data set. This included exploring the initial notes made and searching for key words or terms expressed across the data set.
3. Searching for themes	Codes were then collated into initial themes. This was done by assessing codes for relation to each other, and if appropriate, were collated under a relevant theme.
4. Involved reviewing themes	Themes were checked against the entire data-set and for relevant extracts to support the conceptualised themes.
5. Defining and naming themes	The specifics for each theme were refined and defined. From this definition, themes were separated into two distinct categories: pragmatic, sematic themes and reflexive, latent themes.
6. Producing the report	Final checks were conducted to ensure the extracts selected were appropriate, the themes conceptualised relate back to the purpose of the study, and the relation of themes to the wider literature.

While this approach is useful in defining the process involved in reflexive thematic analysis, they are not prescriptive. The process within the current study did differ between the analytical approach taken in generating the initial codes (see figure 1 and figure 2).

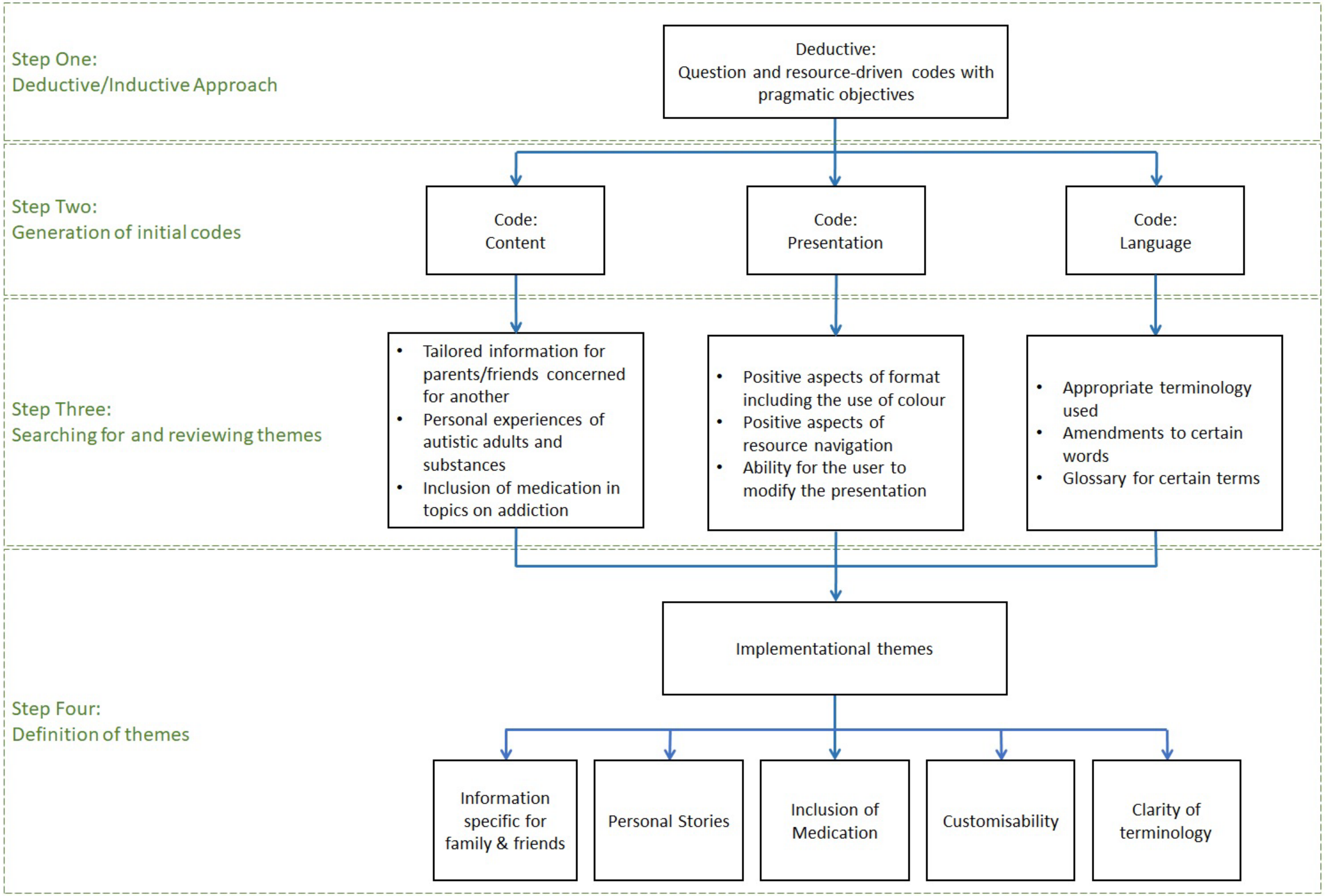
Analytic Approach

The current project used a combined approach to data analysis, namely, the incorporation of both deductive and inductive reasoning. Deductive and inductive approaches are usually aligned with opposing epistemologies, with deductive methodologies tending to employ positivism and inductive methodologies tending to employ interpretivism. However, the current project employs a pragmatist epistemology, allowing flexibility in analytical approaches and the possibility for combing both approaches. In fact, a hybrid or sequential approach of both deductive and inductive approaches have been used in research projects employing reflexive thematic analysis (Fereday & Muir-Cochrane, 2006; Proudfoot, 2022). In their project exploring people's attitudes towards retirement and aging, Swain (2018), described the process they used to combine both deductive and inductive approaches in their analysis. They remarked that the deductive approach provided a useful framework for the analysis, keeping the themes on topic with the research question, while also allowing for unexpected themes and insights to be generated.

The overall PhD project employs a pragmatic paradigm, which allowed for flexibility in the analytical approach the current study could take. As the pragmatic paradigm does not solely ascribe to either inductive or deductive reasoning, a hybrid approach could be successfully implemented within this paradigm. The purpose of a combined approach was selected due to the pragmatic nature of the project and the information gathered from participants. A deductive approach was important in providing focus for the analysis, specifically, in keeping the focus of the analysis on pragmatic and actionable adjustment or inclusions that could be made for the benefit of ADIFA. Whereas, an inductive approach was important as the feedback and experiences provided by participants, particularly those with experiences of substance-related problems, was not simply pragmatic but could provide insight previously absent from wider contexts.

The process for the deductive approach is represented in the flow chart below (see Figure 1).

Figure 1) A flow chart detailing the analytical process used for generation of the deductive codes and themes in the current study

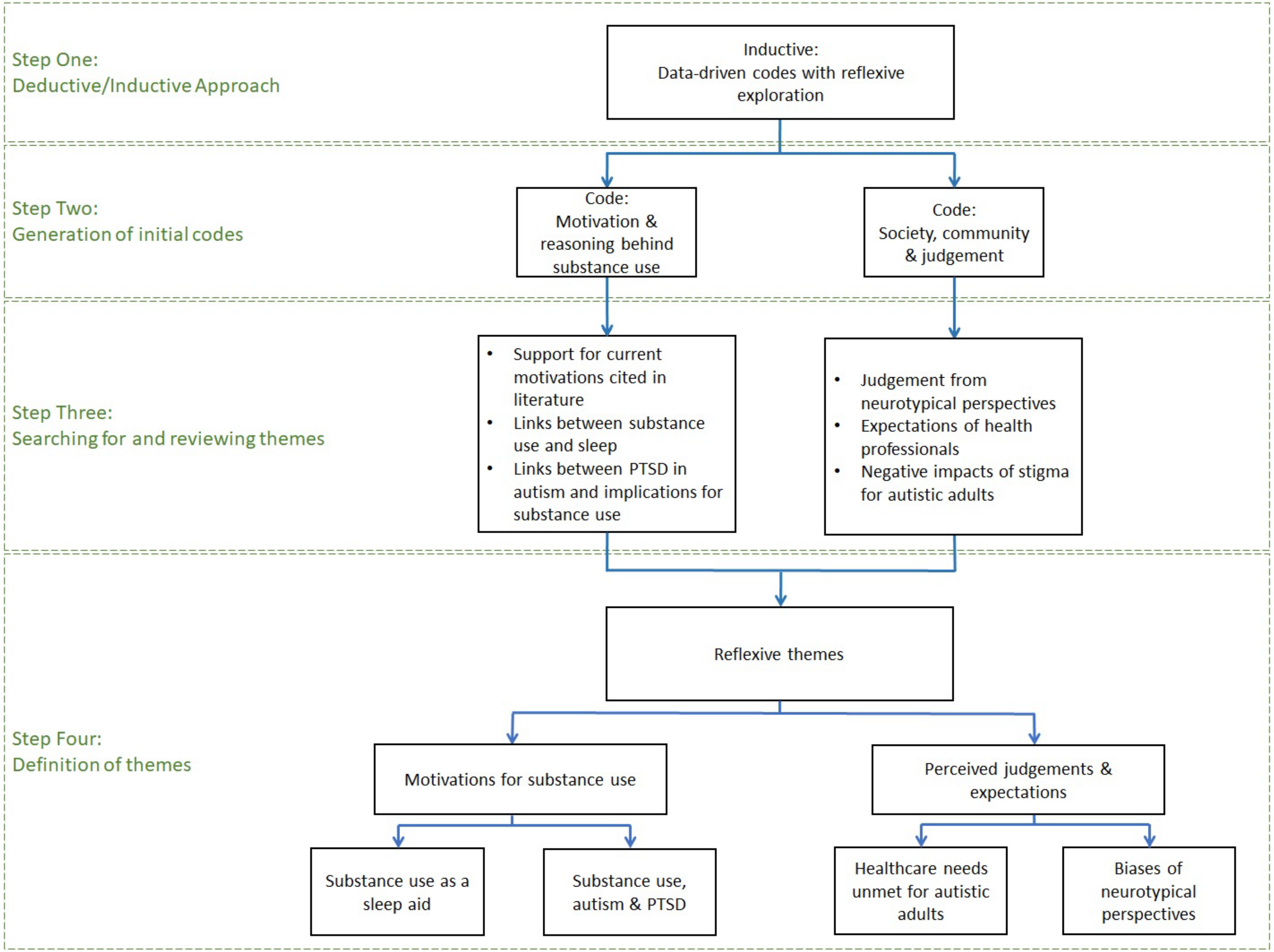


The deductive codes developed for the analysis process occurred before familiarisation of the data was completed. The codes were led by the findings from the previous study (in Chapter Three), the development of ADIFA itself (Chapter Four) and the questions used in the current study. The codes consisted of the content, format, and language used in ADIFA. Content was selected as participants from the previous study in Chapter Three, requested the inclusion of certain topics and themes (e.g., multivarious aspect of substance use, detailed practical information, etc.). In order to determine how well topics were included, and whether there were any missing, themes centred around the content would provide pragmatic suggestions that could be implemented. The format of ADIFA was another area highlighted in Chapter Three. Autistic adults and parents of autistic adults highlighted the importance of a clear, simple, and easy to navigate presentation of the information, that included diagrams and pictures to aid comprehension and not purely for aesthetics. In order to understand whether or not the format achieved these aims, and how it could be improved, themes focused on format were important. The final code selected was for the language used in ADIFA. Participants in Chapter Three clearly stated the importance of clear, concise, and accessible language, as well as inclusion of appropriate terminology when referring to autistic people (i.e., not using person first language such as, “an adult *with* autism”). In the development of ADIFA, focus was given to the language, as the accessibility of the language was assessed via Flesch-Kincaid Reading Ease Score and Grade Level tests (Flesch, 1984), and the terminology included informed by the National Autistic Society’s 2020 guideline. Centring themes around content, presentation and language, provided the analysis with a useful framework in assessing autistic adults and parents of autistic adults’ experiences of ADIFA. It resulted in pragmatic, implementational themes that could be applied to the benefit of ADIFA.

A greater familiarisation of the data was then conducted, through transcription of the data and notetaking from repeated re-reading of the data sets. Searching for themes and review of each theme was conducted within the frameworks of the aforementioned pre-determined codes. Each theme was reviewed in relation to each other and how well they encapsulated the content, presentation or language coding. The themes were then clarified and defined. As the purpose of the deductive approach was to generate actionable suggestions from participants experiences with ADIFA, the themes were grouped together under the over-arching category of implementational themes.

The process for the inductive approach was similar to the deductive approach and is displayed in the flowchart below (see Figure 2).

Figure 2) A flow chart detailing the analytical process used for generation of the inductive codes and themes in the current study



In contrast to the deductive approach, this approach derived the codes and themes solely from the data. This allowed for the codes and subsequent themes to be developed directly from participants' experiences, including a wider context than the evaluation of ADIFA. The initial generation of the codes was conducted in conjunction with familiarisation with the data. Two codes were generated, comprised of motivations behind substance use, and society, community and judgement. These codes were generated throughout the data sets, but particularly in discussions with the individuals who had personal experiences of substance-related problems. Generation and review of themes was then conducted within the parameters of the aforementioned codes. Themes were then synthesised and defined under the collective category of reflexive themes, which reflected the interpretive nature and wider context of the themes. Additionally, collection under this collective category helped to distinguish the themes from the deductive more actionable-focused themes. Two themes were identified—motivations for substance use, and perceived judgements and expectations—each with two sub-themes: substance use as a sleep aid, substance use, autism & PTSD, unmet healthcare needs, and biases from neurotypical perspectives.

Reflexivity

As the analytical approach selected was reflexive thematic analysis, acknowledgement and embracement of the subjective nature of the research is imperative. Therefore, discussion on the role of the researcher, their values and experiences are important to include.

First and foremost, I am a non-disabled, neurotypical researcher. While I do not have any direct experience of autism, my elder brother is autistic. I believe this has given me an insight into the challenges autistic people can encounter, the stereotypes neurotypical people might hold, as well as the positives attributes and favourable activities autistic people can embody. For example, when my brother attended university, in order to stay in university accommodation, he had to be re-assessed and re-diagnosed as autistic, as the University believed he was diagnosed with "*childhood*" autism.

This demonstrated a fundamental lack in understanding of autism as a lifelong condition and provides an example of the additional challenges autistic people can face, including in accessing measures designed as reasonable adjustments for autistic or disabled individuals.

Throughout my life I have grown up with disabled friends and family who all had a range of different conditions and variability in their additional needs, such as muscular dystrophy, multiple sclerosis, Alzheimer’s disease, and cancer. Through their experiences I have developed an interest in pragmatic research. This is because from their personal experiences, pragmatic and practical help can often be hard to find or does not meet the requirements of the individual. Additionally, these experiences had instilled in me the importance of the inclusion of disabled perspectives, particularly in research where they are the intend audiences.

While I do not have a disability or condition, I believe, as an LGBT+ person, my experiences and perspectives may be shaped from the viewpoint of “otherness”. My desire to research topics centred around disabled communities that may also experience feelings of “otherness” or individuals considered atypical could to some degree be influenced by my own perspectives and experiences.

Results

The results for Chapter Five are split into two categories; the deductive themes derived from pre-determined codes are displayed under “Implementational Themes”, whereas, the inductive themes derived solely from the data are displayed under “Reflexive Themes”.

A.0. Implementational Themes

A.1. Customisability

I asked the participants about their experiences of the layout and format of the resource. All of the participants were in agreement that the website was uncluttered, easy to navigate and, in the most part, appealed to their aesthetics.

“And like I said, even kind of the subheadings, even though there's a lot of text, it's good to sort of see like the little submissions in the head, like along the toolbar at the top as well. See if there's a bit of clear part you would want to go through them. That's quite easy to do.” – Alex

“A positive experience. It was clear, easy to read, concise.” – Nicole

“Excellent site, easy to follow, medical information presented in a simple manner, good links to relevant sites for further help and information. Very easy navigation. Colour coding the 4 main sections is a good idea.” – Darren

While this is a positive outcome for the website, it is interesting to note that positive aspects of the formatting and presentation were conditional to their own perspectives. This was expressed by Alex who questioned whether the resource was as accessible as it could be.

"It sort of like it feels like a place where I would go for information, but on the formal level…but like maybe making it accessible because you know the spectrum is a wide thing. So, like, obviously I can kind of like, you know, like and can read the information fine. But then some people may struggle. Others may prefer kind of like an easy read or like a visual resource or something." – Alex

As Alex stated, the presentation and layout of the resource appealed to them and their preferences—which is positive as they are the intended audience—but it was unclear whether this would be felt be other autistic people. The differences in personal preferences were also displayed between participants directly. Claudia suggested the inclusion of more diagrams and images as they prefer that medium of information, whereas, Nicole remarked on the lack of images and "extraneous" information as aligning with their preferences.

"Pictures again would help Autistic people. My recommendation would be more picture, something easy to view. Personally, I do struggle with lots of words." – Claudia

"I think it's exactly right – to the point; it's useful, and has nothing unnecessary or objective/subjective. I love the 'no extraneous bullshit' style." – Nicole

When discussing the layout and presentation further with participants, the notion of different needs for different autistic people was expressed by others. This was particularly relevant with parents of autistic people who were discussing the needs of the children. Sian commented on how her daughter would find navigating the resource.

"My daughter would get confused between the links about the resources and the references. Even though they're clearly separate on the page when I read them through, I know my daughter would be like, well, I'm kind of a bit lost now and I've. Separating those would probably be useful for me." – Sian

"Yeah, the visuals, the step-by-step description, that was fantastic and it is exactly what my daughter would need." – Sian

This highlights that aspects of the layout, navigation and presentation of the resource worked for participants and their children, but other aspects could be improved. It suggests that autistic adults with additional needs may need support when using the resource. However, there becomes the problem of accommodating for a multitude of needs, while ensuring accommodations are not at the expense of others. Jade summarised this dilemma I faced in the development of the resource.

"Depending on the persons level of disability I think there may be too much information and a lot of words, but a too simplified version may insult other people." – Jade

However, when discussing the issue with participants, Emily and Alex suggested a solution to this problem, that centred around customisability.

"I think it would be a good idea to have more options for people to customise it themselves and have different ways to sort of engage with the resource. I think the more options you give, gives a wider range of people more access. If they can't kind of consume information one way, then there's the option to consume it in another. You wouldn't have to have it like all over the page saying 'look

how inclusive we are'. It's just more of a kind of a side option if people would like, you know, read it in a different way." – Alex

"[on being able to change the background colour] Yeah, that would be really cool. Because I know there was one web browser where you actually can go and you can do that, but on Windows you can't, and it's really, really frustrating. It would be good ff you can change it, change all the different backgrounds." – Emily

They proposed that the formatting and presentation of the website should be customisable, meaning that the font size, colour, images can be altered by the user to suit their preferences. This was a great idea that could be incorporated into the resource. This offers users of the resource the option to make certain presentational adjustments to accommodate their needs, and as it is optional, it would not be at the expense of the individuals who like the resource the way it is currently presented.

A.2. Personal Stories

I asked participants about the inclusion of personal stories in the resource. This was met with mixed responses. Sian expressed hesitancy in providing stories that might not be relatable to everyone. Nicole expressed an apathy towards personal stories. Abby, on the other hand, stated her enthusiasm for the inclusion of personal stories.

"Like personal experience from an autistic person in their own words talking about their experiences. It's a difficult one, yes, but I think you would have to be careful about how that that was incorporated. Like the reality of access to treatment isn't quite the same as what, you know, NICE guidelines would recommend. In the same way you know, it's good if you can have somebody personal

experience there that an individual relates to. But if they don't relate to that personal experience, it becomes a problem. So, either you've got to include enough that there's enough different perspectives there." – Sian

I don't usually find other people's stories terribly relevant (neither does my autistic teen, but appreciate we may be in minority)." – Nicole

"Love personal stories. They're my favourite. I love listening to like, you know, this is what happened. There's a really good doesn't really good book. Loads of personal stories in. What's that called, ah yes, the sober Diaries." – Abby

This is interesting as inclusion of personal stories, particularly from autistic perspectives was brought up in the previous research study (Chapter Three). Findings from this study indicated the benefit of including personal stories and the importance of hearing from autistic perspectives. However, as the one of the participants pointed out, personal stories may only be helpful if they are relatable, and sadly, many autistic people's experiences of receiving substance-related support are not positive. Therefore, inclusion of stories needs to be varied and reflect reality.

One of the participants, who works within healthcare promotion, has produced a blog that details their personal experiences with alcohol, drugs, and addiction, including treatment, support and their motivations behind their substance use. They have given me permission to link the blog on the website and select extracts to be used in the resource. Additionally, Abby recommended a multitude of books and podcasts of people's alcohol and drug journeys (not necessarily autistic people) to include in the resource.

While caution is needed in providing personal stories in the resource, the findings from the previous study (Chapter Three) and the recommendation by Abby and Kyle, suggest inclusion of personal stories as a positive aspect. An additional page can be created incorporating the link to Kyle's blog, extracts from said blog, and a list of books and podcasts relating to individuals' experiences with substance-related problems. The information would be contained to one page of ADIFA, contain multiple stories and viewpoints, and would be completely up to the individual to explore if they were interested.

A.3. Information Specific for Family & Friends

I asked participants about the content of the resource and whether there was enough information supplied. All of the participants stated that they found the content of the resource interesting and useful.

"Yes, very clear information. The section about support and references is very useful, and enough information. Not too overloaded which makes it autism." – Mary

"Excellent site, easy to follow, medical information presented in a simple manner, good links to relevant sites for further help and information." – Darren

"Positive experience. The website contains a lot of useful information about alcohol and drug abuse with ideas of how to get help." – Jade

"In terms of the information, I thought it was, you know, kind of like it kept a good sort of balance. It didn't feel like it was pandering or it was trying to lecture people. The information itself was quite interesting. I guess I kind of learned a couple of things along the way." – Alex

This highlights that the information collated and selected for use in the resource was positively reciprocated by the participants. Additionally, across the interviews, none of the participants questioned the inclusion of a particular section. Where participants did express amendments to the information on the website, it was suggestions to incorporate supplementary information. For example, both Nicole and Sian recommended the inclusion of acceptance and commitment therapy (ACT) as a potential treatment alongside cognitive behavioural therapy (CBT).

"[Inclusion of treatments and supports] are useful, wondering if worth mentioning ACT as possible therapy as CBT doesn't always work for autistic people. Might be good to expand at some point with do-it-now techniques and contacts, so links to MIND and stuff like that and maybe even download." – Nicole

"I don't know what's current, but I know there has been some research into act therapy for use with long term disabilities of all kinds. It's Basically the premise of act therapy is that it's kind of an evolution of CBT." – Sian

Inclusions of potential treatments and support that autistic people have found helpful is useful in improving the resource. However, when further discussing what content might be missing or needed to be added, parents of autistic adults stated a need for the incorporation of information for them. Emily, Sian and Jade all expressed a need for information for parents, family members, or friends who are concerned about someone else's substance use.

