# Eating Disorder Recovery Maintenance: A Mixed-Methods Exploration of Protective Factors and Relapse Buffers.

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# Eating Disorder Recovery Maintenance: A Mixed-Methods Exploration of Protective Factors and Relapse Buffers.

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# Acknowledgements

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# Introductory Information

## General Abstract

### *Background*

The impact of eating disorders (EDs) on individuals, their families, healthcare services, and economies is substantial, and maintaining recovery in the long term can be challenging. Many individuals with EDs do not seek treatment due to the secrecy, shame, and stigma associated with these illnesses. Of those who do seek treatment, half of these individuals relapse, a fifth remain chronically ill, and many die prematurely, making EDs the type of mental illness associated with the highest mortality rate. EDs are impacting a rapidly increasing proportion of the global population, and the associated strain on healthcare services as well as individuals must be addressed.

Digital health is a promising area to improve accessibility to treatment and reduce costs; app-based interventions have seen recent success and popularity across various mental health diagnoses and health services. Little research has been conducted to date on apps for EDs. There is a paucity of systematic reviews addressing both usability and effectiveness of app-delivered interventions for EDs. Digital interventions for EDs have increasingly proved to offer promising venues to address low rates of treatment-seeking and engagement, long wait-list times for ED treatment, and the few preventative tools and post-treatment aftercare. Moreover, their progressive development over the past two decades has shown the importance of Patient and Public Involvement (PPI), to account for the lived experiences of service users when developing digital tools to support mental health and long-term improvement of psychological wellbeing.

### *Methods*

The current work refers to multiple studies conducted with the aim of developing a novel digital tool (a mobile app called RecoveRiver) to support people in maintaining ED recovery.

First, a scoping review was conducted on the topic of app-based interventions for EDs. Electronic databases were searched for any studies utilising apps for the prevention, treatment, or recovery maintenance support for people with EDs. Of the 127 screened studies, 12 studies met the inclusion criteria for synthesis and review. The PRISMA-ScR model

and Arksey and O'Malley's (2007) Methodological Framework for Scoping Reviews were utilised to systematically evaluate and select the studies included in the current review. This initial step contributed to informing the research team—who the author of this work was Principal Investigator (PI)—regarding evidence on the effectiveness of mobile apps in promoting long-term recovery from EDs. This formed the basis of the rationale and preliminary ideas for the contents of the RecoveRiver app.

Next, the RecoveRiver app was developed alongside two PPI-based qualitative studies, whose results directly influenced app contents and design. The first PPI study employed an interpretive phenomenological analysis to explore individuals' lived experiences of maintaining ED recovery. Findings shaped the development of the first prototype of the RecoveRiver app. After developing the app prototype, an acceptability and feasibility pilot trial was conducted, for a preliminary evaluation of the product created. The results of this trial have been omitted from the thesis due to lack of data, due largely to high levels of attrition as a consequence of issues related to the app. A second stage of PPI then used thematic analysis (gathering ED patients' feedback and suggestions on the app) to refine the app, in preparation for a larger trial to test its effectiveness, feasibility, and usability.

PPI was a key focus throughout the entire development and design process of RecoveRiver. Qualitative data gathered from interviews with individuals in long-term recovery and a survey asking individuals who had recently completed ED treatment to provide feedback about the app, were synthesised in an iterative multi-stage process of app development. The lived-experience and evidence-informed mobile app developed offers worksheets, journal prompts, guided meditations, activity planning, and mood monitoring. The methods described in this paper underscore the importance of utilising PPI in the development of mental health apps.

### ***Findings***

A succinct overview of the key findings is presented below.

- The scoping review identified 12 papers meeting the inclusion and exclusion criteria. Their findings highlighted that app-based interventions for EDs are largely CBT-based and, on the whole, are deemed acceptable and valuable by users.
- The first qualitative PPI study investigating individuals' lived experiences of maintaining ED recovery in the long-term resulted in the primary themes: 'Recovery

is a Lifelong Process', 'Recovery Requires Tools and Supports' and 'Recovery is a Journey of Self-Discovery'.

- The second qualitative PPI study indicated potential app users agreed on key contents that should and should not be included in an ED recovery support app.

The significance of these findings for research and practice will be presented in greater detail in the empirical paper.

## General Introduction

The layperson's definition of an eating disorder (ED) as given by the British National Health Service (NHS) is, "a mental health condition where you use the control of food to cope with feelings and other situations." EDs can be debilitating psychiatric illnesses which significantly impact a person's mental and physical health, and which can be expensive to treat (Kim et al., 2021). Up to 6.4% of the adult population in the UK demonstrate ED symptoms (Adult Psychiatric Morbidity Survey, 2007). A systematic review of global cases of ED treatment-seeking found that 67-83% of individuals' treatment needs are not met (Hart et al., 2011).

Mobile health (mHealth) apps can offer the opportunity to provide ED treatment at a low cost, in an accessible format, and are a feasible way in which to deliver