"[on the inclusion of a parents/carers section] That would definitely be useful. You could do it for carers and partners. I know my family, bless them, wouldn't know what to do if I needed their help with alcohol." – Emily

"[Incorporating] something for someone to look at and go, 'my friend is showing the signs of addiction, how can I help them'. Something that explains, maybe to parents or family members or friends who are concerned." – Sian

"As a parent it is frustrating that there is very little information and advice of how we can help Autistic people. A specific section aimed at parents and carers etc. could be included in the website offering guidance of what we can do to support Autistic people with these problems and where we can go for support ourselves." – Jade

This is important to include in the resource, as family members and friends of people with substance-related problems also require help and support. For example, in a recent study exploring parents experiences getting support on addiction for their adult children, Richert et al. (2021), found that parents often faced negative effects on their own lives and wellbeing, as well as, barriers to accessing support. Often, it was the parents of the adult child who had to seek support for their child's addiction, experiencing feelings of shame and guilt as well battling with support services on their child's behalf (Richert et al., 2021). In order for the resource to be successful, it must be accessible and useful for parents, family members and friends of autistic people. Including a section for them would be welcomed by parents and increase the useability of the resource.

A.4. Inclusion of Medication

When discussing the content of ADIFA with participants, participants touched on their own experiences with prescription medication. Claudia, Kyle and Nicole all described problems they had experienced with prescription medication.

"People don't realise that there are some other drugs—like diazepam—are extremely addictive… I first got benzos in 2012... If I ran out before I could get more prescribed, I bought it off the internet. My GP knew I was addicted and stopped prescribing them so I carried on online ordering." – Claudia

"I was medicated for very long time. Yeah, so I was on 4 milligrams of clonazepam for 3 1/2 years… I was only able to withdraw from that, with the help of private therapist" – Kyle

"I was prescribed Prozac for anxiety 18 months ago and had an adverse reaction: didn't sleep, eat or talk for 8 days. Ended up in Mental Health A&E. Have since weaned off a subsequent prescribed medication." – Nicole

These accounts highlight the negative implications, particularly the potential for addiction, prescription medication can have for some autistic adults. This is an interesting topic as prescription medication was a theme identified in the pre-development project in Chapter Three. In this chapter, autistic adults identified the need for clarity on the focus of ADIFA, and whether information should be restricted to recreational substances or include topics on prescribed medication and their side-effects. As ADHD, depression, anxiety, and other conditions with high co-occurrence with autism all have medications prescribed for their treatment or management, coupled with the need for a health professional to review any educational information included on specific medications, topics on prescription medication was not included in the development of ADIFA. However, as highlighted by Claudia, more inclusion or discussion of prescription medication may be helpful in improving ADIFA.

"I'd have liked to have used the website to have found out how I can get off them [prescription medication] … I'd love your website to have been broader. I was disappointed to only see class A drugs mentioned alongside a remedy. I was searching for help coming off benzos. They weren't featured." – Claudia

This highlights the importance of including prescription medication as a topic in information or support on addiction. In not acknowledging this topic at all in ADIFA—even briefly—the resource failed to provided relevant information that is needed for autistic communities. The need identified is not for medical information on specific medications, but for support information already provided on ADIFA to be inclusive of support and treatment for addiction to prescription medication. Additionally, clarification in the definition of addiction to include prescription medication alongside recreational substances was needed.

A.5. Clarity of terminology

The choice of language was carefully considered in the development of ADIFA, particularly in regards to appropriate terminology. Talking to the participants in the current study, no mention was made to the terminology used to describe autism and autistic people. This was seen as a positive, as demonstrated in Chapter Three, using inappropriate terminology, particularly person-first language, is noticeable for autistic adults. In terms of the language however, clarification and tone were discussed, such as by Abby.

"A lot of this is written in quite academic language… I, personally for me, I prefer that, and I find it quite comfortable. But I know my daughter and my son would not have." – Abby

This highlights that the language choice may be too formal or academic to be accessible for a wider autistic community. This may be confounded by the use of medical terminology included in some of the sections of ADIFA. However, in further discussions, clarification of terminology was seen as beneficial in making the information more accessible, as discussed by Emily and Jade.

"The spacing of the words and everything are really easy to read. I think it's really good how there are certain words in there that most people will go, 'I don't know what that is', but then you've explained what it is. Which kind of gives all those different levels of somebody coming in who has no idea." – Emily

"It is useful to understand what an addition really is as the term is often widely misused." – Jade

In addition to this, Darren offered a practical solution that makes use of the online formatting to help to make terminology more accessible.

"Add a glossary of terms maybe? Consider the use of mouseover text to provide quick definitions of words." – Darren

This highlights the benefits of clarifying terminology and using accessible language. In order to reduce the number of words present on each screen of ADIFA, employing Darren's suggestion for mouseover quick definitions would be valuable. Employing this technique would reduce the number of words on screen and provide individuals access to definitions if needed without repetition of information other individuals might not need.

B.0. Reflexive Themes

B.1. Current information on motivations for substance use

When reviewing and discussing the sections of the resource related to the motivations for alcohol and drug use in autistic people, participants reacted positively.

"I found the information of why people might use substances very interesting." – Nicole

"I liked the sections about the specific motivations for autistic people and, you know, using alcohol and drugs, to not be something I've thought about before. It was insightful." – Jade

In fact, Nicole, who has had experiences of alcohol/drug problems identified the motivations included in the resource as factors behind their own use and subsequent problems.

"Yes, I was self-medicating heavily with alcohol and drugs in my 20s when I worked in television. They were easy to get and it was before I was diagnosed and I had no idea how to cope with my day-to-day anxiety levels. Had I needed to seek help/advice this would have been very useful and clear." – Nicole

This lends credence to including these specific topic areas in the website. It also supports the insight from the wider literature around alcohol/drug use and problems, namely that alcohol and drugs might be used be autistic people to cope with either negative mood (e.g., feelings of anxiety and depression) or social situations (Clarke et al., 2016). In terms of social situations, this can either be to help lubricate social interactions and inclusion in social groups or specifically to masque or hide the way their autistic presentations (Bargiela et al., 2016; Clarke et al., 2016; Kronenberg et al., 2015). On this point of using substances to masque, Emily, who identified social factors as a feature in their alcohol use, reported the opposite, that drinking increased their presentation of autism.

"I found that when I was drinking, I would become more, have more, I'd be more autistic because I wasn't masking. If that made sense. So, I kind of got to the point of where I kind of well, actually this is who I am and I'll have a drink." – Emily

This is interesting as it suggests that there may be more subtleties to the relationship of autism, camouflaging, and substance use. Emily specifically mentions that they used alcohol to help cope in social situations, but not to masque their presentation of autism to others, as they found they felt more "autistic" after drinking. The alcohol was being used to help alleviate any negative thought processes and emotions within a social setting. More specifically, it was being used to help Emily not care about the way their autism was presented or perceived to others but helping to supress any negative thinking they themselves might have about their autistic presentations. This is interesting as it shows the complexity behind substance use in autistic people and that their use might be personally linked to autistic experiences and might be difficult for neurotypical people to understand.

B.1.1. Substance use as a sleep aid

While Nicole and Emily provided support for the motivations included in the resource, further discussions revealed other motivations for substance use that had not been addressed in the resource or considered in its development. Abby, Emily and Kyle all stated a relationship between substances and sleep, or more specifically, using alcohol and drugs as a sleep aid.

"Substance use for autistic people serves a purpose, things like sleeping and courage." – Abby

"[on motivations to include on the website] trying to sleep. Another good one. Alcohol and sleep." – Emily

"I was on Benzo for, like, 9 and a half years. They were prescribed and I used them in the evening to help me sleep." – Kyle

This is interesting as using alcohol or drugs as a sleep aid is not often discussed in relation to alcohol/drug problems and treatments. However, research indicates that individuals do use substances for this reason. For example, although they found alcohol as a sleep aid to be uncommon, Goodhines, Gellis, Ansell, et al. (2019), found that 38% of the university students in their sample used cannabis as a sleep aid. In a similar study, among university students, 25% of the students sampled reported using at least on substance (alcohol, marijuana, and/or over the counter medications) as a sleep aid (Goodhines, Gellis, Kim et al., 2019). Using substances as a sleep aid is perhaps counter-productive. While alcohol or drugs may help a person to initially fall asleep, it cannot be considered to improve the quality of sleep, leading to shorter sleep duration, breathing related sleep disorders, and even insomnia (He et al., 2019; Britton et al., 2020). In fact, both of the studies highlighted before also reported an increase in negative sleeping behaviours and experiences for those who used substances as a sleep aid (Goodhines, Gellis, Ansell et al., 2019; Goodhines, Gellis, Kim et al., 2019).

Perhaps one of the reasons, using substances as a sleep aid is not discussed in relation to alcohol and drug problems is dependent on the frequency of use. For example, while they found 25% of students used a substance as a sleep aid, when frequency of use was measured at a later date, it was found that there was no significant increase in the use of the substance (Goodhines, Gellis, Kim et al., 2019). This suggests that individuals who use substances as a sleep aid, may not be using them long-term, or at the very least, their frequency of use is not affected. However, this may be different for autistic people, as Kyle and Emily both identified using alcohol or drugs as a sleep aid as a direct factor in the development of their (or their sister's) respective substance-related problems.

"I'm an alcoholic. And I was using it for sleeping, before I started, sadly, to become addicted." – Kyle

"Drinking to sleep. My sister, she was very, very heavily addicted to alcohol. She would have nightmares and so she would drink. She would drink to sleep and stop the nightmares, because it knocks you out." – Emily

For Kyle and Emily's sister, using substances as a sleep aid both presented a way of coping and a direct factor in the development of their problematic use. Additionally, these individuals report using substances not as a general sleeping aid but to cope and counteract with sleep-related problems they were experiencing. For example, Emily mentions her sister's difficulty in sleeping, nightmares, and traumatic memories. The use of alcohol or drugs here is to alleviate this and temporarily gain some relief. This does not seem to be covered by the previous studies into sleep and substances, as they refer more to sleep problems developing in response to using substances as a sleep aid. Schweizer et al. (2019), addressed this area by exploring the use of alcohol as a sleep aid among women veterans, a group where sleep complaints and insomnia caused by PTSD are common. They found that among those who did use alcohol as a sleep aid (which was around 15% of respondents), were more likely to have severe insomnia than the respondents who didn't use alcohol as a sleep aid. Additionally, those who used alcohol as a sleep aid were more likely to drink daily and use other medications (such as over-the-counter or prescription) than those who didn't use alcohol as a sleep aid. This highlights that insomnia or PTSD may complicate the relationship between alcohol use specifically as a sleep aid. Additionally, this research shows that using alcohol as a sleep aid can lead to an increase in alcohol use, meaning the potential for developing problems with alcohol is present for people who use alcohol as a sleep aid. More research on the relationship between substances and sleep problems, or use as a sleep aid, is needed for autistic adults, who might be using substances in this way.

B.1.2. PTSD, autism & substance use

In addition to sleep issues as a potential motivation, Abby, Kyle and Emily, discussed the role of PTSD in their (or their daughter's) substance-related problems.

"I think yeah. Like with me till like I've always been a drinker, but not to the extent as to when I was so upset over what was happening when my son and he went into residential and stuff and it was just traumatic and fighting with the Council and stuff like that, that it was that, that tipped me over." – Abby

"The idea of using substances as self-punishment…is the thing that I used to do. Lots of us also have complex PTSD, I do, and have histories of abuse." – Kyle

“[on her daughter’s alcohol problems] so she would drink because she's also got PTSD.” – Emily

This is interesting, as PTSD and substance problems have long been explored together in the wider literature. The prevalence and overlap of PTSD with substance problems have been long documented as having a high rate of co-occurrence (Saladin et al., 1995). Research has indicated PTSD as a risk factor, as individuals with PTSD are 4 to 5 times more likely to have substance-related problems than those without PTSD (Brady et al., 2021). There are many hypotheses to try to explain why this is—such as individuals using substances as self-medication for PTSD symptoms (e.g., Hawn, Cusack et al., 2020), that long-term substance use inhibits the processing of trauma (e.g. Back et al., 2006), or that substances are used to alleviate PTSD symptoms but ultimately maintain or worsen them (e.g. Kaysen et al., 2011)—however, there is still considerable debate. Despite this, it is clear that PTSD and substance problems are often co-occurring.

In exploring the wider literature, it is clear that experiences of PTSD in autistic adults is more prevalent than one might expect. Recent research has highlighted that rates and prevalence of trauma and PTSD symptoms may be higher in autistic people than in neurotypical people (Rumball et al., 2021). For example, in their study exploring self-reported frequency of PTSD symptoms and trauma, Rumball et al. (2021) found that rates of trauma expose and PTSD symptomatology were significantly higher for autistic people, and in the case of PTSD symptoms, were 10 times higher than neurotypical people. In addition, Rumball et al. (2020), found that when using the DSM-5’s criteria for PTSD, 40% of the autistic adults sampled in the study showed probable PTSD in the last month and 60% showed probable PTSD at some point in their life.

What’s interesting is that some studies have shown that what constitutes a traumatic life event for autistic people may not be considered as one in the diagnostic sense (Rumball et al., 2020). This is significant as events that autistic adults may consider traumatic may not be acknowledged by neurotypical health professionals and doctors. For example, Abby’s experiences of her son being sent to residential care and the complications that surround this, for her was a tipping point, a significant traumatic event. However, it is difficult to know whether this would be treated as such in the medical sense. This can lead to autistic adults not receiving the help and support with trauma and PTSD that they need, due to the diagnostic considerations not reflecting the needs of autistic people and is, perhaps unintentionally, bias towards neurotypical experiences and expectations. This has in part been acknowledged by health professionals, as in a study exploring PTSD in autistic people and people with learning disabilities, clinicians who work in these settings find it difficult to identify PTSD symptomology and may instead conflate such symptoms with the way in which autism or learning disabilities are presented (Kildahl et al., 2020).

B.2. Perceived judgements and expectations

B.2.1. Health Care needs unmet for Autistic Adults

One of the areas I discussed with participants was their views and experiences of health care and health care professionals. When it came to these experiences, it was expressed by Emily, Kyle and Claudia, that health care professionals didn’t understand, acknowledge, or properly address their experiences and relationship with substance-related problems as an autistic person.

“Because I found that when I had kind of my breakdowns recently, not recently, but kind of within the last year. I'd have the ambulance people coming in and they didn't understand. And so, I'd say to them I'm not addicted to alcohol. I can drink, and then I can stop. I can stop and I don't have any symptoms. I don't have any withdrawals, anything. I said it's a coping strategy and it's uh, it's almost like a cry for help. They just don't have any idea whatsoever.” – Emily

"I have had questions before from people asking about support. I wouldn't be able to give them any answers, either because what we've got is a severe lack of accessible health care for addiction." – Kyle

"I first got benzos in 2012, my GP had me diagnosed as having Emotionally unstable borderline personality disorder. He prescribed them to calm my anger down. No one told me how addictive benzos would be. I was put on higher and higher amounts and lorazepam and temazepam. I even got these in liquid form so just drank them from the bottles like lemonade all through the day… I had three weeks on a detox programme but it wasn't long enough and I went home and got more [benzos]" – Claudia

"I start getting medicated all the time out of the frustration that they don't know—the doctors don't know—what to do with me. So yeah, that's not their fault because what do they get on autism? Like maybe an hour and a half or Tuesday's lecture in their second year of medical school." – Kyle

These experiences detail a lack of support from health care professionals and an inability for these services to address the needs for autistic people with substance-related problems. This notion is also evident in the wider literature. Research indicates that autistic adults are more likely to experience barriers to healthcare than neurotypical adults, including neurotypical adults with disabilities (Raymaker et al., 2017). In their systematic review exploring the barriers autistic adults face from healthcare providers, Mason et al. (2019), identified patient—provider miscommunication and misinterpretation as an impediment to support. They describe that this is due to autistic adults communicating symptoms or problems in way that do not meet the conventional expectations of the healthcare professionals, and partly a result of services misunderstanding or not interpreting the significance of the communication. This experience is echoed by Kyle, Emily and Claudia who expressed a mismatch between their needs, specific to their relationship with substances, and the healthcare providers conventional views on thresholds needed for requested support. The experiences from the participants describe a lack of awareness and training on autism and the differences in the presentation of substance-related problems in autistic adults. This is worrying as it could impact on a healthcare professionals' ability to provide support or treatment for autistic people.

This is further evident when Kyle and Emily discussed their experiences with classifications and the expectations healthcare providers have for the presentation of substance-related problems.

"Medication issues that I dealt with was without my doctors. Because [the medication use] wasn't, classified as an addiction because I never went to the open market to look for benzos." – Kyle

"[describing their relationship between substance use and late diagnosis of autism] I found I used alcohol to cope as a coping strategy. I call it my negative coping strategy. I found that that was the only route I could go down, so, for those undiagnosed, waiting for a diagnosis, alcohol can help you cope." – Emily

These experiences demonstrate that for some, healthcare providers were not acknowledging the use of substances in the same way as the autistic adults were themselves. As highlighted above, there is a mismatch in communication between how the healthcare providers typically view substance-related problems and the experiences of substance-related problems for autistic people. Until healthcare professionals are able to recognise how substance-related problems may present for autistic people, suitable support cannot be provided.

This idea was felt by some outside of experiences with alcohol and drug professionals, and in other areas of health care. Sian described their views on cognitive behavioural therapy (CBT), and how they felt it wasn't appropriate or beneficial for autistic people.

"The thing that I know about that [CBT for anxiety in autistic people] is because anxiety for autistic people is usually based on some form of actual real effects that's happening. It is not from a dysfunctional process. So, if somebody who is anxious about taking the bus trip, they might be worried

about if the bus breaks down and they won't be able to get off. That's an irrational process that can be deconstructed. Yeah, somebody who's autistic, who's worried about taking a bus trip? Might be worried about taking that bus trip because the trip could cause sensory overload, which will cause them physical pain. Yeah, that's not a big functional thought that can be changed. That's just a reality. That impacts their reality and their life. Their anxiety is valid, so CBT isn't really very helpful for that." – Sian

This expresses that the fundamental principles behind treatments and support offered by health care professionals may not consider autistic people and autistic perspectives. Sian expressed that the cognitive process behind CBT is not concurrent with the cognitive processes of autistic people. Health services are promoting the use of treatment and support that may not be beneficial for autistic people, as the provider will be assessing CBT from a neurotypical perspective. In fact, Sian states that the resource should include a disclaimer on supports and treatments, clarifying that the treatments and supports listed are the typical treatments provided by health professionals, but may not be appropriate for autistic people.

"[Including] something that says that you know what you likely to be offered on the NHS is, but you know that there isn't necessarily anything specific for autistic people." – Sian

In the two studies discussing CBT as a treatment option for autistic adults with substance-related problems, the study that incorporated a group dynamic comprised of autistic people (Ressel et al., 2020), had greater success than the study that simply incorporated autistic training for CBT professionals (Helverschou et al., 2019). This supports Sian's notion, as the incorporation and support from a group of autistic adults who may processes experiences in a similar way, was more beneficial for their treatment then simply providing neurotypical CBT professionals with training about autistic people. This idea has been expressed by Kyle.

"The medical practitioner or the support worker have been trained on how addiction works in neurotypicals, yeah? Is it something that we can change? No, we can't. Unless there is funding available to have a kind of an autistic self-advocacy Universal Support Group available and someone's got to pay [financially] for that. It's valuable, but we can't be expected to do that all ourselves." – Kyle

This is interesting as it questions the benefits of an educational resource, specifically in regards to treatment information, when there is a lack of appropriate treatment or support options for autistic adults with substance-related problems. Despite the accommodations suggested in the treatments section of ADIFA (e.g., whether treatment can be done one-on-one or in one's own home), and Kyle themselves stating the benefits of and need for the educational resource, the resource is limited until there are treatment and support groups run by, or involving, autistic people and perspectives. This highlights the importance for further research in the area of substance-related problems and autistic people, particularly in the development of suitable and appropriate treatment or support options.

In addition to a lack of tailored support, Sian indicated that even if you wanted to access an intervention provided by the NHS, there were no guarantees to access.

"I feel like it's very difficult right now on the NHS to get access to the services that are purported to be present. It's not that I don't understand that they're very overwhelmed, and there's, you know, horrendous waiting lists and all the rest of it, but I feel like that is a level of social standing which I could do without." – Sian

Access to health services, particularly mental health services has been identified as a problem worldwide, particularly due to the increased pressure from the COVID-19 pandemic (Kola, 2020; Werlen et al., 2020). However, as Sian demonstrates, this lack of access can lead to feelings of scepticism in health services in providing support or treatments. Additionally, the mention of a social standing suggests that access to healthcare is not uniform across society, and that some groups of individuals may receive easier access than others.

B.2.2. Societal, Neurotypical Biases

When considering why autistic people's experiences and problems might not be acknowledged or considered by health professionals, it may be reflective of their own experiences or perceptions of autism, or lack thereof. Out of all the participants, Kyle discussed this issue in the most detail. Kyle detailed the biases he believes autistic people face in a society whose perspective is focused from a neurotypical perspective.

"We do live in a society that doesn't want us to exist, and it's very good at telling us it doesn't want to exist, and even better at telling itself. We are continually. Devalued and discriminated against and disproved. So, people using alcohol and drug discovery mechanisms are. Actually, relative like in my view, that's a pretty healthy way to approach, right? Because it's reasonable, it is justified and it stops suicide from happening." – Kyle

"There's still a widely held view that autistic people cannot be trans or have any sexuality at all, ever. My friend, Rose was told by an NHS practitioner that she couldn't be trans because she was autistic and that she didn't fit a set of fairly limited stereotypes for people who weren't able to be trans." – Kyle

This notion may be able to distinguish why autistic people may be sceptical or untrusting of health professionals and why their experiences of substance-related problems go unnoticed. In fact, clinicians themselves have acknowledged that they find it difficult to identify certain symptoms in autistic people, perhaps because their understandings or expectations are based in neurotypical people (Kildahl et al., 2020). Not only can these biases or perceptions be present in the presentation of particular conditions or symptomology, but can also be representative of the types of care, support and treatment provided. For example, in their study Como et al. (2020), explored the language paediatric dentists used in relation to their autistic patients. They found several themes in relation to the language used by the healthcare providers; microaggressions were used to describe autistic patients in subtle but negative ways (e.g., describing visits by autistic patients as avoiding landmines), autistic patients were marginalised through the use of exclusionary language (e.g., describing autistic patients as "them" or "those kids"), and preconceptions about autistic children were also present (e.g., that parents of autistic children don't bother with their child's oral healthcare because it is a hassle for them; Como et al., 2020). This highlights that neurotypical healthcare providers perspectives are rooted in their expectations of neurotypical people, and when faced with an autistic individual, they hold—unintentionally or not—biases that can inform treatments or care for them. This was experienced by Kyle when he sought treatment for depression.

"Even these self-help organizations support organizations, talking therapies, medical treatments are always going to be a massive gamble. Even when it says trained in autism like it can. Like things still go really badly even if they've trained. Using outdated and stereotypical perceptions about autistic people can do a lot more damage. I had a therapist last year, who caused me to get even worse in my depression because all her misunderstanding of autistic people were like how they presented, yeah. That's normal for us." – Kyle

This experience highlights how misconceptions and misunderstandings about autism and autistic people can negatively impact upon autistic people themselves, particularly in regards to seeking treatment or support.

These societal misconceptions may, to an extent, be linked to previous studies (and the current study) about using substances as a tool for autistic people to “camouflage”. Using substances to “hide” or “camouflage” presentations of their autism or how their autism might be perceived by others, would not be a factor if societal viewpoints accurately reflected and incorporated autistic people and perspectives. Instead, this motivation for substance use is present because autistic people feel the need to “fit in” with the neurotypical norm, or that being autistic may make them stand out and invite negative experiences or perceptions.

In fact, for Emily, alcohol use was a form of freedom from the pressures to mask their autism in society.

“I found that I've been able to mask now, so I don't have to use alcohol to mask. I found that when I was drinking, I would become more, have more, I'd be more autistic because I wasn't masking. If that made sense. So, I kind of got to the point of where I kind of well, actually this is who I am and I'll have a drink. And you know what? I don't care if, you know, if I'm going to stutter if I'm staring at people or if I'm kind of being really, really loud or I’m not suppressing anything anymore.” – Emily

The effects of these biases can be problematic for autistic people requiring support outside of health care environments. Kyle describes a distressing experience of the biases faced in a community support group for victims of sexual assault.

“I was abused as a child and I'm I was diagnosed with PTSD early 2020. I started to accept that yes, I was raped when I was seven. And I tried to seek support for that, yeah, via a charity called Survives UK. I had a really shit experience for the first two meeting where someone mistook me for a perpetrator instead of someone that was affected by assault. He wouldn't have done that if I hadn't been autistic. Because, you know, I didn't say anything meaningfully different than the other ones.” – Kyle

This experience is incredibly difficult and upsetting to hear. The thought of seeking support for an assault and then being treated as a perpetrator instead of a victim, simply because you are autistic is deeply distressing. This experience demonstrates the biases autistic people can face outside of health care environments and are present within the wider community. Research has shown that these biases, stigma, and marginalisation are present in wider society. For example, the way in which autism and autistic people are presented in film, tv and other media is not normally reflective of real life, as they usually involve the perpetuation of stereotypes and can lead to false beliefs and perceptions of autistic people (Ressa & Goldstein, 2021; Fontes & Pino-Juste, 2022).

The discussion of unintentional or unconscious biases from the perspectives of neurotypical people has made me consider my own perspectives. For example, towards the beginning of my project, I conducted a structured online interview in order to determine autistic adults' preferences for the educational resource before it was created (see Chapter Three). Autistic adults were referred to using person first language (i.e., individuals *with* autism) within the questions in this structured interview. One of the findings of that interview was the preference for identity first language (i.e., autistic person) as opposed to person first language, which was then adopted in full throughout the educational resource and in the questions for semi-structured interview discussed in this chapter. While at the time, I saw this as a perfect example of why engaging with autistic adults is crucial to the development of a successful and appropriate resource that would be used by autistic adults, perhaps this also demonstrates my own unintentional bias as a neurotypical researcher. In fact, the use of person first terms has been identified by autistic researchers as ableist language (Bottema-Beutel et al., 2021). I used this language without considering or comprehending the implication it had for autistic people, therefore unintentionally presenting my research from a neurotypical perspective. Interestingly, my interest in this area and my relation to autism was asked by some participants in the current study.

“Are you autistic?” – Kyle

“Can I ask, what is your involvement, or interest is, in this area?” – Emily

When I was asked directly if I was autistic by Kyle, he was pleased to know that although I am not autistic, my brother is. Although I am neurotypical, I can draw on my experiences with my autistic brother and I am able to recognise certain stereotypes or misinformation about autism and autistic people thanks to these experiences. However, I am not autistic and inclusion of autistic people in projects directly impacting them is, I think, crucial to their success.

Discussion

In summary, the current research study provided useful feedback from autistic adults and parents of autistic adults on ADIFA.

This feedback could be directly applied and incorporated in the resource, increasing the accessibility and appropriateness of the resource for its intended audience (autistic adults). Feedback was overwhelmingly positive, as participants praised the format and content of the website. Furthermore, the positive feedback reinforced the need for pragmatic educational information to be tailored and created on substance-related topics for autistic people. The findings from this study also demonstrated a need for further research in this field, as many additional topics and barriers (such as motivations for use and scepticism of healthcare providers) were identified.

Chapter Six: Discussion and implications for future directions

Overview

The purpose of this chapter is to discuss the findings from the current project in a wider context. This chapter discusses how the current project can help in furthering research in this area and suggestions for future projects. This chapter also acknowledges and discusses the limitations of the project, including how they can be remedied in future projects.

1.0. Positioning and implications of the current project

The purpose of the current project was to address a gap in the literature, namely, the lack of tailored and pragmatic resources on substance use information for autistic adults. This was achieved through the development of ADIFA, which can be accessed immediately and independently online by autistic adults and the wider population:

www.adifa.co.uk

The key benefit of developing this online resource was that it is instantly implementational, and can be offered by charities, autistic health professionals, and substance use healthcare professionals. Throughout the process of the development and production of this resource, the current project has contributed to and developed upon current understanding of substance use and addiction in autistic communities.

1.1. Community-identified need for substance use information

Throughout the different stages of the project, autistic adults themselves voiced their need for tailored information and support on substance-related topics. This is important as often, literature refers to substance use issues contextually, though the identification of the extent of the problem (e.g., Butwicka et al., 2017). The problem is often addressed from the viewpoint and inference of the researcher. The current project differed from this, as this need for tailored support and information was articulated directly by the autistic communities themselves. Self-identification of the need for more tailored support and information further supports adaptations to substance use therapies as an important research area. Participants in Chapter Five expressed the need for more tailored support, and suggested that without appropriate substance use support, the positive impacts of educational measures are limited. This stresses the importance of previous research studies addressing this issue (Helverschou et al., 2019; Walhout et al., 2022; Brosnan & Adams, 2022). All of the aforementioned studies aimed to adapt CBT or other therapies for substance use-problems specifically for autistic individuals. The findings from the current project highlight the importance of research in this area.

Consideration is needed in selecting an appropriate approach to incorporate the perspectives of autistic communities when adapting or developing therapies. Cooper et al., (2018) proposed an approach to adapting services for autistic communities through consultation first with health professionals to develop and select the adaptations, followed by gaining the perspectives of autistic communities on the proposed adaptations. This approach was applied in substance use therapies by Brosnan & Adams (2022), which resulted in pragmatic adaptations therapists can apply to sessions, and a list of top tips compiled by autistic communities on how the adaptations can best be implemented. While this approach is valid and logical, as the therapists are the individuals leading the sessions and providing the service, it could be argued that autistic communities' needs are treated secondary to the therapists. It is important to consider this issue, as displayed in the current project and the wider literature, perceived judgement or misunderstanding of autistic communities and their needs hindered their engagement with services and resulted in their needs being unmet.

Moving forward, future studies that aim to adapt or tailor support interventions on substance use-problems should, at a minimum, contain an aspect to explore the preferences and needs of the intended user. Preferably, the needs of the autistic individual would be explored prior to, and form the basis of, the development of the adaptions. A similar model could be used to the one in the current project, namely, a pre-development exploratory phase and a post-development evaluation or analysis.

1.2. Experiences of substance use and barriers to healthcare

While the focus was on the development and evaluation of ADIFA, the current project was able to gain personal perspectives on autistic adults' experiences of substance use and addiction. Particularly in Chapter Five, participants articulated the problems they faced with substance use and the impacts it had on them and their lives. This is important as within the wider literature, there is little research on how substance use and addiction impacts upon the autistic individual. Of note, autistic adults throughout the project (in both Chapters 3 & 5) reported a mixture of negative and positive impacts of substance use. Some participants described the autistic community as a vulnerable one, and how, in their opinion, using substances puts the individual at greater risk and makes them even more vulnerable. Others, however, reported that substance use was a necessary coping method that could be applied to help manage living in a neurotypical world, where expectations and judgements are skewed through a neurotypical viewpoint. The duality in the impact on the individual found in the current project is also present in Tinsley & Hendrickx's (2008) book, in which the author discusses their own experiences of addiction to alcohol. As in the current project, the author's experiences were of using alcohol to as a coping method, which at first, they felt was successful, but ultimately, over-time, developed into an over-reliance and addiction. In order to better understand substance use in autistic communities, more research should be conducted on the emotional and social impacts for the individual. In better understanding the impacts substance use has, the more effective and beneficial educational and support interventions will be for autistic communities.

Another personal perspective that was voiced by participants was that of their experiences with healthcare professionals, both specific to substance use and healthcare in general. In Chapter Five, participants articulated their frustration at the interactions and care they received from healthcare professionals for issues with substance use. For these participants, their unmet substance-related needs can be attributed to two reasons: the neurotypical healthcare professional's misunderstanding of autism and misconceptions about autistic people, and a lack of understanding for what constitutes a substance use-problem for the autistic individual. As in the current project, Brosnan & Adams (2020) identified being misunderstood and judged by the health professional as a barrier to seeking help for problematic alcohol use. In order to better address the needs of this community, more research should be conducted on unmet healthcare needs for autistic adults specific to substance use care and support. Substance use healthcare professionals need more comprehensive training on autism and the needs of autistic people. Application of the information contained in ADIFA could be used in future research for education in wider contexts. For example, one of the participants in Chapter Five suggested the idea of applying ADIFA into a training programme targeted specifically for healthcare professionals.

1.3. Detailed choice and process outlined in the development of ADIFA

A key aspect to the current project was in the implementation of the preferences and opinions of autistic communities gained in Chapter Three. To best achieve this, each deliberation and consideration of implementation was described in Chapter Four in detail. Examples were included to demonstrate how each point was incorporated specifically into ADIFA's design. Detailing the process behind its development resulted in design facets that could be applied to future studies, in which the aim is to develop or adapt psychoeducational material for autistic communities.

The design facets mentioned relate mostly to the formatting and presentation of the resource. For instance, online mediums were identified as preferable for resources providing information. This preference has been highlighted in the wider literature, as they are flexible, can be accessed independently, and can be accessed in a comfortable and familiar environment (Backman et al., 2018; Sehlin et al., 2018). However, the findings from Chapter Three highlight that while online mediums were a preference for information, a preference for in-person mediums was stated for finding support for issues. This was despite the potential pitfalls or challenges participants might have experienced in receiving support. This highlights that resources developed for autistic adults need to consider the purpose of their resource, whether it be for information, support, or both. Either way, it is important for any resource developed to consider how autistic adults can access information in both ways. For example, ADIFA was primarily developed to inform autistic adults on substance-related issues and so an online medium was selected. However, the resource also includes detailed practical information on how and where to get support, including what that support might look like (e.g., discussions of what takes place at the GPs). This was to give the user a sense of what in-person support would look like, which is important given a preference for in-person support stated.

Another facet which can be utilised in other resources relates to the presentation of the information and language. The most widely specified format described by autistic adults was the use of clear, direct language and formatting that focused on the functional (i.e., images and diagrams used to convey meaning and not purely aesthetic). Presenting information in a clear, direct and unambiguous manner is conducive with the proclivity for concrete thinking styles identified in other research studies exploring educational preferences in autistic people (e.g., "He doesn't work in greys. He works in black and white" Vindin et al., 2021:5). The use of clear, concrete language and simple, practical presentation of information should be considered when designing psychoeducational material for autistic communities.

1.4. Additional information on motivations for substance use

Through both research studies in Chapter Three & Five, autistic adults articulated the motivations behind their substance use. The findings from these studies corroborate the findings in the wider literature, namely, the role of self-medication and “camouflaging” in social situations (Bargiela et al., 2016; Clarke et al., 2016). The wider literature is limited on the motivations behind substance use in autistic communities.

One motivation suggested in the wider literature is using substances to self-medicate (Clarke et al., 2016). Through interviews with autistic adults in the current project (in Chapters 3 & 5), self-medication was identified by some as a reasoning behind their substance use. While autistic adults did mention self-medication in relation to mental distress (which is typically the focus of the self-medication hypothesis of substance use), other factors were articulated. These factors were autism-specific, such as managing sensory issues or sensory overload in social situations, or were factors not typically discussed in the fields of autism and substance use, such as self-medicating for sleep or to manage trauma and PTSD. This suggests that motivations for substance use in autistic adults is complex. Motivations for substance use in these communities are themselves under-researched. The findings from the current project could be used to help guide future research on this topic. Future research could be conducted on one or more of the specific motivations discussed. This would be beneficial for the development or tailoring of support or information specific for this population, as they can help influence a more appropriate approach or content of the programme or material.

Another motivation highlighted in the wider literature is the idea of substances acting to hide or “camouflage” behaviour, particularly in regards to behavioural presentations of autism (Bargiela et al., 2016; Clarke et al., 2016). However, currently, research on this topic specific to substance use is limited. The findings from the present project (Chapters 3 & 5) support camouflaging in social situations, as some autistic adults articulated the use of substances specifically related to “feeling less autistic” or “masking their symptoms” to feel accepted by certain societal groups. However, this was not universal. One participant that did articulate their experiences of alcohol were counter to the typical notion of “camouflaging”. They found that they felt *more* autistic after drinking, and that the use of alcohol actually caused them to stop “camouflaging” or masking. Instead, what changed was their internal considerations of how they were perceived by others. Interestingly, this has not been found in wider literature. This shows how complex and contradictory “camouflaging” can be in regards to substance use. Future projects could build from both the current project and look to explore motivations, particularly masking or “camouflaging” motivations, in more detail. ADIFA incorporated motivations as a topic area and was received favourably. Greater exploration of this area would help to further improve support and information for autistic adults.

2.0. Reflexivity

Through my experiences on this project, it has solidified in my mind the need and importance of exploring the first-hand perspectives and experiences of the people who the project is about. This is especially important if there are to be real-world applications implemented as a result of the research project. I do not believe I would have achieved the results I did if I did not incorporate their perspectives and feedback.

This is not to discredit the role of the researcher, or the involvement of perspectives from other groups (such as parents of autistic people), but there is an adage often voiced by autistic communities about research and policies that affect them, “nothing about us, without us”. In my experience during this project, I believe this to be true. Some of the most impactful insights came from conversations with autistic adults who have had problems with alcohol or drugs and I believe that in order to better support a community, involvement with that community is crucial.

When deciding on the degree in which autistic adults should be incorporated in the project, a choice was made to include autistic adults as research participants only and not as participatory co-researchers. This approach was selected as it provided autistic adults the chance to discuss the factors they deemed important in creating a tailored resource (pre-development), how successfully they were incorporated and how they could be improved (post-development), while I could use my expertise as a researcher to create and amend the resource informed by their insights. While I believe this approach was successful due to the feedback from autistic adults themselves, that same feedback raises questions as to whether a more participatory approach may have elicited a stronger resource.

Interviews with autistic communities have made me reflect on the appropriateness of conducting research into areas in which I have no or limited personal experiences. While I have an autistic brother, I myself am not autistic, nor have I had personal experiences with alcohol or drug problems. This is conflated by the issues surrounding research into autism topics in general, as the autistic adults included in the current project highlighted how they can be misinterpreted or misunderstood by neurotypical people.

While ADIFA may have been developed by me, the online nature of the resource means it can be easily amended and adopted by the autistic community themselves. Being a relative outsider of the autistic community at the beginning of this PhD project, I lacked the necessary connections within the community to conduct co-researcher projects. However, through the process of developing the educational resource, I have now created connections with people in this community. Some have offered to be a referee for funding of future projects, and one person has even expressed an interest in collaborating on an educational research project in this area.

3.0. Limitations

3.1. Lack of representation of autistic adults with learning disabilities

The literature discussed in Chapter One highlighted the high prevalence of certain co-occurring conditions in autistic communities. While the current project included autistic adults with co-occurring ADHD, no participant had a co-occurring learning disability. The relationship between co-occurring learning disabilities and the prevalence of substance use or addiction in autistic communities is unknown. However, some autistic adults with learning disabilities do use substances, and may require additional needs for substance-related support or therapies (Drake et al., 2018). Due to their absence from the current project, it is unknown how helpful or accessible ADIFA is for this population

In order to address this issue in the future, methodologies should specifically involve autistic adults with mild learning disabilities. To counteract the potential difficulties in recruiting this community, a greater immersion within the community itself would be needed. This could be achieved through engagement with specific and localised community groups or charities. This would help to determine whether ADIFA is suitable for this community and help identify potential amendments or inclusions needed. Another avenue that could be explored is collaboration with schools that cater to additional educational needs. While ADIFA was designed for use by autistic adults, several of the participants in Chapter Five suggested expanding the information and procedure used in the development of ADIFA to create several related resources targeted at specific groups. For example, a related resource specifically targeted for autistic teenagers, or a resource for carers and autistic individuals with a learning disability. While collaboration with schools or carers will incur additional ethical considerations (due to age and ability to provide informed consent), this could be an important avenue for engagement with this community. Additionally, this could also provide an avenue for future projects that wish to explore how effective incorporation of ADIFA in an educational, teacher-led programme, could be for autistic students.

3.2. Lack of quantitative evaluation and implications for generalisation

While the qualitative approach taken in the current project was appropriate for the research aim and objectives, quantitative analysis was not included in the approach. The qualitative information gained from interviews with autistic adults and parents of autistic adults was useful in evaluating, and gaining feedback on the improvement of ADIFA. However, without a quantitative approach, the positive feedback cannot be generalised for a wider autistic audience.

To address this limitation, future projects could aim to evaluate ADIFA using a quantitative methodological design. This could be used in several different research directions. For example, ADIFA could be evaluated by a large group of autistic adults using a survey, Likert-style quantitative design. This could be used to provide quantitative statistics on several different aspects of the evaluation of ADIFA, such as satisfaction, accessibility, and trustworthiness. While the current project provided in-depth experiences of autistic adults using ADIFA, with the aim of improving the ADIFA, a quantitative design could be used to assess ADIFA in a wider context.

4.0. Future Directions

This research area can be further explored in a variety of different ways. Firstly, and specific to this project, the educational resource ADIFA could be expanded, assessed, and adopted by autistic communities. Future projects could aim to quantitatively assess the potential benefits or drawbacks of ADIFA for autistic adults, such as through measures of satisfaction, accessibility, knowledge, and/or behavioural change. These measures could be assessed immediately on use (i.e., comparison of scores before and after use of ADIFA), or longitudinally (i.e., whether there is any behavioural change over time after use of ADIFA).

Secondly, future research projects could be conducted in this area using participatory or co-production methodologies. The current project demonstrated not only a need for more research in the area of substance use and addiction in autistic populations, but also a willingness from autistic individuals to be involved in greater participation or co-production on specific research projects. For example, one of the participants who took part in the current project stated an interest in co-producing a training programme on addiction in autistic communities to be delivered for autistic individuals and/or health professionals. These potential projects could implement ADIFA in their design or use ADIFA as a resource (among others) to help inform the development or materials of the potential project.

Finally, future research could aim to explore the issues or areas discussed in the current project within a wider context. For example, projects could aim to explore motivations for substance use in autistic communities in more detail, whether that be through further qualitative approaches on autistic individuals' experiences or through quantitative approaches on the prevalence of particular motivations within autistic communities. The current project has highlighted how more research in general on this topic is not only required but requested by autistic communities themselves.

5.0. Concluding remarks

When I began this project in 2018, there was relatively little information or support tailored for autistic communities. While this is still an under-researched area, it has gained an increasing amount of focus and attention. Charities and organisations, such as the National Autistic Society, are increasingly incorporating more substance use and addiction information as part of their educational or supportive repertoire. As indicated by the wider literature and the autistic adults who took part in the current project, there is a clear need for tailored information and support on substance use and addiction. I am very proud to have developed ADIFA and for it to be well received by the autistic adults and parents of autistic adults who took part in this project. This project will hopefully only be the start of more tailored information and support for autistic communities.

References

Adewumi, M. T., Vo, N., Tritz, D., Beaman, J., & Vassar, M. (2021) An evaluation of the practice of transparency and reproducibility in addiction medicine literature. Addictive Behaviors, 112, 106560–106560. https://doi-org.mmu.idm.oclc.org/10.1016/j.addbeh.2020.106560American Psychiatric Association. 2013. DSM 5. *Washington*: American Psychiatric Association.

Aliu, O., & Chung, K.C. (2010) Readability of ASPS and ASAPS educational websites: An analysis of consumer impact. *Plastic and reconstructive surgery*, *125*(4), 1271.

Allemang, B., Sitter, K., & Dimitropoulos, G. (2021) Pragmatism as a paradigm for patient-oriented research. Health Expectations, 25(1). https://doi.org/10.1111/hex.13384

de Alwis D., Agrawal A., Reiersen A. M., Constantino J. N., Henders A., Martin N. G., Lynskey, M.T. (2014) ADHD symptoms, autistic traits, and substance use and misuse in adult Australian twins. *Journal of Studies on Alcohol and Drugs, 75*(2), 211–221

Amri, M., Angelakis, C., & Logan, D. (2021) Utilizing asynchronous email interviews for health research: overview of benefits and drawbacks. BMC Research Notes, 14(1). https://doi.org/10.1186/s13104-021-05547-2

American Psychiatric Association (2013) *Diagnostic and statistical manual of mental disorders: DSM-5.* 5th edn. Washington, D.C.: American Psychiatric Publishing.

Anderson, C.M., Gerard, E., Hogarty, G.E., & Reiss, D.J. (1980) Family treatment of adult schizophrenic patients: A psychoeducational approach. *Schizophrenia Bulletin*, *6*, 490–505

Anderson, A.H., Stephenson, J., Carter, M., & Carlon, S. (2019) A Systematic Literature Review of Empirical Research on Postsecondary Students with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders, 49*(4), 1531-1558

Arnevik, E.A., & Helverschou, S.B. (2016) Autism Spectrum Disorder and Co-occurring Substance Use Disorder – A Systematic Review. *Substance Abuse: Research and Treatment, 10*, 69-75

Arnstein, S. R. (1969) A Ladder of Citizen Participation. Journal of the American Institute of Planners, 35(4), 216–224. https://doi.org/10.1080/01944366908977225

Arts, D. L. (2019) Formative Evaluation of an eHealth Tool for Attention Problems in Higher Education. Accessed via https://www.huisartsenamsterdam.nl/wp-content/uploads/2019/11/Concentratie-problemen.pdf

van Asselt-Goverts, A.E., Embregts, P.J.C.M., Hendriks, A.H.C., Wegman, K.M., & Teunisse, J.P. (2015) Do Social Networks Differ? Comparison of the Social Networks of People with Intellectual Disabilities, People with Autism Spectrum Disorders and Other People Living in the Community. *Journal of Autism and Development Disorders, 45*(5), 1191-1203

Atkinson N.L., Saperstein S.L., Desmond S.M., Gold R.S., Billing A.S., & Tian J. (2009) Rural eHealth nutrition education for limited-income families: an iterative and user-centered design approach. *Journal of Medical Internet Research*, *11*(2), p.e1148.

Autistica. No date. *Learning disability and autism*. https://www.autistica.org.uk/what-is-autism/signs-and-symptoms/learning-disability-and-autism

Babor, T.F., Higgins-Biddle, J.C., Saunders, J.B., & Monteiro, M.G. (2001) *The alcohol use disorders identification test* (pp. 1-37). Geneva: World Health Organization.

Back, S.E., Brady, K.T., Sonne, S.C., & Verduin, M.L. (2006) Symptom improvement in co-occurring PTSD and alcohol dependence. *The Journal of nervous and mental disease*, *194*(9), 690-696.

Backman, A., Mellblom, A., Norman-Claesson, E., Keith-Bodros, G., Frostvittra, M., Bölte, S., & Hirvikoski, T. (2018) Internet-delivered psychoeducation for older adolescents and young adults with autism spectrum disorder (SCOPE): An open feasibility study. *Research in Autism Spectrum Disorders, 54*, 51-64

Bargiela, S., Steward R., & William, M. (2016) The Experiences of Late-diagnosed Women with Autism Spectrum Conditions: An Investigation of the Female Autism Phenotype. *Journal of Autism and Development Disorders, 46*(10), 3281.

Barry, C.L., McGinty, E.E., Pescosolido, B.A., & Goldman, H.H. (2014) Stigma, discrimination, treatment effectiveness, and policy: public views about drug addiction and mental illness. Psychiatric Services, 65(10), 1269-1272.

Bauer, M. S., & Kirchner, J. (2020) Implementation science: What is it and why should I care? Psychiatry Research, 283, 112376. https://doi.org/10.1016/j.psychres.2019.04.025

Becker, S.J., Midoun, M.M., Zeithaml, V.A., Clark, M.A., & Spirito, A. (2015) Dimensions of treatment quality most valued by adolescent substance users and their caregivers. Professional Psychology: Research and Practice, 47(2), 120-129.

Beggiato, A., Peyre, H., Maruani, A., Scheid, I., Rastam, M., Amsellem, F., Gillberg, C. I., Leboyer, M., Bourgeron, T., Gillberg, C., & Delorme, R. (2017) Gender differences in autism spectrum disorders: Divergence among specific core symptoms. *Autism Research*, *10*(4), 680–689. https://doi-org.mmu.idm.oclc.org/10.1002/aur.1715

Boekel, L.C., Brouwers, E.P.M., Weeghel, J., & Garretsen, H.F.L. (2013) Stigma among health professionals towards patients with substance use disorders and its consequences for healthcare delivery: Systematic review. *Drug and Alcohol Dependence, 131*(1-2), 23-35.

Bonsack, C., Rexhaj, S., & Favrod, J. (2015) Psychoeducation: Definition, history, interest and limits. *Annales medico-psychologiques, 173(1).*

Bottema-Beutel, K., Kapp, S.K., Lester, J.N., Sasson, N.J., & Hand, B.N. (2021) Avoiding ableist language: Suggestions for autism researchers. *Autism in adulthood, 3*(1), 18-29.

Brady, K.T., McCauley, J.L., & Back, S.E. (2021) The comorbidity of post-traumatic stress disorder (PTSD) and substance use disorders. *Textbook of addiction treatment: International perspectives*, 1327-1339.

Branson, D.C., Martin, J.S., Westbrook, O.E., Ketcherside, R.J. and Bradley, C.S. (2022) “Why People Gotta be so Judgy?”: The Importance of Agency-Wide, Non-judgmental Approach to Client Care. *Alcoholism Treatment Quarterly*, *40*(1), pp.65-82.

Braun, V., & Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative research in psychology*, *3*(2), 77-101.

Braun, V., & Clarke, V. (2019) Reflecting on reflexive thematic analysis. *Qualitative research in sport, exercise and health*, *11*(4), 589-597.

Braun, V., Clarke, V., Boulton, E., Davey, L., & McEvoy, C. (2021). The online survey as a qualitative research tool. *International Journal of Social Research Methodology, 24*(6), 1–14. https://doi.org/10.1080/13645579.2020.1805550

Bridges, A.J., Karlsson, M., & Lindly, E. (2015) The effect of brief, passive psychoeducation on knowledge and ratings of intimate partner violence in the United States and Argentina. *Journal of interpersonal violence, 30*(2), 272-94.

Brink, P. J., & Wood, M. J. (2001) Basic steps in planning nursing research: From question to proposal (5th ed.). *London: Jones & Bartlett.*

Britton, A., Fat, L.N., & Neligan, A. (2020) The association between alcohol consumption and sleep disorders among older people in the general population. *Scientific reports*, *10*(1), 5275.

Brosnan, M. and Adams, S. (2020) The expectancies and motivations for heavy episodic drinking of alcohol in autistic adults. *Autism in adulthood*, *2*(4), 317-324.

Brosnan, M. and Adams, S. (2022) Adapting drug and alcohol therapies for autistic adults. *Autism in Adulthood*, *4*(3), 214-223.

Brown, H. (2018) Commentary on “The bounds of liberty: lessons learnt from treating a man with alcohol use disorder, autism and learning disability”. *Tizard Learning Disability Review, 23*(1).

Buell, S., Langdon, P. E., Pounds, G., & Bunning, K. (2019) An open randomized controlled trial of the effects of linguistic simplification and mediation on the comprehension of “easy read” text by people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*. https://doi-org.mmu.idm.oclc.org/10.1111/jar.12666

Burnette, C.E., Roh, S., Liddell, J. and Lee, Y.S. (2019) American Indian women cancer survivors' coping with depressive symptoms. *Journal of psychosocial oncology*, *37*(4), 494-508.

Butwicka, A., Långström, N., Larsson, H., Lundström, S., Serlachius, E., Almqvist, C., Frisén, L., & Lichtenstein, P. (2017) Increased risk for substance use-related problems in autism spectrum disorders: a population-based cohort study. *Journal of Autism and Developmental Disorders*, *47*(1), 80-89.

Camm-Crosbie, L., Bradley, L., Shaw, R., Baron-Cohen, S., & Cassidy, S. (2019) 'People like me don't get support': Autistic adults' experiences of support and treatment for mental health difficulties, self-injury and suicidality. *Autism, 23*(6), 1431–1441. https://doi.org/10.1177/1362361318816053

Carlsson, E., Miniscalco, C., Kadesjö, B., & Laakso, K. (2016) Negotiating knowledge: parents' experience of the neuropsychiatric diagnostic process for children with autism. *International Journal of Language & Communication Disorders, 51*(3), 328–338. https://doi.org/10.1111/1460-6984.12210

Cascio, M.A., Weiss, J.A., & Racine E. 2021. Empowerment in decision-making for autistic people in research. *Disability & Society*, *36*(1), 100-144.

Castro-Alonso, J. C., de Koning, B. B., Fiorella, L., & Paas, F. (2021) Five strategies for optimizing instructional materials: instructor- and learner-managed cognitive load. Educational Psychology Review, 33(4), 1379–1407. https://doi-org.mmu.idm.oclc.org/10.1007/s10648-021-09606-9

Chinn, D., (2019) Talking to producers of Easy Read health information for people with intellectual disability: Production practices, textual features, and imagined audiences. *Journal of Intellectual & Developmental Disability*, *44*(4), pp.410-420.

Chandrananth J, Fraval A, Chong YM, Chandrananth, M., & Tran, P. (2017) A Guide to Writing eHealth Websites with Orthopaedics as an Example–- Readability, Reliability, Usability. *Journal of Orthopaedics and Rheumatism, 1*(2), 28-32.

Chinn, D., & Homeyard, C. (2017) Easy read and accessible information for people with intellectual disabilities: Is it worth it? A meta-narrative literature review. *Health Expectations: An International Journal of Public Participation in Health Care & Health Policy*, *20*(6), 1189–1200. https://doi-org.mmu.idm.oclc.org/10.1111/hex.12520

Chown, N., Robinson, J., Beardon, L., Downing, J., Hughes, L., Leatherland, J., Fox, K., Hickman, L., & MacGregor, D. (2017) Improving research about us, with us: a draft framework for inclusive autism research. *Disability & Society, 32*(5), 720-734.

Clarke, C., Tickle, A., & Gillott, A. (2016) Substance use disorder in Asperger syndrome: An investigation into the development and maintenance of substance use disorder by individuals with a diagnosis of Asperger syndrome. *International Journal of Drug Policy, 27*, 154-163, https://doi.org/10.1016/j.drugpo.2015.06.003.

Clinical Guidelines on Drug Misuse and Dependence. 2017. Drug misuse and dependence: UK guidelines on clinical management. *London: Department of Health.*

Como, D. H., Floríndez, L. I., Tran, C. F., Cermak, S. A., & Stein Duker, L. I. (2020) Examining unconscious bias embedded in provider language regarding children with autism. *Nursing & Health Sciences*, *22*(2), 197–204. https://doi.org/10.1111/nhs.12617

Cooper, K., Loades, M.E., & Russell, A. (2018) Adapting psychological therapies for autism. *Research in autism spectrum disorders, 45*, 43-50.

Copeland, J., Rooke, S., Rodriquez, D., Norberg, M. M., & Gibson, L. (2017) Comparison of brief versus extended personalised feedback in an online intervention for cannabis users: Short-term findings of a randomised trial. *Journal of Substance Abuse Treatment, 76*, 43–48. https://doi.org/10.1016/j.jsat.2017.01.009

Cotugna N., Vickery, C.E., & Carpenter-Haefele, K.M. (2005) Evaluation of literacy level of patient education pages in health-related journals. *Journal of Community Health, 30*, 213-219.

Crane, L., Adams, F., Harper, G., Welch, J., & Pellicano, E. (2019) ‘Something needs to change’: Mental health experiences of young autistic adults in England. *Autism, 23*(2), 477–493. https://doi.org/10.1177/1362361318757048

Crane, L., Batty, R., Adeyinka, H., Goddard, L., Henry, L.A., & Hill, E.L. (2018) Autism Diagnosis in the United Kingdom: Perspectives of Autistic Adults, Parents and Professionals. *Journal of Autism and Developmental Disorders 48*, 3761–3772 https://doi-org.mmu.idm.oclc.org/10.1007/s10803-018-3639-1

Crane, L., Chester, J. W., Goddard, L., Henry, L. A., & Hill, E. (2015) Experiences of autism diagnosis: A survey of over 1000 parents in the United Kingdom. *Autism, 20*(2), 153–162.

Donker, T., Griffiths, K.M., Cuijpers, P., & Christensen, H. (2009) Psychoeducation for depression, anxiety and psychological distress: a meta-analysis. *BMC Medicine, 7(79).*

Doumas, D.M., Miller, R.M., & Esp, S. (2019) Continuing education in motivational interviewing for addiction counselors: Reducing the research-to-practice gap. *Journal of Addictions & Offender Counseling*, *40*(1), 36-51.

Drake, A.C.L., Hank, D., Edwards, R., Ensum, J., & Bateman, L. (2018) The bounds of liberty: lessons learnt from treating a man with alcohol use disorder, autism and learning disability. *Tizard Learning Disability Review, 23*(1).

Dudley, K.M., Klinger, M.R., Meyer, A., Powell, P., & Klinger, L.G. (2019) Understanding service usage and needs for adults with ASD: The importance of living situation. *Journal of Autism and Developmental Disorders*, *49*, 556-568.

van Duijvenbode, N., VanDerNagel, J.E., Didden, R., Engels, R.C., Buitelaar, J.K., Kiewik, M., & de Jong, C.A. (2015) Substance use disorders in individuals with mild to borderline intellectual disability: Current status and future directions. *Research in Developmental Difficulties, 38*, 319-328.

Dunn, K., Rydzewska, E., MacIntyre, C., Rintoul, J., and Cooper, S.-A. (2019) The prevalence and general health status of people with intellectual disabilities and autism co-occurring together: a total population study. *Journal of Intellectual Disability Research, 63*: 277– 285. https://doi-org.mmu.idm.oclc.org/10.1111/jir.12573.

Elo, S., & Kyngäs, H. (2008) The qualitative content analysis process*. Journal of Advanced Nursing, 62*(1), 107–115. https://doi.org/10.1111/j.1365-2648.2007.04569.x

van Emmerik-van Oortmerssen, K., van de Glind, G., van den Brink, W., Smit, F., Crunelle, C., Swets, M., & Schoever, R. (2012) Prevalence of attention-deficit hyperactivity disorder in substance use disorder patients: A meta-analysis and meta-regression analysis. *Drug and Alcohol Dependence, 122*(1-2), 11-19.

Esrick, J., Kagan, R. G., Carnevale, J. T., Valenti, M., Rots, G., & Dash, K. (2019) Can scare tactics and fear-based messages help deter substance misuse: a systematic review of recent (2005-2017) research. *Drugs: Education, Prevention and Policy, 26*(3), 209–218. https://doi-org.mmu.idm.oclc.org/10.1080/09687637.2018.1424115

Farrugia, A., Treloar, C., & Fraser, S. (2021) Overdoselifesavers.org: a mixed-method evaluation of a public information website on experiences of overdose and using take-home naloxone to save lives. *Drugs: Education, Prevention and Policy*, *29*(1), pp.43-53 DOI: 10.1080/09687637.2020.1858758

Fereday, J., & Muir-Cochrane, E. (2006). Demonstrating Rigor Using Thematic Analysis: A Hybrid Approach of Inductive and Deductive Coding and Theme Development. *International Journal of Qualitative Methods, 5*(1), 80–92.

Fermina, V., & Rachelle, L. (2020) War on drugs: the readability and comprehensibility of illegal drug awareness campaign brochures. *International Journal of Language and Literary Studies, 2*(4), 98–121. https://doi-org.mmu.idm.oclc.org/10.36892/ijlls.v2i4.412

Field, B., Booth, A., Ilott, I. & Gerrish K. (2014) Using the Knowledge to Action Framework in practice: a citation analysis and systematic review. *Implementation Science 9***,** 172 https://doi.org/10.1186/s13012-014-0172-2

Fitzsimmons, P.R., Michael, B.D., Hulley, J.L., & Scott, G.O. (2010) A readability assessment of online Parkinson's disease information. *The Journal of the Royal College of Physicians of Edinburgh, 40*, 292-296.

Flesch, R. 1984. A new readability yardstick. *Journal of Applied Psychology, 32*, 221-233

Fletcher-Watson, S., Adams, J., Brook, K., Charman, T., Crane, L., Cusack, J., Leekam, S., Milton, D., Parr, J. R., & Pellicano, E. (2018) Making the future together: Shaping autism research through meaningful participation. *Autism, 23*(4), 943–953. https://doi.org/10.1177/1362361318786721

Fontes, R., & Pino-Juste, M. (2022) Portrayals of autism and social awareness: A scoping review. *Advances in Autism*, *8*(3), 196-206.

FRANK. No date. *What is drug treatment like?* [Online] [Accessed 3rd July 2020]. https://www.talktofrank.com/get-help/what-is-drug-treatment-like#treatments-for-drug-addiction-and-dependence

Frank, F., Jablotschkin, M., Arthen, T., Riedel, A., Fangmeier, T., Hölzel, L.P., & van Elst, L.T. (2018) Education and employment status of adults with autism spectrum disorders in Germany – a cross-sectional-survey. *BMC Psychiatry 18*, 75.

Gillberg, C.I., Helles, A., Billstedt, E., & Gillberg, C. (2016) Boys with Asperger syndrome grow up: psychiatric and neurodevelopmental disorders 20 years after initial diagnosis. *Journal of Autism and Developmental Disorders, 46*(1), 74-82.

Gillespie-Lynch, K., Kapp, S.K., Shane-Simpson, C., Smith, D.S., & Hutman, T. (2014) Intersections Between the Autism Spectrum and the Internet: Perceived Benefits and Preferred Functions of Computer-Mediated Communication. *Intellectual & Developmental Disabilities, 52* (6), 456–469. doi: https://doi.org/10.1352/1934-9556-52.6.456

Goodhines, P.A., Gellis, L.A., Ansell, E.B., & Park, A. (2019) Cannabis and alcohol use for sleep aid: A daily diary investigation. *Health Psychology*, *38*(11), 1036.

Goodhines, P.A., Gellis, L.A., Kim, J., Fucito, L.M., & Park, A. (2019) Self-medication for sleep in college students: concurrent and prospective associations with sleep and alcohol behavior. *Behavioral sleep medicine*, *17*(3), 327-341.

Gordon, K., Murin, M., Baykaner, O., Roughan, L., Livermore-Hardy, V., Skuse, D. and Mandy, W. (2015) A randomised controlled trial of PEGASUS, a psychoeducational programme for young people with high-functioning autism spectrum disorder. *Journal of child psychology and psychiatry, 56*(4), 468-476. doi:10.1111/jcpp.12304

Gotham, K., Marvin, A.R., Taylor, J.L., Warren, Z., Anderson, C.M., Law, P.A., Law, J.K., & Lipkin, P.H. (2015) Characterizing the daily life, needs, and priorities of adults with autism spectrum disorder from Interactive Autism Network data. *Autism, 19*(7), https://doi-org.mmu.idm.oclc.org/10.1177/1362361315583818

GOV UK Government Design Principles webpage. 2022. https://www.gov.uk/guidance/government-design-principles

Graham I.D., Logan J., Harrison M.B., Straus S.E., Tetroe J., Caswell W., Robinson N. (2006) Lost in knowledge translation: time for a map? *Journal of continuing education in the health professions*, 26(1), 13-24. doi: 10.1002/chp.47. PMID: 16557505.

Green, J.L. (2018) Peer support systems and professional identity of student nurses undertaking a UK learning disability nursing programme. *Nurse Education in Practice, 20*, 56-61.

Grzadzinski, R., Dick, C., Lord, C., & Bishop, S. (2016) Parent-reported and clinician-observed autism spectrum disorder (ASD) symptoms in children with attention deficit/hyperactivity disorder (ADHD): implications for practice under DSM-5. *Molecular Autism, 7*(4). Retrieved from https://link-gale-com.mmu.idm.oclc.org/apps/doc/A440786238/AONE?u=mmucal5&sid=AONE&xid=d00d5115

Guimarães, K. (2019) Extension of Reward-Attention Circuit Model: Alcohol's Influence on Attentional Focus and Consequences on Autism Spectrum Disorder. *Neurocomputing, 325*, 242-253

Guse, K., Spagat, A., Hill, A., Lira, A., Heathcock, S., & Gilliam, M. (2013) Digital storytelling: A novel methodology for sexual health promotion. *American Journal of Sexuality Education*, *8*(4), 213-227.

Hadie, S.N.H. (2020) Five Tips for Managing Diagrams in Anatomy Lecture: The Cognitive Load Theory Perspective. *Education in Medicine Journal*, *12*, 65-74. 10.21315/eimj2020.12.3.8.

Hall, C.M., Culler, E.D., Frank-Webb, A. (2016) Online Dissemination of Resources and Services for Parents of Children with Autism Spectrum Disorders (ASDs): a Systematic Review of Evidence. *Review Journal of Autism and Developmental Disorders, 3*(4), 273-285

Harnish, A., Corrigan, P., Byrne, T., Pinals, D.A., Rodrigues, S., & Smelson, D. (2016) Substance Use and Mental Health Stigma in Veterans with Co-Occurring Disorders. *Journal of Dual Diagnosis, 12*(3-4), 238-243

Haroun El Rasheed, A., El Sheikh, M., El Missiry, A., Hatata, H.A., & Ahmed, N. (2016) Addiction stigma among mental health professionals and medical students in Egypt. *Addictive Disorders and their Treatments, 15*(4), 165-174.

Hawn, S. E., Bountress, K. E., Sheerin, C. M., Dick, D. M., & Amstadter, A. B. (2020) Trauma-related drinking to cope: A novel approach to the self-medication model. *Psychology of Addictive Behaviors*, *34*(3), 465–476. https://doi-org.mmu.idm.oclc.org/10.1037/adb0000552

Hawn, S. E., Cusack, S. E., & Amstadter, A. B. (2020) A systematic review of the self-medication hypothesis in the context of posttraumatic stress disorder and comorbid problematic alcohol use. *Journal of Traumatic Stress, 33*(5), 699-708. https://doi-org.mmu.idm.oclc.org/10.1002/jts.22521

He, S., Hasler, B.P., & Chakravorty, S. (2019) Alcohol and sleep-related problems. *Current opinion in psychology*, *30*, 117-122.

Heeks, R., Ospina, A.V., & Wall, P.J. (2019) Combining pragmatism and critical realism in ICT4D research: an e-Resilience Case Example. In *Information and Communication Technologies for Development. Strengthening Southern-Driven Cooperation as a Catalyst for ICT4D: 15th IFIP WG 9.4*

International Conference on Social Implications of Computers in Developing Countries, ICT4D 2019, Dar es Salaam, Tanzania, May 1–3, 2019, Proceedings, Part II 15 (pp. 14-25). Springer International Publishing.

Helverschou, S. B., Brunvold, A. R., & Arnevik, E. A. (2019) Treating Patients With Co-occurring Autism Spectrum Disorder and Substance Use Disorder: A Clinical Explorative Study. *Substance Abuse: Research and Treatment, 13,* p.1178221819843291. https://doi.org/10.1177/1178221819843291

Hess, M.E. (2014) A new culture of learning: Digital storytelling and faith formation. *Dialog*, *53*(1), 12-22.

Hidalgo-Mazzei, D., Mateu, A., Reinares, M., Undurraga, J., Bonnin, C. D. M., Sanchez-Moreno, J., Colom, F. (2015) Self-monitoring and psychoeducation in bipolar patients with a smart-phone application (SIMPLe) project: design, development and studies protocols. *BMC Psychiatry, 15*(1), 1-9.

Ho, K., Bloch, R., Gondocz, T., Laprise Réjean, Perrier, L., Ryan, D., Thivierge, R., & Wenghofer, E. (2004) Technology-enabled knowledge translation: frameworks to promote research and practice. *Journal of Continuing Education in the Health Professions*, *24*(2), 90–99. https://doi-org.mmu.idm.oclc.org/10.1002/chp.1340240206Ihle

Hollingdale, J., Woodhouse, E., Young, S., Fridman, A., & Mandy, W. (2020) Autistic spectrum disorder symptoms in children and adolescents with attention-deficit/hyperactivity disorder: A meta-analytical review. *Psychological Medicine, 50*(13), 2240-2253. doi:10.1017/S0033291719002368

Hollocks, M., Lerh, J., Magiati, I., Meiser-Stedman, R., & Brugha, T. (2019) Anxiety and depression in adults with autism spectrum disorder: A systematic review and meta-analysis. *Psychological Medicine, 49*(4), 559-572. doi:10.1017/S0033291718002283

den Houting J. (2019) Neurodiversity: An insider's perspective*. Autism, 23*(2):271–73. doi: 10.1177/1362361318820762 den Houting, J., Higgins, J., Isaacs, K., Mahony, J., & Pellicano, E. (2021) “I’m not just a guinea pig”: Academic and community perceptions of participatory autism research. *Autism, 25*(1), 148-163. 136236132095169. https://doi.org/10.1177/1362361320951696

Hsieh, H. F., & Shannon, S. E. (2005) Three Approaches to Qualitative Content Analysis. *Qualitative Health Research, 15*(9), 1277–1288.

Hull, L., Mandy, W., & Petrides, K.V. (2017) Behavioural and cognitive sex/gender differences in autism spectrum condition and typically developing males and females. *Autism*, *21*(6), pp.706-727.

Hurlbert, M., & Gupta, J. (2015) The split ladder of participation: A diagnostic, strategic, and evaluation tool to assess when participation is necessary. *Environmental Science & Policy, 50*, 100–113. https://doi.org/10.1016/j.envsci.2015.01.011

Hurtado, B., Jones, L., & Burniston, F. (2014) Is Easy Read information really easier to read? *Journal of Intellectual Disability Research*, *58*(9), 822–829.

Ihle M., Winney, I. S., Krystalli, A., & Croucher, M. (2017) Striving for transparent and credible research: practical guidelines for behavioral ecologists. Behavioral Ecology, 28(2), 348–354. https://doi-org.mmu.idm.oclc.org/10.1093/beheco/arx003

Jackson, S.L.J., Hart, L., Brown, J.T., & Volkmar, F.R. (2018) Brief Report: Self-Reported Academic, Social, and Mental Health Experiences of Post-Secondary Students with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders, 48*(3), 643.

James, W. (1907) *Pragmatism: A new name for some old ways of thinking.* Longmans, Green and Co. https://doi.org/10.1037/10851-000

Jordan, C.J. (2010) Evolution of Autism Support and Understanding Via the World Wide Web. *Intellectual & Developmental Disabilities, 48*(3), 220–227. doi: https://doi.org/10.1352/1934-9556-48.3.220

Kahlke, R.M. (2014) Generic qualitative approaches: Pitfalls and benefits of methodological mixology. *International journal of qualitative methods*, *13*(1), 37-52.

Kaltenegger, H.C., Doering, S., Gillberg, C., Wennberg, P., & Lundström., S. (2021) Low prevalence of risk drinking in adolescents and young adults with autism spectrum problems. *Addictive Behaviours, 113*, 106671. https://doi.org/10.1016/j.addbeh.2020.106671.

Karalunas, S.L., Hawkey, E., Gustafsson, H., Miller, M., Langhorst, M., Cordova, M., Fair, D. and Nigg, J.T. (2018) Overlapping and distinct cognitive impairments in attention-deficit/hyperactivity and autism spectrum disorder without intellectual disability. *Journal of abnormal child psychology*, *46*, 1705-1716.

Kaushik, V., & Walsh, C. A. (2019). Pragmatism as a Research Paradigm and Its Implications for Social Work Research. *Social Sciences, 8*(9), 255.

Kaysen, D., Atkins, D.C., Moore, S.A., Lindgren, K.P., Dillworth, T. and Simpson, T. (2011) Alcohol use, problems, and the course of posttraumatic stress disorder: A prospective study of female crime victims. *Journal of Dual Diagnosis*, *7*(4), 262-279.

Kennedy, M.A., Bayes, S., Galvão, D.A., Singh, F., Spry, N.A., Davis, M., Chee, R., Zissiadis, Y., Hart, N.H., Taaffe, D.R., & Newton, R.U. (2020) If you build it, will they come? Evaluation of a co-located exercise clinic and cancer treatment centre using the RE-AIM framework. *European Journal of Cancer Care*, *29*(4), p.e13251.

Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., & Pellicano, E. (2016) Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism, 20*(4), 442–462.

Khantzian, E.J. (1985) The self-medication hypothesis of addictive disorders. *American Journal of Psychiatry, 142*, 1259-1264.

Kildahl, A.N., Helverschou, S.B., Bakken, T.L., & Oddli, H.W. (2020) “If we do not look for it, we do not see it”: Clinicians' experiences and understanding of identifying post-traumatic stress disorder in adults with autism and intellectual disability. *Journal of Applied Research in Intellectual Disabilities, 33(*5), 1119-1132.

Kingsbury, C.G., Sibert, E.C., Killingback, Z., & Atchison, C.L. (2020) “Nothing about us without us:” The perspectives of autistic geoscientists on inclusive instructional practices in geoscience education. *Journal of Geoscience Education, 68*:4, 302-310, DOI: 10.1080/10899995.2020.1768017

Kola, L., 2020. Global mental health and COVID-19. *The Lancet Psychiatry*, *7*(8), pp.655-657.

Kollia, B., Basch, C. H., Kamowski-Shakibai, M. T., Tsiamtsiouris, J., & Garcia, P. (2019) Testing the readability of online content on autism spectrum disorders. *Advances in Neurodevelopmental Disorders: Multidisciplinary Research and Practice Across the Lifespan, 3*(1), 85–90. https://doi-org.mmu.idm.oclc.org/10.1007/s41252-019-0095-7

Kronenberg, L.M., Goossens, P.J.J., van Etten, D.M., van Achterberg, T., & van den Brink, W. (2015) Need for care and life satisfaction in adult substance use disorder patients with and without attention deficit hyperactivity disorder (ADHD) or autism spectrum disorder (ASD). *Perspectives in Psychiatric Care, 51*(1), 4-15.

Lai, M.C., Lombardo, M.V., Pasco, G., Ruigrok, A.N., Wheelwright, S.J., Sadek, S.A., Chakrabarti, B., MRC Aims Consortium and Baron-Cohen, S., (2011) A behavioral comparison of male and female adults with high functioning autism spectrum conditions. *PloS one*, *6*(6), p.e20835.

Lalanne, L., Weiner, L., Trojak, B., Berna, F., & Bertschy, G. (2015) Substance-use disorder in high-functioning autism: clinical and neurocognitive insights from two case reports. *BMC Psychiatry, 15*(1), 1-5. http://dx.doi.org.mmu.idm.oclc.org/10.1186/s12888-015-0541-7

Lee, S.S., Humphreys, K.L., Flory, K., Liu, R., & Glass, K. (2011) Prospective association of childhood attention-deficit/hyperactivity disorder (ADHD) and substance use and abuse/dependence: A meta-analytic review. *Clinical Psychology Review, 31*(3), 328-341

Liebrenz, M., Frei, A., Fisher, C.E., Gamma, A., Buadze, A., & Eich, D. (2014) Adult attention-deficit/hyperactivity disorder and nicotine use: a qualitative study of patient perceptions. *BMC Psychiatry 14*, 1-11.

Lipari, M., Berlie, H., Saleh, Y., Hang, P., & Moser, L. (2020) Understandability, actionability, and readability of online patient education materials about diabetes mellitus. *American Journal of Health-System Pharmacy, 76*(3), 182–186, https://doi.org/10.1093/ajhp/zxy021

Lipschitz, J., Hogan, T.P., Bauer, M.S. and Mohr, D.C., 2019. Closing the research-to-practice gap in digital psychiatry: the need to integrate implementation science. *The Journal of Clinical Psychiatry*, *80*(3), 8712.

Lord, C., Elsabbagh, M., Baird, G., & Veenstra-Vanderweele, J. (2018) Autism Spectrum Disorder. *The Lancet, 392*(10146), 508-520

Lugo-Marín, J., Magán-Maganto, M., Rivero-Santana, A., Cuellar-Pompa, L., Alviani, M., Jenaro-Rio, C., Díez, E., & Canal-Bedia, R. (2019) Prevalence of psychiatric disorders in adults with autism spectrum disorder: A systematic review and meta-analysis. *Research in Autism Spectrum Disorders, 59*, 22-33

Lundstrom S., Chang Z., Kerekes N., Gumpert C. H., Rastam M., Gillberg C., Lichtenstein P, Anckarsäter H. (2011) Autistic-like traits and their association with mental health problems in two nationwide twin cohorts of children and adults. *Psychological Medicine, 41*(11),2423–2433.

Maddox, B. B., Crabbe, S., Beidas, R. S., Brookman-Frazee, L., Cannuscio, C. C., Miller, J. S., Nicolaidis, C., & Mandell, D. S. (2020) “I wouldn’t know where to start”: Perspectives from clinicians, agency leaders, and autistic adults on improving community mental health services for autistic adults. *Autism, 24*(4), 919–930. https://doi.org/10.1177/1362361319882227

Mahmoud, K.F., Finnell, D., Savage, C.L., Puskar, K.R., & Mitchell, A.M. (2017) A Concept Analysis of Substance Misuse to Inform Contemporary Terminology. *Archives of Psychiatric Nursing, 31*(6),532-540. https://doi.org/10.1016/j.apnu.2017.06.004.

Marsack, C.N., & Samuel, P.S. (2017) Mediating Effects of Social Support on Quality of Life for Parents of Adults with Autism. *Journal of Autism and Developmental Disorders, 47*(8), 2378-2389

Martin, J. A. 2015. Research with adults with Asperger's syndrome—participatory or emancipatory research? Qualitative Social Work, 14(2), 209–223. https://doi.org/10.1177/1473325014535964

Masi, A., DeMayo, M.M., Glozier, N., & Guastella, A.J. (2017) An Overview of Autism Spectrum Disorder, Heterogeneity and Treatment Options. *Neuroscience Bulletin, 33*, 183–193. https://doi-org.mmu.idm.oclc.org/10.1007/s12264-017-0100-y

Mason, D., Ingham, B., Urbanowicz, A., Michael, C., Birtles, H., Woodbury-Smith, M., Brown, T., James, I., Scarlett, C., Nicolaidis, C., & Parr, J.R. (2019) A systematic review of what barriers and facilitators prevent and enable physical healthcare services access for autistic adults. *Journal of autism and developmental disorders*, *49*, 3387-3400.

Mattoo, S.K., Prasad, S., & Ghosh, A. (2018) Brief intervention in substance use disorders. *Indian Journal of Psychiatry*, *60*(4), p.S466.

McDonald, K. E., Raymaker, D. M. (2013) Paradigm shifts in disability and health: Toward more ethical public health research. *American Journal of Public Health, 103,* 2165–2173.

McDougall, F., Willgoss, T., Hwang, S., Bolognani, F., Murtagh, L., Anagnostou, E., & Rofail, D. (2018) Development of a patient-centered conceptual model of the impact of living with autism spectrum disorder. *Autism, 22*(8), 953–969. https://doi.org/10.1177/1362361317718987

McHugh, R., & McBride, O. (2020) Self-medicating low mood with alcohol use: Examining the role of frequency of alcohol use, quantity consumed and context of drinking. *Addictive Behaviors*, *111*, p.106557. https://doi-org.mmu.idm.oclc.org/10.1016/j.addbeh.2020.106557

Mellifont, D., Smith-Merry, J., Dickinson, H., Llewellyn, G., Clifton, S., Ragen, J., Raffaele, M., & Williamson, P. (2019) The ableism elephant in the academy: A study examining academia as informed by Australian scholars with lived experience. *Disability & Society*, *34*(7-8), 1180-1199.

Melvin, K., Meyer, C. and Ryan, B., (2019) “We don't know what we don't know”: Providing information about communication to families of children with Down syndrome. *Child: Care, Health and Development*, *45*(3), 423-432.

Mencap, no date. *What is a learning disability?* https://www.mencap.org.uk/learning-disability-explained/what-learning-disability

Mold, A. (2021) Just say know: Drug education and its publics in 1980s Britain. *International Journal of Drug Policy*, *88*, p.103029.

Mousing, C. A., & Lomborg, K. (2012) Self-care 3 months after attending chronic obstructive pulmonary disease patient education: a qualitative descriptive analysis. *Patient preference and adherence*, 19-25.

Mulligan, R.C., Reiersen, A.M., & Todorov, A.A. (2014) Attention-deficit/hyperactivity disorder, autistic traits, and substance use among Missouri adolescents. *Scandinavian Journal of Child and Adolescent Psychiatry and Psychology*, *2*(2), 86-92.

National Autistic Society. (2016) *Autism: What is Autism?* https://www.autism.org.uk/about/what-is/asd.aspx

National Autistic Society. (2020) *How to talk and write about autism*. https://www.autism.org.uk/what-we-do/help-and-support/how-to-talk-about-autism

NHS. (2023) *Design Principles Webpage*. https://service-manual.nhs.uk/design-system/design-principles’

NHS. (2019) *Alcohol Support.* [Online] [Accessed on 3rd of July 2020]. https://www.nhs.uk/live-well/alcohol-support/

Nicolaidis, C. (2012) What can physicians learn from the neurodiversity movement? *American Journal of Ethics,* 14(6), 503-510.

Nicolaidis, C., Raymaker, D. M., Ashkenazy, E., McDonald, K. E., Dern, S., Baggs, A. E., Kapp, S. K., Weiner, M., & Boisclair, W. C. (2015) "Respect the way I need to communicate with you":

Healthcare experiences of adults on the autism spectrum. *Autism: the international journal of research and practice, 19*(7), 824–831. https://doi.org/10.1177/1362361315576221

Nicolaidis, C., Raymaker, D., Kapp, S.K., Baggs, A., Ashkenazy, E., McDonald, K., Weiner, M., Maslak, J., Hunter, M. and Joyce, A. (2019) The AASPIRE practice-based guidelines for the inclusion of autistic adults in research as co-researchers and study participants. *Autism*, *23*(8), 2007-2019.

Nielsen, J. (2006) F-Shaped Pattern For Reading Web Content (original study). Retrieved online via: https://www.nngroup.com/articles/f-shaped-pattern-reading-web-content-discovered/

Nilsen, P. (2015) Making sense of implementation theories, models and frameworks. *Implementation* Science*, 10*, 53. https://doi.org/10.1186/s13012-015-0242-0

Nylander, L., Axmon, A., Bjorne, P., Ahlstrom, G., & Gillberg, C. (2018) Older Adults with Autism Spectrum Disorders in Sweden: A Register Study of Diagnoses, Psychiatric Care Utilization and Psychotropic Medication of 601 Individuals. *Journal of Autism and Developmental Disorders, 48,* 3076-3085.

Odell, A. P. , Reynolds, G. L. , Fisher, D. G. , Huckabay, L. M. , Pedersen, W. C. , Xandre, P. & Miočević, M. (2017) Attention Deficit Hyperactivity Disorder, Aggression, and Illicit Stimulant Use. *The Journal of Nervous and Mental Disease, 205*(5), 372–379.

Ostrove, J.M., Kornfeld, M., & Ibrahim, M. (2019) Actors against ableism? Qualities of nondisabled allies from the perspective of people with physical disabilities. *Journal of Social Issues*, *75*(3), 924-942.

Palmer, M., San José Cáceres, A., Tarver, J., Howlin, P., Slonims, V., Pellicano, E., & Charman, T. (2020) Feasibility study of the National Autistic Society EarlyBird parent support programme*. Autism, 24(1), 147–159. https://doi.org/10.1177/1362361319851422*

Palmqvist, M., Edman, G., & Bölte, S. (2014) Screening for substance use disorders in neurodevelopmental disorders: a clinical routine? *European Child & Adolescent Psychiatry, 23*(5), 365-368

Panerai, S., Suraniti, G. S., Catania, V., Zingale, M., Ferri, R., Raggi, A., Trubia, G., & Elia, M. (2019) Early results from a combined low-intensive psychoeducational intervention for preschoolers with autism spectrum disorder. *Disability and Rehabilitation, 42*(9), 1275–1283. https://doi.org/10.1080/09638288.2018.1522553

Pasque, P., Carducci, R., Kuntz, A., & Gildersleeve, R. (2012) *Qualitative inquiry for equity in higher education: Methodological innovations, implications, and interventions: AEHE, Volume 37, Number 6* (Vol. 164). John Wiley & Sons.

Patra, S., Arun, P., & Chavan, B.S. (2015) Impact of psychoeducation intervention module on parents of children with autism spectrum disorders: A preliminary study. *Journal of Neurosciences in Rural Practice, 6*(4), 529-535.

Pellicano, E. (2020) Commentary: Broadening the research remit of participatory methods in autism science – a commentary on Happé and Frith (2020). *Journal of Child Psychology & Psychiatry, 61*(3), 233-235. https://doi-org.mmu.idm.oclc.org/10.1111/jcpp.13212

Peñalba, E.H., Samaniego, C.R.C., & Romero, S.M.A. (2020) Digital storytelling: a tool for promoting historical understanding among college students. *Research in Learning Technology*, *28*.

Pernice, K. (2017). F-Shaped Pattern of Reading on the Web: Misunderstood, But Still Relevant (Even on Mobile). Retrieved online via: https://www.nngroup.com/articles/f-shaped-pattern-reading-web-content/

Proudfoot, K. (2022) Inductive/Deductive Hybrid Thematic Analysis in Mixed Methods Research. *Journal of Mixed Methods Research,* 155868982211268. https://doi.org/10.1177/15586898221126816

Ramos, M., Boada, L., Moreno, C., Llorente, C., Romo, J., & Parellada, M. (2013) Attitude and risk of substance use in adolescents diagnosed with Asperger syndrome. *Drug and alcohol dependence*, *133*(2), 535-540.

Raymaker, D.M., McDonald, K.E., Ashkenazy, E., Gerrity, M., Baggs, A.M., Kripke, C., Hourston, S., & Nicolaidis, C. (2017) Barriers to healthcare: Instrument development and comparison between autistic adults and adults with and without other disabilities. *Autism*, *21*(8), 972-984.

Rengit, A.C., McKowen, J.W., O'Brien, J., Howe, Y.J., & McDougle, C.J. (2016) Brief report: autism spectrum disorder and substance use disorder: a review and case study. *Journal of Autism and Developmental Disorders, 46*(7), 2514-2519.

Ressa, T.W., & Goldstein, A. (2021) Autism in the Movies: Stereotypes and Their Effects on Neurodiverse Communities. *Journal of Disability Studies*, *7*(2), 55-63.

Ressel, M., Thompson, B., Poulin, M.-H., Normand, C. L., Fisher, M. H., Couture, G., & Iarocci, G. (2020) Systematic review of risk and protective factors associated with substance use and abuse in individuals with autism spectrum disorders. *Autism*, *24*(4), 899–918. https://doi.org/10.1177/1362361320910963

Richert, T., Svensson, B. and Johnson, B., (2021) Experiences of Swedish parents seeking social services support for their adult children with drug addiction. *Journal of the Society for Social Work and Research*, *12*(4), pp.677-704.

Roberts, C.A., Smith, K.C., & Sherman, A.K. (2019) Comparison of Online and Face-to-Face Parent Education for Children with Autism and Sleep Problems. *Journal of Autism and Developmental Disorders, 49*(4), 1410-1422

Rommelse, N., Buitelaar, J.K. & Hartman, C.A. (2017) Structural brain imaging correlates of ASD and ADHD across the lifespan: a hypothesis-generating review on developmental ASD–ADHD subtypes. *Journal of Neural Transmission, 124*, 259–271. https://doi-org.mmu.idm.oclc.org/10.1007/s00702-016-1651-1

Rumball, F., Brook, L., Happé, F., & Karl, A. (2021) Heightened risk of posttraumatic stress disorder in adults with autism spectrum disorder: The role of cumulative trauma and memory deficits. *Research in Developmental Disabilities*, *110*, 103848.

Rumball, F., Happé, F., & Grey, N. (2020) Experience of trauma and PTSD symptoms in autistic adults: risk of PTSD development following DSM-5 and non-DSM-5 traumatic life events. *Autism Research*, *13*(12), 2122-2132.

Saladin, M.E., Brady, K.T., Dansky, B.S., & Kilpatrick, D.G. (1995) Understanding comorbidity between PTSD and substance use disorders: Two preliminary investigations. *Addictive behaviors*, *20*(5), 643-655.

Sanetti, L.M.H., & Collier-Meek, M.A. (2019) Increasing implementation science literacy to address the research-to-practice gap in school psychology. *Journal of School Psychology*, *76*, 33-47.

Santosh, P.J., & Mijovic, A. (2006) Does pervasive developmental disorder protect children and adolescents against drug and alcohol use? *European child & adolescent psychiatry*, *15*, 183-188.

Sarkhel S, Singh O P, Arora M. (2020) Clinical Practice Guidelines for Psychoeducation in Psychiatric Disorders General Principles of Psychoeducation. *Indian journal of psychiatry*, *62*(2), p.S319.

Saunders, M.N., Lewis, P., Thornhill, A. and Bristow, A., 2015. Understanding research philosophy and approaches to theory development. In: Saunders, M.N., Lewis, P., Thornhill, A. and Bristow, A. *Research Methods for Business Students.* Harlow: Pearson Education, pp. 122–161

Schomerus, G., Lucht, M., Holzinger, A., Matschinger, H., Carta, M.G., & Angermeyer, M.C. (2011) The stigma of alcohol dependence compared with other mental disorders: a review of population studies. *Alcohol and Alcoholism, 46*(2), 105-112.

Schroeder, N. L., & Cenkci, A. T. (2018) Spatial contiguity and spatial split-attention effects in multimedia learning environments: a meta-analysis. *Educational Psychology Review, 30*(3), 679–701.

Schweizer, C.A., Hoggatt, K.J., Washington, D.L., Bean-Mayberry, B., Yano, E.M., Mitchell, M.N., Alessi, C.A., & Martin, J.L. (2019) Use of alcohol as a sleep aid, unhealthy drinking behaviors, and sleeping pill use among women veterans. *Sleep health*, *5*(5), 495-500.

Sehlin, H., Hedman Ahlström, B., Andersson, G., & Wentz, E. (2018) Experiences of an internet-based support and coaching model for adolescents and young adults with ADHD and autism spectrum disorder –a qualitative study. *BMC Psychiatry, 18*, 1-13.

Shadur, J.M., Hussong, A.M. and Haroon, M. (2015) Peer context and self-medication. *Drug Alcohol Review, 34*, 571-580. doi:10.1111/dar.12260

Sharma, S., Marara, P., Srinivas, S., & Townsend, N. (2018) Developing and testing a culturally sensitive health information leaflet on the consequences of alcohol abuse: Rhodes university support staff with limited literacy in focus. *Ethiopian Journal of Health Development, 32*(1), 44–51.

Sheldon, J. (2017) Problematizing reflexivity, validity, and disclosure: Research by people with disabilities about disability. *The Qualitative Report*, *22*(4), 984-1000.

Shillingsburg, M. A., Bowen, C. N., Peterman, R. K., & Gayman, M. D. (2015) Effectiveness of the Direct Instruction Language for Learning Curriculum Among Children Diagnosed With Autism Spectrum Disorder. *Focus on Autism and Other Developmental Disabilities*, *30*(1), 44–56. https://doi.org/10.1177/1088357614532498

da Silva, H.C.C., de Oliveira Siqueira, A., Araújo, M.A.V., & Dornelas, J.S. (2018) Let's be Pragmatic: Research in Information Systems with Relevance and Rigor. *International Journal of Business Management & Economic Research*, *9*(4).

Sizoo, B., van den Brink, W., Gorissen van Eenige, M., & van der Gaag, R.J. (2009) Personality characteristics of adults with autism spectrum disorders or attention deficit hyperactivity disorder with and without substance use disorders. *The Journal of Nervous and Mental Diseases, 197*(6), 450-454

Slotterback, C. S., & Lauria, M. (2019) Building a Foundation for Public Engagement in Planning. *Journal of the American Planning Association, 85*(3), 183–187.

Solberg, B.S., Zayats, T., Posserud, M.B., Halmøy, A., Engeland, A., Haavik, J., & Klungsøyr, K. (2019) Patterns of Psychiatric Comorbidity and Genetic Correlations Provide New Insights into

Differences Between Attention-Deficit/Hyperactivity Disorder and Autism Spectrum Disorder. *Biological Psychiatry, 86*(8), 587-598. https://doi.org/10.1016/j.biopsych.2019.04.021

Solomon, P., Salbach, N.M., O'Brien, K.K., Nixon, S., Worthington, C., Baxter, L., Tattle, S., & Gervais, N. (2018) Collaborative development of an educational resource on rehabilitation for people living with HIV. *Disability and Rehabilitation, 40*:22, 2671-2676, DOI: 10.1080/09638288.2017.1347719

Sturrock, A., Marsden, A., Adams, C., & Freed, J. (2020) Observational and Reported Measures of Language and Pragmatics in Young People with Autism: A Comparison of Respondent Data and Gender Profiles. *Journal of Autism and Developmental Disorders, 50***,** 812–830, https://doi-org.mmu.idm.oclc.org/10.1007/s10803-019-04288-3

Swain, J. (2018) A Hybrid Approach to Thematic Analysis in Qualitative Research: Using a Practical Example. *Sage Research Methods.* https://doi.org/10.4135/9781526435477

Sweller, J., Ayres, P., Kalyuga, S., Sweller, J., Ayres, P., & Kalyuga, S. (2011) Measuring cognitive load. *Cognitive load theory*, 71-85.

Sweller, J., van Merriënboer, J.J., & Paas, F. (2019) Cognitive architecture and instructional design: 20 years later. *Educational Psychology Review*, *31*, 261-292.

Szmuda, T., Özdemir, C., Ali, S., Singh, A., Syed, M. T., & Słoniewski, P. (2020) Readability of online patient education material for the novel coronavirus disease (COVID-19): a cross-sectional health literacy study. *Public health, 185*, 21–25. https://doi.org/10.1016/j.puhe.2020.05.041

Taggart, L., McLaughlin, D., Quinn, B., & McFarlane, C. (2007) Listening to people with intellectual disabilities who misuse alcohol and drugs. *Health & social Care in the Community*, *15*(4), 360-368.

Tang, S.H., Chio, O.I., Chang, L.H., Mao, H.F., Chen, L.H., Yip, P.K., & Hwang, J.P. (2018) Caregiver active participation in psychoeducational intervention improved caregiving skills and competency. *Geriatrics & gerontology international, 18*(5), 750-757.

Taylor, J. L., Henninger, N. A., & Mailick, M. R. (2015) Longitudinal patterns of employment and postsecondary education for adults with autism and average-range IQ. *Autism, 19*(7), 785–793. https://doi.org/10.1177/1362361315585643

Terblanche, M., & Burgess, L. 2010. Examining the readability of patient-informed consent forms. *Journal of Clinical Trials, 2*, 157-162.

Tinsley, M. and Hendrickx, S., 2008. *Asperger syndrome and alcohol: Drinking to cope?*. Jessica Kingsley Publishers.

Treloar, C., Pienaar, K., Dilkes-Frayne E., & Fraser, S. (2019) Lives of Substance: a mixed-method evaluation of a public information website on addiction experiences. *Drugs: Education, Prevention and Policy, 26:2*, 140-147, DOI: 10.1080/09687637.2017.1397602

Tritter, J. Q., & McCallum, A. (2006) The snakes and ladders of user involvement: Moving beyond Arnstein. *Health Policy, 76*(2), 156–168. https://doi.org/10.1016/j.healthpol.2005.05.008

Turner, S, Mota, N, Bolton, J, Sareen, J. (2018) Self-medication with alcohol or drugs for mood and anxiety disorders: A narrative review of the epidemiological literature. *Depression and Anxiety, 35*, 851– 860. https://doi-org.mmu.idm.oclc.org/10.1002/da.22771

Vasa, R.A., Mazurek, M.O., Mahajan, R., Bennett, A.E., Bernal, M.P., Nozzolillo, A.A., Arnold, L.E., & Coury, D.L. (2016) Assessment and Treatment of Anxiety in Youth With Autism Spectrum Disorders. *Pediatrics, 137*(2), S115-S123. DOI: 10.1542/peds.2015-2851J

Vasko, J.M., Meinzer, M.C., Murphy, J.G., Oddo, L.E., McCauley, K.L., Rooney, M.E., Lejuez, C.W., & Chronis-Tuscano, A. (2019) Brief intervention to reduce problem drinking in college students with ADHD. *Cognitive and Behavioral Practice*, *26*(3), 506-521.

Vindin, P., Wilson, N. J., Lee, H., & Cordier, R. (2021) The Experience of Learning to Drive for People With Autism Spectrum Disorder. *Focus on Autism and Other Developmental Disabilities*, *36*(4), 225–236. https://doi.org/10.1177/10883576211023312

Vukovic, V., Favaretti, C., Ricciardi, W., & de Waure, C. (2018) Health technology assessment evidence on e-health/m-health technologies: evaluating the transparency and thoroughness. *International Journal of Technology Assessment in Health Care, 34*(1), 87–96. https://doi-org.mmu.idm.oclc.org/10.1017/S0266462317004512

Waddell, J. T., Sher, K. J., & Piasecki, T. M. (2021) Coping motives and negative affect: An ecological study of the antecedents of alcohol craving and alcohol use. *Psychology of Addictive Behaviors*, *35*(5), 565. https://doi-org.mmu.idm.oclc.org/10.1037/adb0000696.supp

Wakefield, J.C. (2015) DSM -5 substance use disorder: how conceptual missteps weakened the foundations of the addictive disorders field. *Acta Psychiatrica Scandinavica, 132*, 327-334. doi:10.1111/acps.12446

Walhout, S.J., Zanten, J.V., DeFuentes-Merillas, L., Sonneborn, C.K., & Bosma, M. (2022) Patients With Autism Spectrum Disorder and Co-occurring Substance Use Disorder: A Clinical Intervention Study. *Substance Abuse: Research and Treatment*, *16*, p.11782218221085599.

Werlen, L., Gjukaj, D., Mohler-Kuo, M., & Puhan, M.A. (2020) Interventions to improve children's access to mental health care: a systematic review and meta-analysis. *Epidemiology and psychiatric sciences*, *29*, p.e58.

WHO. (2016) World Health Organisation (WHO). International Classification of Disease (ICD-10 Version:2016). Available online: http://apps.who.int/classifications/icd10/browse/2016/en#/F70-F79

Williamson, J.M.L., & Martin, A. (2010) Analysis of patient information leaflets provided by a District General Hospital by the Flesch and Flesch-Kincaid method. *International Journal of Clinical Practice, 64*(13), 1824-1831.

Woodbury-Smith, M.R., Clare, I.C.H., Holland, A.J., & Kearns, A. (2006) High functioning autistic spectrum disorders, offending and other law-breaking: findings from a community sample. *The Journal of Forensic Psychiatry & Psychology*, *17*(1), 108-120.

Young, S., Hollingdale, J., Absoud, M., Bolton, P., Branney, P., Colley, W., Craze, E., Dave, M., Deeley, Q., Farrag, E., Gudjonsson, G., Hill, P., Liang, H.I., Murphy, C., Mackintosh, P., Murin, M., O'Regan, F., Ougrin, D., Rios, P., Stover, N., Taylor, E., & Woodhouse, E. (2020) Guidance for identification and treatment of individuals with attention deficit/hyperactivity disorder and autism spectrum disorder based upon expert consensus. *BMC Medicine, 18*(1), 1-29.

Yvonne Feilzer, M. (2010) Doing Mixed Methods Research Pragmatically: Implications for the Rediscovery of Pragmatism as a Research Paradigm. *Journal of Mixed Methods Research, 4*(1), 6–16. https://doi.org/10.1177/1558689809349691

Zauche, L.H., Mahoney, A.E.D., & Higgins, M.K. (2017) Predictors of co-occurring neurodevelopmental disabilities in children with autism spectrum disorders. *Journal of Paediatric Nursing, 35*, 113-119.

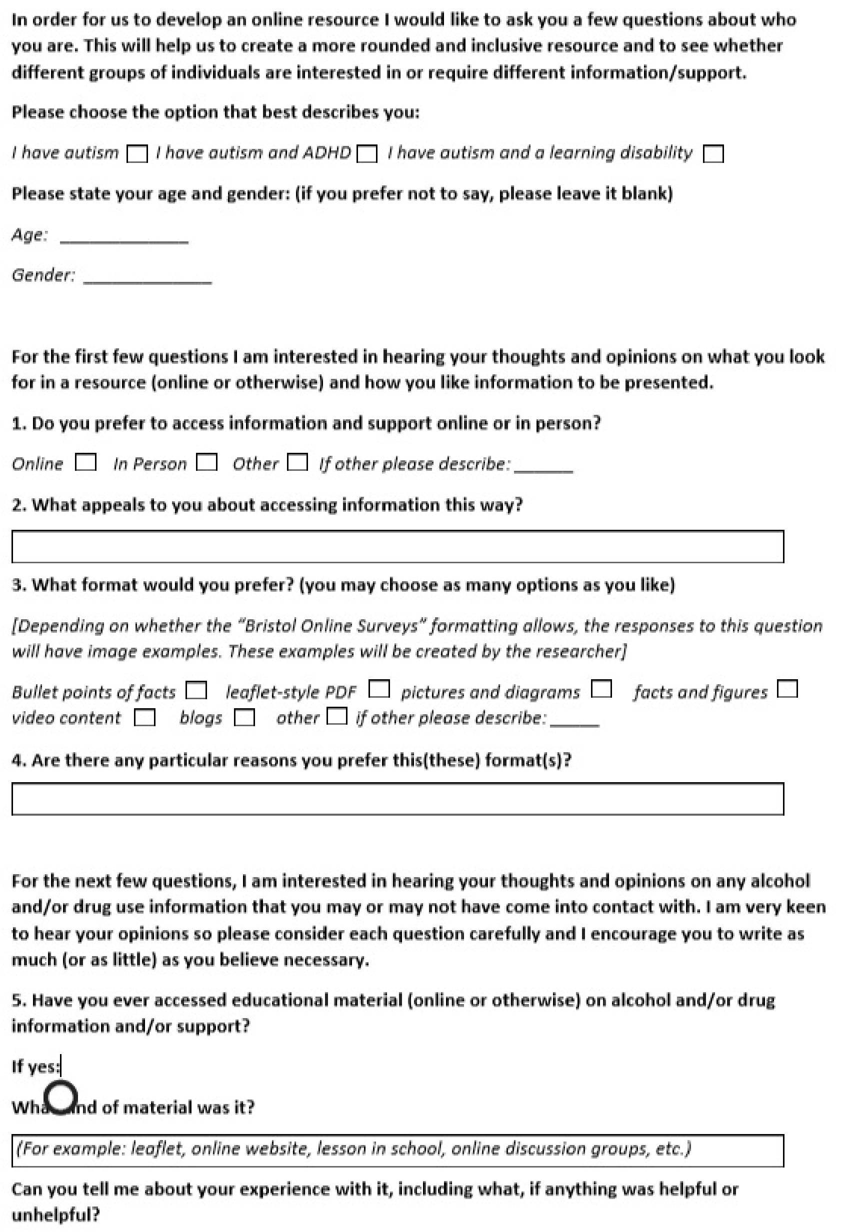
Zgierska, A.E., Miller, M.M., Rabago, D.P., Hilliard, F., McCarthy, P., Cowan, P., & Salsitz, E.A. (2021) Language matters: It's time we change how we talk about addiction and its treatment. *Journal of addiction medicine*, *15*(1), 10.

Zhang, X., Wan, Q., Lyu, S., Li, O., & Liu, Y. (2021) Overlearning is as ineffective as underlearning? a cross-culture study from PISA 2015. *Learning and Individual Differences*, 88. https://doi-org.mmu.idm.oclc.org/10.1016/j.lindif.2021.102005

Appendices

Appendix 1 - **Interview questions for pre-development project**

Pre-Development
Survey&Interview Qu



In order for us to develop an online resource I would like to ask you a few questions about who you are. This will help us to create a more rounded and inclusive resource and to see whether different groups of individuals are interested in or require different information/support.

Please choose the option that best describes you:

I have autism ☐ *I have autism and ADHD* ☐ *I have autism and a learning disability* ☐

Please state your age and gender: (if you prefer not to say, please leave it blank)

Age: ____________

Gender: ____________

For the first few questions I am interested in hearing your thoughts and opinions on what you look for in a resource (online or otherwise) and how you like information to be presented.

1. Do you prefer to access information and support online or in person?

Online ☐ *In Person* ☐ *Other* ☐ *If other please describe:* ______

2. What appeals to you about accessing information this way?

3. What format would you prefer? (you may choose as many options as you like)

[Depending on whether the "Bristol Online Surveys" formatting allows, the responses to this question will have image examples. These examples will be created by the researcher]

Bullet points of facts ☐ *leaflet-style PDF* ☐ *pictures and diagrams* ☐ *facts and figures* ☐
video content ☐ *blogs* ☐ *other* ☐ *if other please describe:* _____

4. Are there any particular reasons you prefer this(these) format(s)?

For the next few questions, I am interested in hearing your thoughts and opinions on any alcohol and/or drug use information that you may or may not have come into contact with. I am very keen to hear your opinions so please consider each question carefully and I encourage you to write as much (or as little) as you believe necessary.

5. Have you ever accessed educational material (online or otherwise) on alcohol and/or drug information and/or support?

If yes:

What kind of material was it?

(For example: leaflet, online website, lesson in school, online discussion groups, etc.)

Can you tell me about your experience with it, including what, if anything was helpful or unhelpful?

If no:

Can you tell me whether, (if any) there are any particular reasons you haven't accessed or sought this material?

Is educational material on this topic something you would be interested in? Can you tell me why you would or would not be interested in educational material on this topic?

6. Who would you feel comfortable with talking about drugs and/or alcohol?

(For example: Friends; Family; Charity Provider; NHS services (e.g. GP); Internet (e.g. websites); Social Media Groups?)

7. In what ways, if any, does this person/source help you to feel comfortable talking about this topic?

8. Where would you go to find more information on or support with drugs and/or alcohol?

(For example: Friends; Family; Charity Provider; NHS services (e.g. GP); Internet (e.g. websites); Social Media Groups?)

9. Can you explain your reasoning behind choosing this(these) source(s)?

Thank you for your response so far! For the final questions I am interested in learning more about what you would like to see in an online resource on alcohol and drug use and addiction information. Please be as detailed in your responses as you can, this will really help me to make the resource useful.

10. In what ways, (if any) would having information on alcohol/drugs help you access help from alcohol/drug services if you needed it?

11. What do you think would be particularly helpful or useful in an online resource about drug and alcohol information and support? Please be as detailed as you can.

(For example: Information on treatments; information on support services; information on how drugs work; information on how alcohol works; signs and symptoms of alcohol-related problems; signs and symptoms of drug-related problems; practical information on where to go for help with alcohol/drug related problems; facts and figures relating to alcohol and/or drug use and addiction?)

12. Is there anything else that you think it is important for me to know about creating an online resource on this topic for those with autism? Please include anything that feels relevant or significant to you.

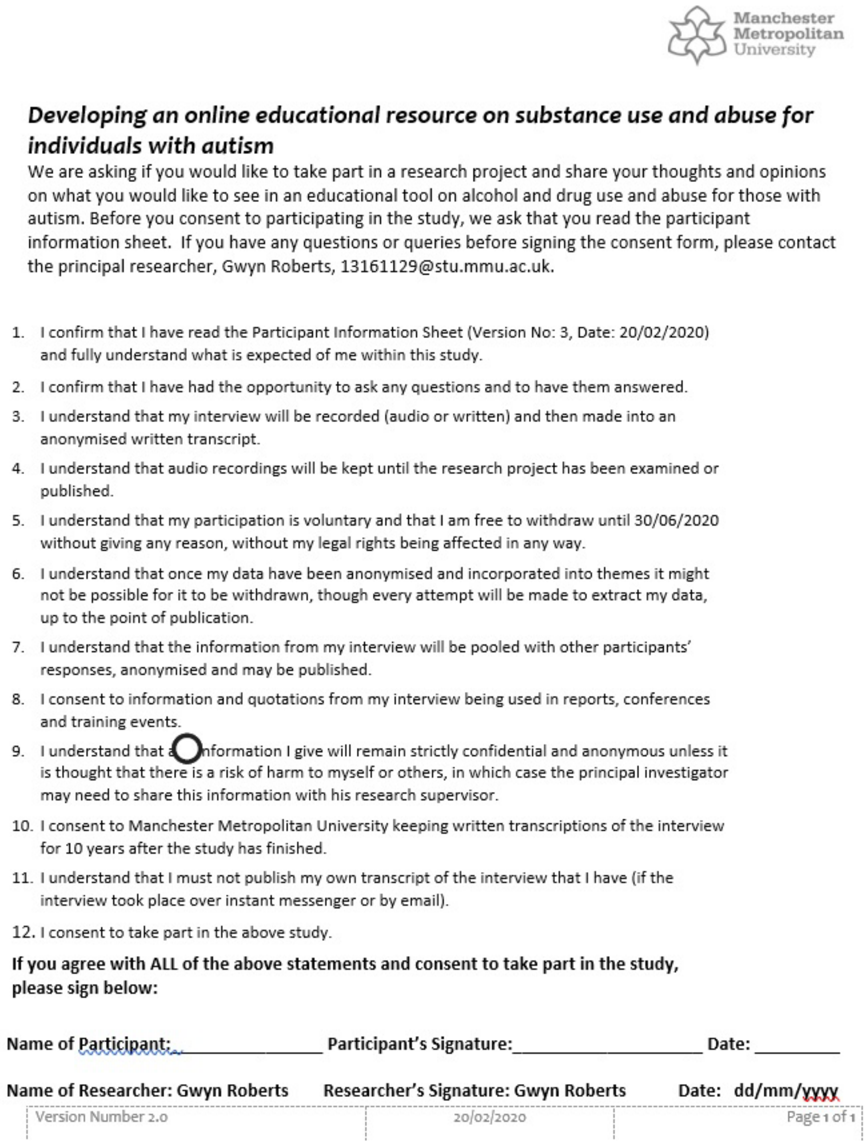
Thank you very much for taking the time to share your thoughts and opinions with me. If you are satisfied with your responses, please click the continue button to submit your answers and complete the survey. You will then be presented with the final completion screen that will contain any resources you may need.

Continue

Appendix 2 – Information sheet for pre-development project

Pre-Development Information Sheet.pdf

Appendix 3 – Consent form for email/messenger pre-development project



Manchester Metropolitan University

Developing an online educational resource on substance use and abuse for individuals with autism

We are asking if you would like to take part in a research project and share your thoughts and opinions on what you would like to see in an educational tool on alcohol and drug use and abuse for those with autism. Before you consent to participating in the study, we ask that you read the participant information sheet. If you have any questions or queries before signing the consent form, please contact the principal researcher, Gwyn Roberts, 13161129@stu.mmu.ac.uk.

1. I confirm that I have read the Participant Information Sheet (Version No: 3, Date: 20/02/2020) and fully understand what is expected of me within this study.
2. I confirm that I have had the opportunity to ask any questions and to have them answered.
3. I understand that my interview will be recorded (audio or written) and then made into an anonymised written transcript.
4. I understand that audio recordings will be kept until the research project has been examined or published.
5. I understand that my participation is voluntary and that I am free to withdraw until 30/06/2020 without giving any reason, without my legal rights being affected in any way.
6. I understand that once my data have been anonymised and incorporated into themes it might not be possible for it to be withdrawn, though every attempt will be made to extract my data, up to the point of publication.
7. I understand that the information from my interview will be pooled with other participants' responses, anonymised and may be published.
8. I consent to information and quotations from my interview being used in reports, conferences and training events.
9. I understand that a[illegible]nformation I give will remain strictly confidential and anonymous unless it is thought that there is a risk of harm to myself or others, in which case the principal investigator may need to share this information with his research supervisor.
10. I consent to Manchester Metropolitan University keeping written transcriptions of the interview for 10 years after the study has finished.
11. I understand that I must not publish my own transcript of the interview that I have (if the interview took place over instant messenger or by email).
12. I consent to take part in the above study.

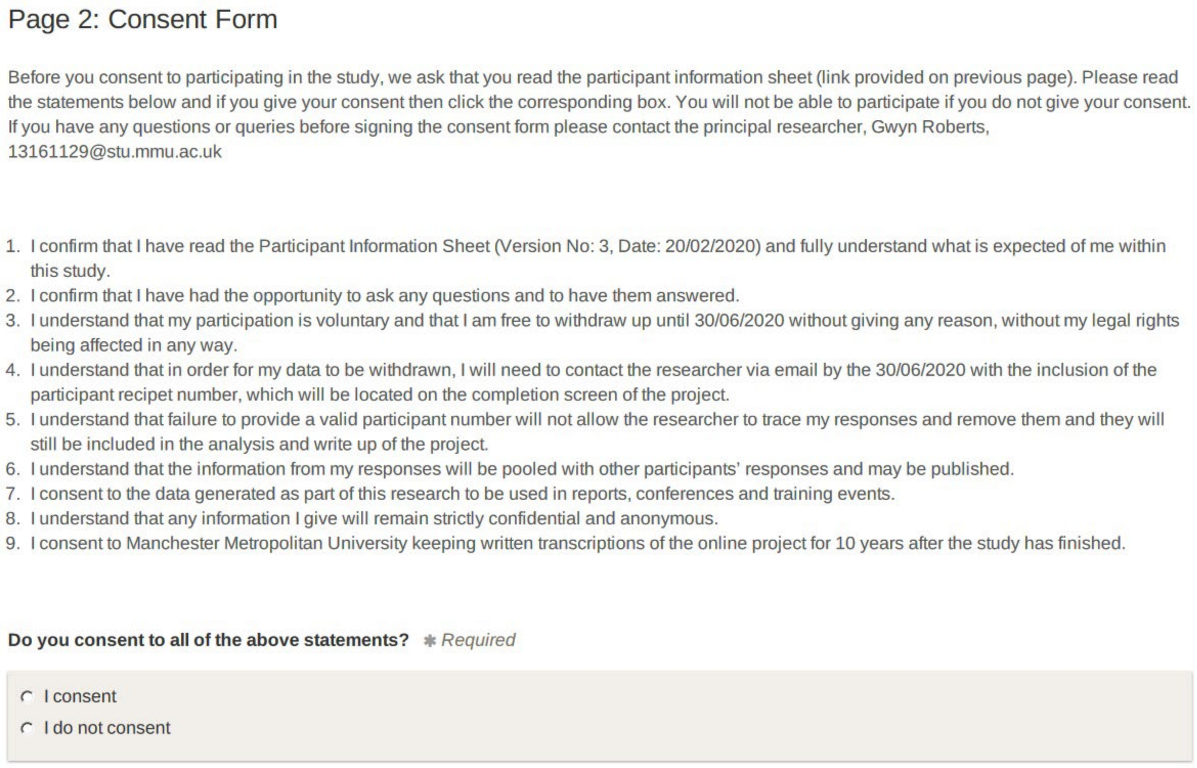
If you agree with ALL of the above statements and consent to take part in the study, please sign below:

Name of Participant:_______________ Participant's Signature:___________________ Date: _________

Name of Researcher: Gwyn Roberts Researcher's Signature: Gwyn Roberts Date: dd/mm/yyyy

Version Number 2.0 | 20/02/2020 | Page 1 of 1

Appendix 4 – Consent form for online qualitative survey for pre-development project



Page 2: Consent Form

Before you consent to participating in the study, we ask that you read the participant information sheet (link provided on previous page). Please read the statements below and if you give your consent then click the corresponding box. You will not be able to participate if you do not give your consent. If you have any questions or queries before signing the consent form please contact the principal researcher, Gwyn Roberts, 13161129@stu.mmu.ac.uk

1. I confirm that I have read the Participant Information Sheet (Version No: 3, Date: 20/02/2020) and fully understand what is expected of me within this study.
2. I confirm that I have had the opportunity to ask any questions and to have them answered.
3. I understand that my participation is voluntary and that I am free to withdraw up until 30/06/2020 without giving any reason, without my legal rights being affected in any way.
4. I understand that in order for my data to be withdrawn, I will need to contact the researcher via email by the 30/06/2020 with the inclusion of the participant recipet number, which will be located on the completion screen of the project.
5. I understand that failure to provide a valid participant number will not allow the researcher to trace my responses and remove them and they will still be included in the analysis and write up of the project.
6. I understand that the information from my responses will be pooled with other participants' responses and may be published.
7. I consent to the data generated as part of this research to be used in reports, conferences and training events.
8. I understand that any information I give will remain strictly confidential and anonymous.
9. I consent to Manchester Metropolitan University keeping written transcriptions of the online project for 10 years after the study has finished.

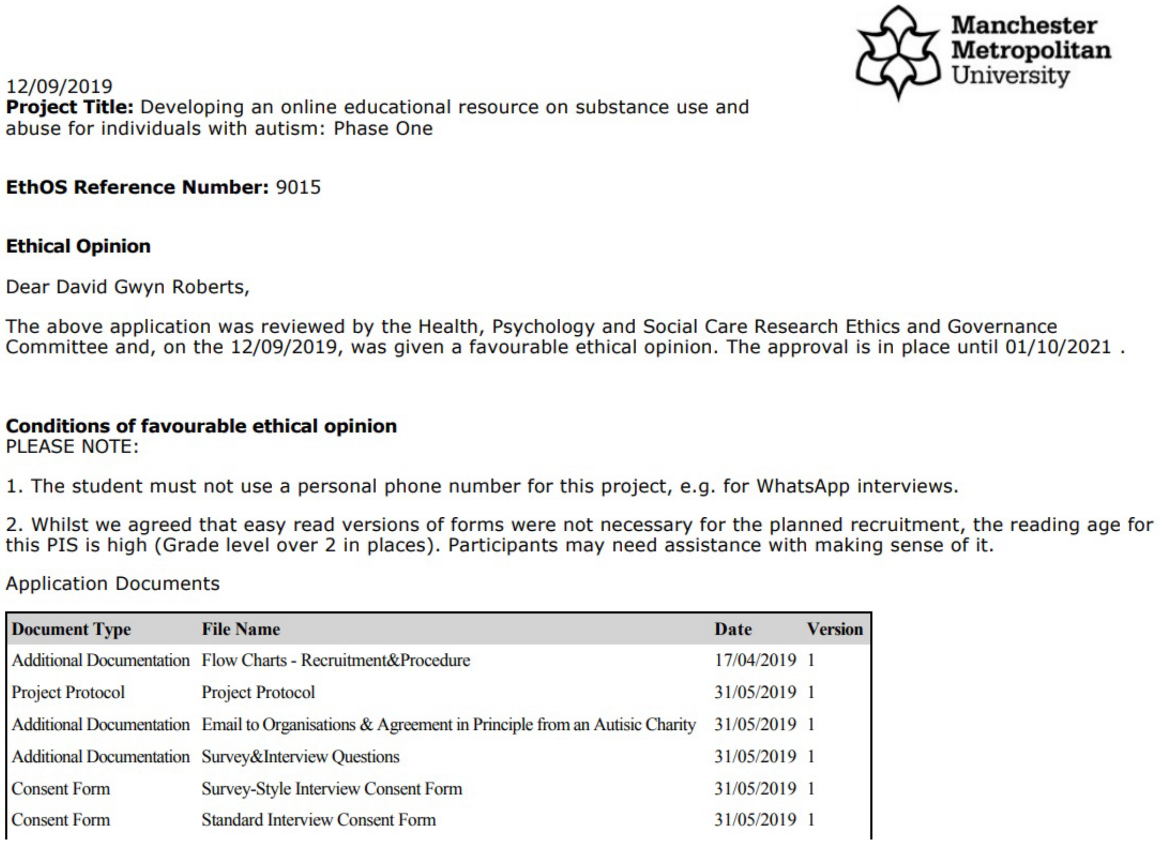
Do you consent to all of the above statements? ✱ *Required*

○ I consent
○ I do not consent

Appendix 5 – Survey completion times for pre-development project

Start Time	Starting Date	Time of Completion	Date of Completion	Total Time Took to Complete
17:08	07/05/2020	17:12	07/05/2020	00:04
17:03	07/05/2020	17:14	07/05/2020	00:11
17:11	07/05/2020	17:20	07/05/2020	00:09
17:11	07/05/2020	17:23	07/05/2020	00:12
17:04	07/05/2020	17:25	07/05/2020	00:21
17:28	07/05/2020	17:38	07/05/2020	00:10
17:24	07/05/2020	17:39	07/05/2020	00:15
17:37	07/05/2020	17:41	07/05/2020	00:04
17:25	07/05/2020	17:44	07/05/2020	00:19
17:28	07/05/2020	17:49	07/05/2020	00:21
17:27	07/05/2020	17:55	07/05/2020	00:28
18:09	07/05/2020	18:17	07/05/2020	00:08
18:10	07/05/2020	18:19	07/05/2020	00:09
18:20	07/05/2020	18:29	07/05/2020	00:09
18:24	07/05/2020	18:41	07/05/2020	00:17
18:51	07/05/2020	19:03	07/05/2020	00:12
18:34	07/05/2020	19:06	07/05/2020	00:32
19:09	07/05/2020	19:23	07/05/2020	00:14
19:21	07/05/2020	19:30	07/05/2020	00:09
19:17	07/05/2020	19:39	07/05/2020	00:22
19:46	07/05/2020	19:52	07/05/2020	00:06
19:56	07/05/2020	20:13	07/05/2020	00:17
19:51	07/05/2020	20:18	07/05/2020	00:27
20:27	07/05/2020	20:36	07/05/2020	00:09
21:04	07/05/2020	21:46	07/05/2020	00:42
21:54	07/05/2020	22:08	07/05/2020	00:14
21:59	07/05/2020	22:24	07/05/2020	00:25
22:13	07/05/2020	22:51	07/05/2020	00:38
23:18	07/05/2020	23:30	07/05/2020	00:12
22:43	07/05/2020	23:36	07/05/2020	00:53
19:03	07/05/2020	06:41	08/05/2020	11:38
12:04	08/05/2020	12:24	08/05/2020	00:20
13:35	08/05/2020	13:43	08/05/2020	00:08
13:53	08/05/2020	14:10	08/05/2020	00:17
16:32	08/05/2020	16:38	08/05/2020	00:06
15:12	08/05/2020	16:59	08/05/2020	01:47
14:58	08/05/2020	17:27	08/05/2020	02:29
09:56	09/05/2020	10:11	09/05/2020	00:15
13:31	09/05/2020	13:53	09/05/2020	00:22
14:47	09/05/2020	14:59	09/05/2020	00:12
22:07	09/05/2020	22:25	09/05/2020	00:18
11:26	10/05/2020	11:32	10/05/2020	00:06
14:09	10/05/2020	14:17	10/05/2020	00:08
20:31	10/05/2020	20:45	10/05/2020	00:14
09:00	11/05/2020	09:33	11/05/2020	00:33
09:42	11/05/2020	09:57	11/05/2020	00:15
11:44	11/05/2020	12:05	11/05/2020	00:21
21:24	11/05/2020	21:37	11/05/2020	00:13
00:06	12/05/2020	00:44	12/05/2020	00:38
09:20	12/05/2020	09:52	12/05/2020	00:32
12:07	12/05/2020	12:41	12/05/2020	00:34
19:20	12/05/2020	20:46	12/05/2020	01:26
23:53	14/05/2020	23:58	14/05/2020	00:05
10:00	15/05/2020	10:16	15/05/2020	00:16
08:25	28/05/2020	08:38	28/05/2020	00:13
17:24	06/06/2020	17:49	06/06/2020	00:25
18:57	07/06/2020	12:41	11/06/2020	3 days 17 hrs 44 mins

Appendix 6 – Ethical approval for pre-development project



Manchester Metropolitan University

12/09/2019
Project Title: Developing an online educational resource on substance use and abuse for individuals with autism: Phase One

EthOS Reference Number: 9015

Ethical Opinion

Dear David Gwyn Roberts,

The above application was reviewed by the Health, Psychology and Social Care Research Ethics and Governance Committee and, on the 12/09/2019, was given a favourable ethical opinion. The approval is in place until 01/10/2021 .

Conditions of favourable ethical opinion
PLEASE NOTE:

1. The student must not use a personal phone number for this project, e.g. for WhatsApp interviews.

2. Whilst we agreed that easy read versions of forms were not necessary for the planned recruitment, the reading age for this PIS is high (Grade level over 2 in places). Participants may need assistance with making sense of it.

Application Documents

Document Type	File Name	Date	Version
Additional Documentation	Flow Charts - Recruitment&Procedure	17/04/2019	1
Project Protocol	Project Protocol	31/05/2019	1
Additional Documentation	Email to Organisations & Agreement in Principle from an Autisic Charity	31/05/2019	1
Additional Documentation	Survey&Interview Questions	31/05/2019	1
Consent Form	Survey-Style Interview Consent Form	31/05/2019	1
Consent Form	Standard Interview Consent Form	31/05/2019	1

Appendix 7 - Full quotations used in pre-development project

B.3.2 Presentation and subject of practical information/support

“Reasonable adjustments to reaching out and how to put some structure to your life to manage e.g., Wellbeing strategies, how to make a Network of support, Sensory, Executive functioning, Links to autism.”

“Information presented for autistic people would be helpful. Services rarely have accessibility guides explaining what to expect when you attend - people, rooms, how waiting works etc. What the expectations would be of an autistic person e.g., re groups as many services run a lot of group-based interventions which strike fear into the heart of the average autistic person!”

“How to request Reasonable adjustments to reaching out to services (1:1 instead of groups, text instead of phone calls, having key person). Sensory information, executive functioning difficulties etc explaining what some of the reasons are why an autistic person uses substances and why it might be harder to stop. Steps like a visual structure or schedule of what you can do to manage reaching out or stopping etc.”

“Factual information about impact, ways to access services that are not automatically 'come in and be assessed', information about how interventions can be tailored… Many alcohol services have positive 'emerging from addiction' stories - so many of these seem to focus on social and work-related interventions/benefits that seem miles away from possible (and enormously anxiety inspiring) for autistic people.”

“Video of people who have accessed support or people who offer the support so you know who you will be talking to ahead of time.”

B.5.1. Input from Autistic adults

“I smoke Cannabis because it provides me with a slightly disconnected feeling from the outside world which does not seem to have a place for me where I do not stick out or screw things up. I am not stupid but the only jobs I have ever had have been low grade manual where I frequently find myself working with some of the rougher elements of society who find me an irresistible target for bullying. It's psychological bullying, they try to provoke a violent response, I resist but it takes so much energy I feel totally drained-not just by this but by trying to get on in life in general. I have achieved nothing in my life and have tortured myself over my shortcomings, mistakes and lost opportunities since the beginning, I just wish that my conditions could have been recognised and at least addressed to some extent when I was younger, so many of my life choices would have been different and cannabis use would probably never even have been considered.”

B.6.2. Judgemental Language

“What would be most important is the presentation of facts and reasoning. It should be supportive and not judgemental… It must at all costs be based on evidence and facts, not opinion and morals.”

“Do not preach! Inform! No tales of terror like the cancer adverts do.”

“[in relation to self-medicating with substances] Please do not default on saying this is 'bad'. I'm not suggesting you promote it, but recognise that there are many people consuming these products as safely as possible for medical use, not recreational, and therefore should not be subjected to shaming tactics, however subtle.”

“I think that the most important thing would be to not ask people to give up drinking or even cut down, but to provide a place where they can talk openly about their drinking. My experience is that people who can talk honestly about their drinking find that they no longer need to drink. For that to happen, they need unconditional positive regard, acceptance and to be given hope.”

“Real answers, not just 'don't do drugs kids'.”

"The language should be non-judgemental and offer comfort to the client."

"The information should be clear. Based on proven research. No alarmism. It should be non-judgemental."

B.6.3. Clarity of language and content

"Autistic people benefit from information, from things being very clear and explicit, and from knowing what is and isn't normal."

"The links to impact on your body and others needs to be clear because some might not understand the links."

"The language being autistic friendly, so direct and literal, concise, use visual aids, any steps broken down, introductions explaining how the information will be laid out and WHY!!! (a huge thing people forget) and facts about impact on the body (including the brain) that are comprehensive with resources referenced."

"Simple language that can be understood by anyone… The online site should be simple to navigate and offer simple click on menu."

"AA is really good, but the language of the meetings, programme, and literature is really antiquated…language can be a barrier for people with autism and/or learning disability."

"Ensuring it was up to date and not cringey...some sites I've seen are really trying too hard to be 'down with the kids', with all the faux graffiti type 'street' aesthetic and the young people I work with find that sort of thing quite off putting."

"Information needs to be stripped down to what I need to know. Too much writing, font style, layout can be an immediate put off."

B.7.2. Prescription medication vs recreational substances

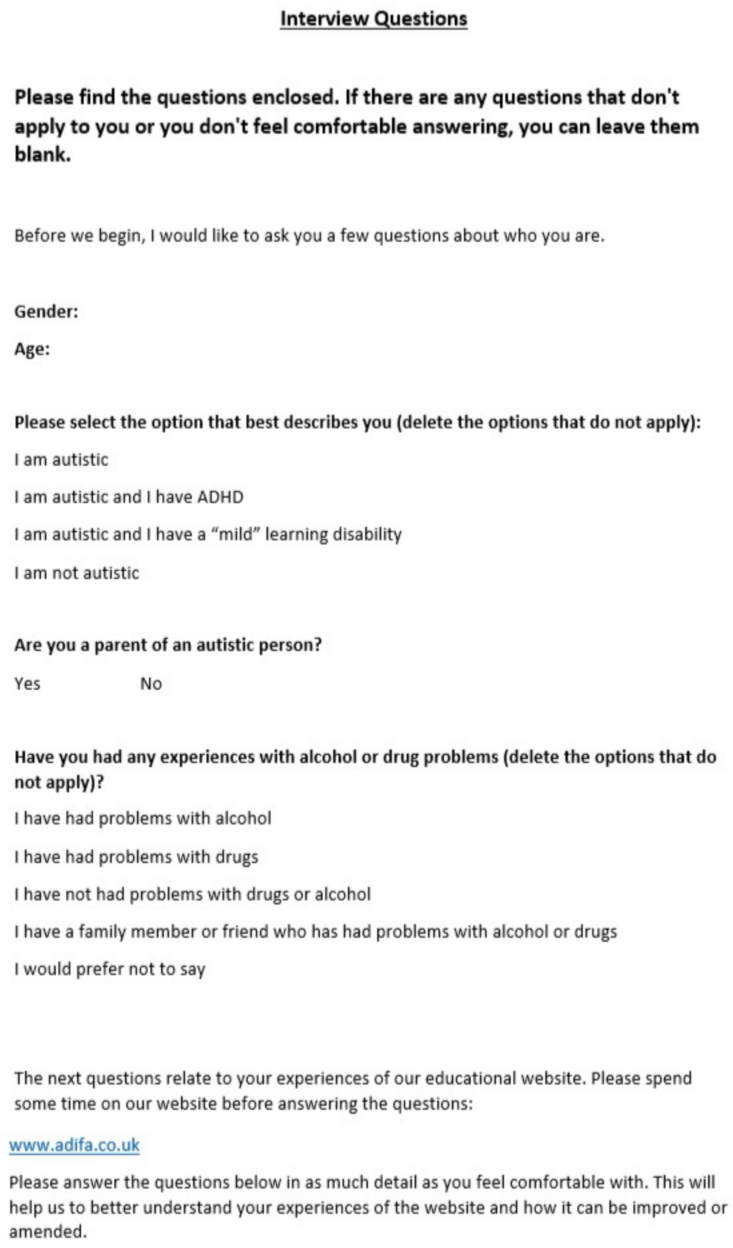
"I think you need to clarify whether it's addiction you are focussing on. Or whether there would be information on how to manage taking prescription drugs which aim to support aspects of life with autism."

"I use Solpadine SOLUBLE daily as this seems to help calm my nervous system in a milder way and help keep my stomach working. Would be nice to know how this works?"

"I am not interested in alcohol or recreational drugs as these aren't my problems but I am interested in the side effects of prescription drugs given to me to help with chronic depression and anxiety exacerbated by autism. I have had a really difficult time discontinuing Sertraline last year and am now too fearful to take a small dose of aripiprazole just prescribed to me by NHS psychiatrist because side effects look dreadful and discontinuation not clear if possible. Not enough research or general knowledge."

"Make sure there are distinctions made in that drug addiction doesn't just mean illegal drugs - it can refer to things like painkillers and other medications. I've struggled for years with painkiller addiction and haven't been able to find any help."

Appendix 8 – Questions for post-development project



Interview Questions

Please find the questions enclosed. If there are any questions that don't apply to you or you don't feel comfortable answering, you can leave them blank.

Before we begin, I would like to ask you a few questions about who you are.

Gender:

Age:

Please select the option that best describes you (delete the options that do not apply):

I am autistic

I am autistic and I have ADHD

I am autistic and I have a "mild" learning disability

I am not autistic

Are you a parent of an autistic person?

Yes No

Have you had any experiences with alcohol or drug problems (delete the options that do not apply)?

I have had problems with alcohol

I have had problems with drugs

I have not had problems with drugs or alcohol

I have a family member or friend who has had problems with alcohol or drugs

I would prefer not to say

The next questions relate to your experiences of our educational website. Please spend some time on our website before answering the questions:

www.adifa.co.uk

Please answer the questions below in as much detail as you feel comfortable with. This will help us to better understand your experiences of the website and how it can be improved or amended.

If there are any questions that don't apply to you or you don't feel comfortable answering, you can leave them blank.

1. **What were your overall experiences using the website?**

2. **How easy did you find it to navigate and use the website?**

3. **Do you think the website is presented in an autism friendly way?**

4. **Did you find the website's content to be interesting or useful?**

5. **How trustworthy do you think the website is?**

6. **How appropriate and accessible do you think the website is for autistic people with a learning difficulty or disability?**

7. **How appropriate and accessible do you think the website is for autistic people with ADHD?**

8. **In your experiences with alcohol or drugs, would you have found this website helpful in seeking help, support, or treatment?**

9. **Is there anything that you think should be included to help autistic adults who are struggling with alcohol or drugs?**

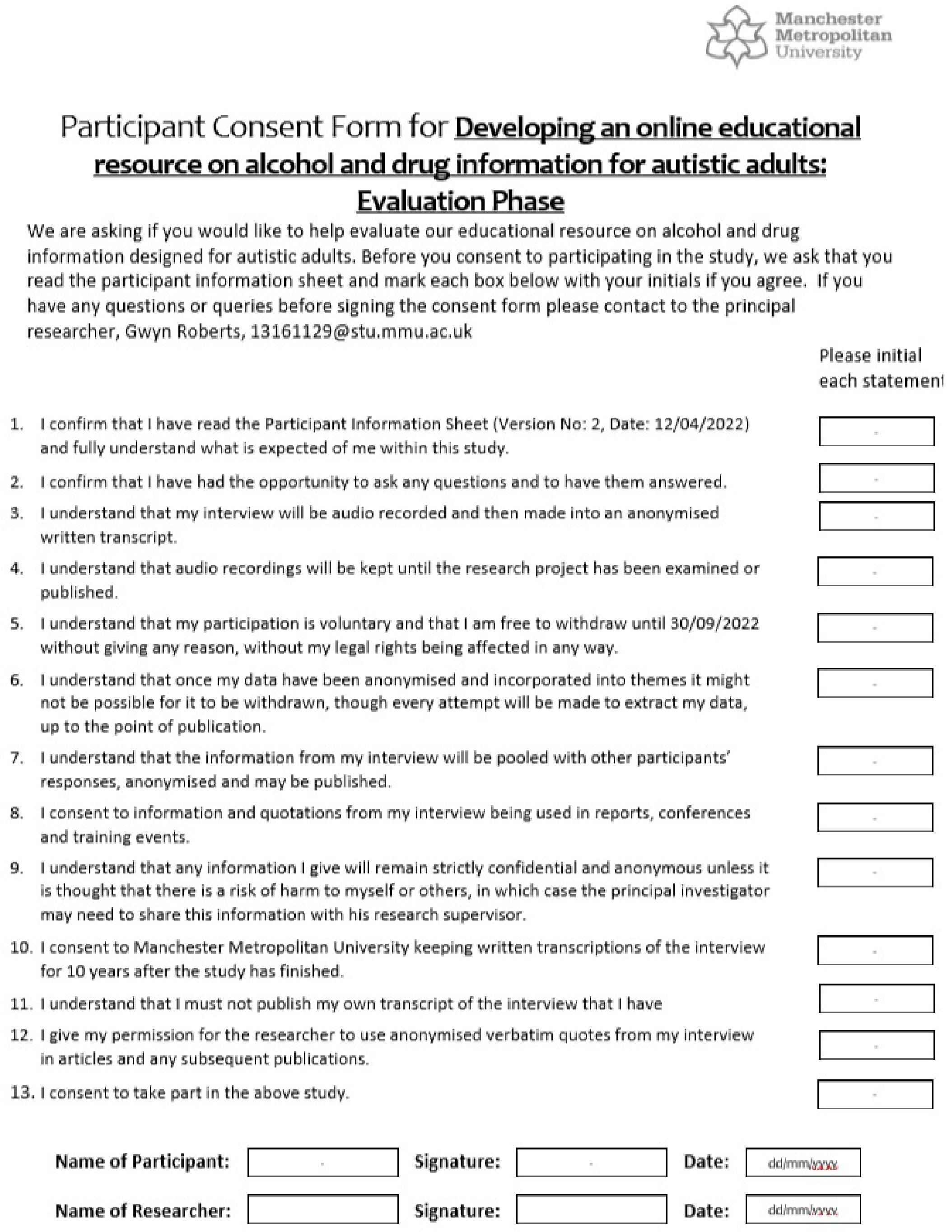
10. **Would you recommend this website for autistic adults?**

11. **Please let me know any other thoughts, comments, or feedback you may have about the website or the project in general.**

Appendix 9 – Information sheet for post-development project

Post-Development
Information Sheet.pdf

Appendix 10 – Consent form for post-development project



Manchester
Metropolitan
University

Participant Consent Form for **<u>Developing an online educational resource on alcohol and drug information for autistic adults: Evaluation Phase</u>**

We are asking if you would like to help evaluate our educational resource on alcohol and drug information designed for autistic adults. Before you consent to participating in the study, we ask that you read the participant information sheet and mark each box below with your initials if you agree. If you have any questions or queries before signing the consent form please contact to the principal researcher, Gwyn Roberts, 13161129@stu.mmu.ac.uk

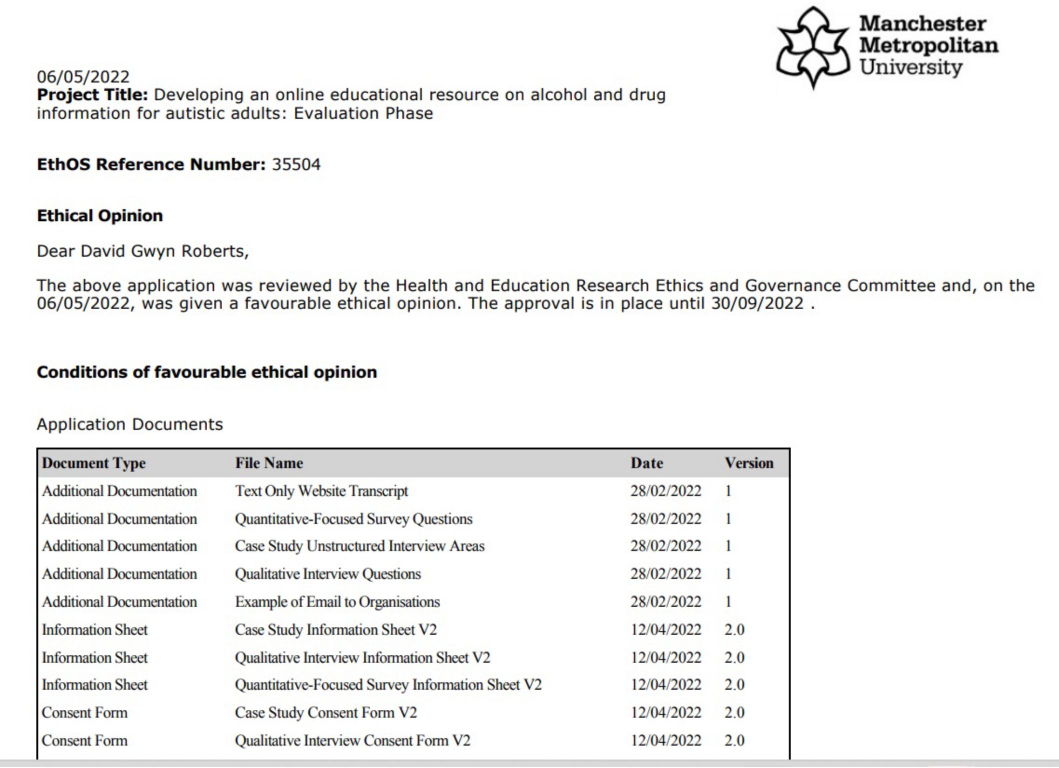
Please initial each statement

1. I confirm that I have read the Participant Information Sheet (Version No: 2, Date: 12/04/2022) and fully understand what is expected of me within this study. ☐
2. I confirm that I have had the opportunity to ask any questions and to have them answered. ☐
3. I understand that my interview will be audio recorded and then made into an anonymised written transcript. ☐
4. I understand that audio recordings will be kept until the research project has been examined or published. ☐
5. I understand that my participation is voluntary and that I am free to withdraw until 30/09/2022 without giving any reason, without my legal rights being affected in any way. ☐
6. I understand that once my data have been anonymised and incorporated into themes it might not be possible for it to be withdrawn, though every attempt will be made to extract my data, up to the point of publication. ☐
7. I understand that the information from my interview will be pooled with other participants' responses, anonymised and may be published. ☐
8. I consent to information and quotations from my interview being used in reports, conferences and training events. ☐
9. I understand that any information I give will remain strictly confidential and anonymous unless it is thought that there is a risk of harm to myself or others, in which case the principal investigator may need to share this information with his research supervisor. ☐
10. I consent to Manchester Metropolitan University keeping written transcriptions of the interview for 10 years after the study has finished. ☐
11. I understand that I must not publish my own transcript of the interview that I have ☐
12. I give my permission for the researcher to use anonymised verbatim quotes from my interview in articles and any subsequent publications. ☐
13. I consent to take part in the above study. ☐

Name of Participant: ☐ **Signature:** ☐ **Date:** dd/mm/yyyy

Name of Researcher: ☐ **Signature:** ☐ **Date:** dd/mm/yyyy

Appendix 11 – Ethical approval for post-development project



Manchester
Metropolitan
University

06/05/2022
Project Title: Developing an online educational resource on alcohol and drug information for autistic adults: Evaluation Phase

EthOS Reference Number: 35504

Ethical Opinion

Dear David Gwyn Roberts,

The above application was reviewed by the Health and Education Research Ethics and Governance Committee and, on the 06/05/2022, was given a favourable ethical opinion. The approval is in place until 30/09/2022 .

Conditions of favourable ethical opinion

Application Documents

Document Type	File Name	Date	Version
Additional Documentation	Text Only Website Transcript	28/02/2022	1
Additional Documentation	Quantitative-Focused Survey Questions	28/02/2022	1
Additional Documentation	Case Study Unstructured Interview Areas	28/02/2022	1
Additional Documentation	Qualitative Interview Questions	28/02/2022	1
Additional Documentation	Example of Email to Organisations	28/02/2022	1
Information Sheet	Case Study Information Sheet V2	12/04/2022	2.0
Information Sheet	Qualitative Interview Information Sheet V2	12/04/2022	2.0
Information Sheet	Quantitative-Focused Survey Information Sheet V2	12/04/2022	2.0
Consent Form	Case Study Consent Form V2	12/04/2022	2.0
Consent Form	Qualitative Interview Consent Form V2	12/04/2022	2.0

Appendix 12 – Data sample from pre-development project

Clear, concise and visual information. Don't take drugs or drink much, but if I wanted to look online again for info, looking online is helpful because it's pretty private and discreet. I could also look when I'm relaxed, and it would help take the scariness and some of the unknown away.	
I do not seek help for alcohol / substance misuse personally. However, this information is always useful as alcohol and recreational drugs seem to be a big part of our culture. The more knowledge on this, the better. I'm aware that it is useful to seek information from more reliable sources / many sources. However, I'm also aware that much information is contested regarding this subject.	490937-490928-59570867

15 What do you think would be particularly helpful or useful in an online resource about drug and alcohol information and support? Please be as detailed as you can.

Showing all 56 responses	
Information on services available and how to access them.	490937-490928-59563301
A very high level of usability and ease of access, and signs that it is maintained and updated, for example links are kept up to date, terminology and so on are still current.	490937-490928-59562987
Sorry, no idea.	490937-490928-5956351
It should be as comprehensive as possible with pointers for support organisations.	490937-490928-5956353
Helpline websites and numbers including emergency helpline/s. Visual information and support. Contact lists for support. 'Less is more' format with key information and facts. Featured relevant case studies. Recommendations for safe practice and keeping self and others safe.	490937-490928-5956306
Can give advice without having to ask badly about it.	490937-490928-5956476
There is a lack of information on the effects of alcohol and drugs in conjunction with ASD, particularly hallucinogenic substances. I don't want to take something if I'm not certain the effect it will have on me.	490937-490928-5956451
It being created by autistic professionals and experts by experience. Testimonials - I want to hear the voices of the people who've used it. It's important to know that I'm not alone.	490937-490928-59564551
- Autistically led workshops - Facts around autism focusing on drugs/alcohol to raise the awareness - Interviews	490937-490928-5956478
Alternative coping strategies, and help for transitioning to them from alcohol/drug misuse. Things like 'drinking yourself sober', that may be controversial but still help some people.	490937-490928-5956471
Ensuring it was up to date and not cringey...some sites I've seen are really trying too hard to be 'down with the kids', with all the faux grafitti type 'street' aesthetic and the young people I work with find that sort of thing quite off putting.	490937-490928-5956798

34 / 43

Alcohol/drugs + Autism

Clarity of information – presented simply

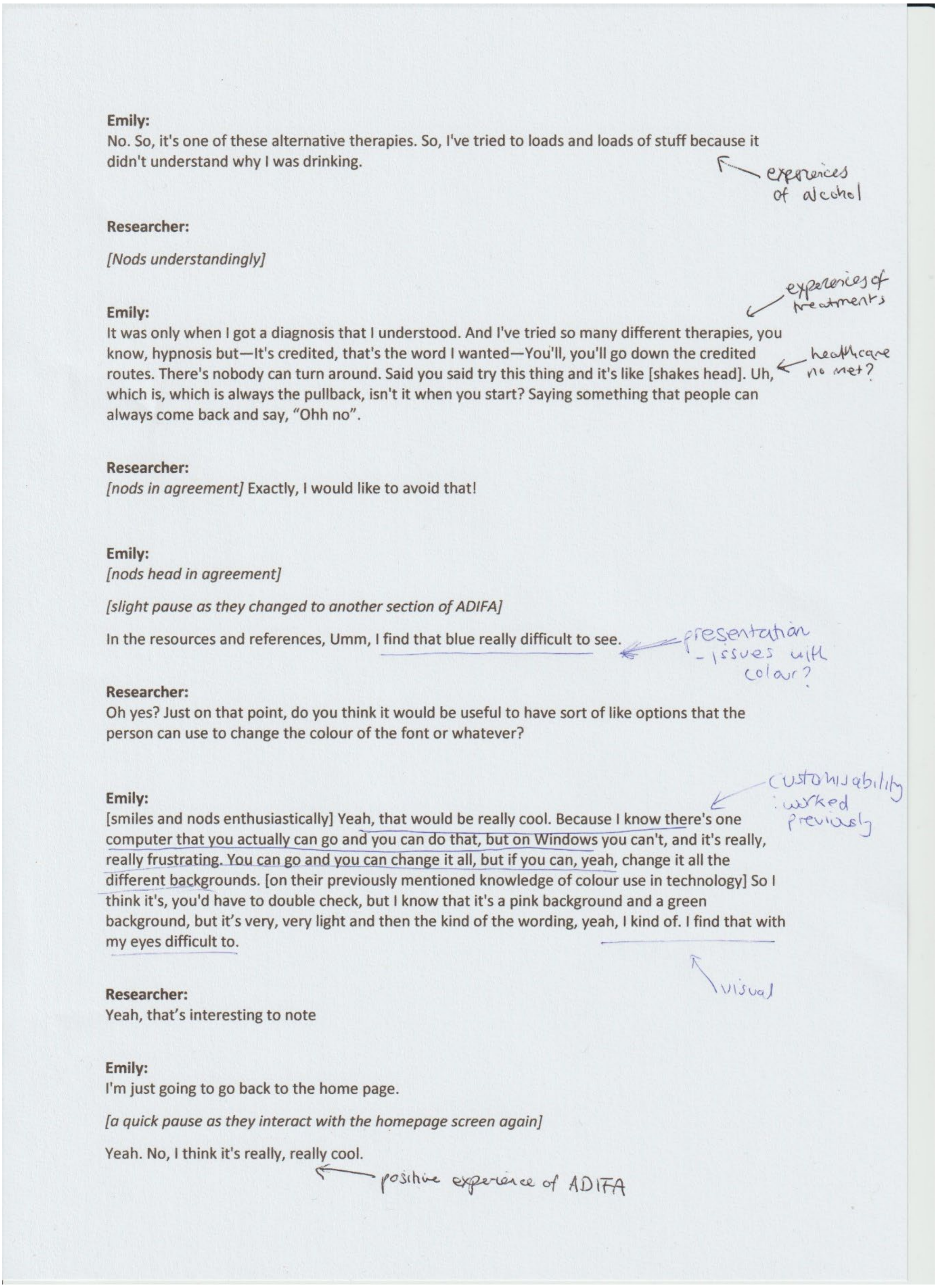
Practical support + techniques

Testimonials – perspectives from those with lived experience

Information on alcohol/drug use (how it works, when it does it become a problem)

An anonymous forum that had a moderator	490937-490928-59567989
I have been through half of medical school so far, so any information about drugs and alcohol is not new news. Practical things would probably be good.	490937-490928-59568560
Simple language that can be understood by anyone. Also for the language should be non judgemental and offer comfort to the client. The online site should have an memorable and catchy IP address. The online site should be simple to navigate and offer simple click on menu.	490937-490928-59568838
For me, exercise helped me hugely overcome alcohol addiction, so anything to help promote exercise and the mental health benefits of it	490937-490928-59570491
All of this will already be available, but perhaps not in a form that some Autistic/LD people can understand. Perhaps simplified versions.	490937-490928-59569402
More understanding from the perspective of the user. Most resources do not acknowledge what is attractive about drugs nor how they really make you feel.	490937-490928-59571546
Interactions with prescribed medication. Real answers, not just 'don't do drugs kids'	490937-490928-59572192
Signposting on to local expert providers	490937-490928-59571976
How they work Signs of problems Practical info	490937-490928-59573564
Awareness on the health implications. Information about the effects of alcohol on Individuals with Autism e.g. how the experience can differ, tolerance etc...	490937-490928-59574146
Exact quantities of substances to explain the levels at which they cause damage, and exactly what the damage is, with illustrations. Like those pictures of tar in the lungs for the stop smoking campaign.	490937-490928-59573830
Contacts other than phone lines and shelters	490937-490928-59575806
A sign posted direction where you can access actual help for the person with the problem.	490937-490928-59577663
Contact information for organisations Accurate figures on consumption and use and when this becomes problematic. Information about addiction	490937-490928-59580023
Accurate descriptions of what it's like to go through inpatient and outpatient rehabilitation	490937-490928-59580215
It would obviously advise people not to take hard drugs but would also advise that soft drugs such as Canabis effect the Autistic brain differently and should be avoided. Just because your neurotypical friends are fine it doesn't mean that you will be, because your brain is wired differently.	490937-490928-59580769
A person to speak with in addition to the on-line info. I worry that on-line support will replace this.	490937-490928-59583097

Appendix 13 – Data sample from post-development project



Emily:
No. So, it's one of these alternative therapies. So, I've tried to loads and loads of stuff because it didn't understand why I was drinking.

experiences of alcohol

Researcher:

[Nods understandingly]

experiences of treatments

Emily:
It was only when I got a diagnosis that I understood. And I've tried so many different therapies, you know, hypnosis but—It's credited, that's the word I wanted—You'll, you'll go down the credited routes. There's nobody can turn around. Said you said try this thing and it's like [shakes head]. Uh, which is, which is always the pullback, isn't it when you start? Saying something that people can always come back and say, "Ohh no".

healthcare no met?

Researcher:
[nods in agreement] Exactly, I would like to avoid that!

Emily:
[nods head in agreement]

[slight pause as they changed to another section of ADIFA]

In the resources and references, Umm, I find that blue really difficult to see.

presentation - issues with colour?

Researcher:
Oh yes? Just on that point, do you think it would be useful to have sort of like options that the person can use to change the colour of the font or whatever?

customisability: worked previously

Emily:
[smiles and nods enthusiastically] Yeah, that would be really cool. Because I know there's one computer that you actually can go and you can do that, but on Windows you can't, and it's really, really frustrating. You can go and you can change it all, but if you can, yeah, change it all the different backgrounds. [on their previously mentioned knowledge of colour use in technology] So I think it's, you'd have to double check, but I know that it's a pink background and a green background, but it's very, very light and then the kind of the wording, yeah, I kind of. I find that with my eyes difficult to.

visual

Researcher:
Yeah, that's interesting to note

Emily:
I'm just going to go back to the home page.

[a quick pause as they interact with the homepage screen again]

Yeah. No, I think it's really, really cool.

positive experience of ADIFA

Researcher:
That's good.

Emily:
Umm, because sometimes you can go in and there's just so much information.

Clarity in ADIFA: positive aspect of clear, concise presentation

Researcher:
Yeah, I was trying to like make it so that it was easier to digest, but still cover enough because it's quite, I mean it's quite a broad topic really.

Emily:
Yeah, yeah, definitely. And especially when you're saying drugs and alcohol, when you're kind of going down, OK, that whole drug side of thing. There's so many of them.

editing of material

Researcher:
Yeah, yeah.

Emily:
Just double checking... It's really annoying because usually I go into things and I'm like, *[uses noises, sounds and hand movements to portray the number of comments and feedback they usually give]*

But when I saw this, I was like, "it's really good!"

positive experience with ADIFA

Researcher:
[Laughter] I mean I'll take that, thank you! Do you think that there is a section that could be, um, like a topic I haven't covered yet that could be included?

Emily:
I'm just trying to think so. I suppose. Kind of. But then you it might be going off topic, so drugs and alcohol addiction. Because you could always go into, a bit more about, why is it as autistic individuals we use alcohol for things like depression?

content; why autistic adults use ~~alcoh~~ substances specifically in regards to depression?

Researcher:
Yeah. *[nods encouragingly]*

Emily:

But then that, again, it's kind of going into something that people might not be interested in. I just know that when I was when I was drinking, I kind of needed and wanted to know that there was somewhere I could kind of, go on and you can kind of get that real easy background information which you've got it there. But then you've got all the help books as well—which I think is really, really good—and the references.

positive experience with ADIFA

support for this type of independently accessed psychoeducation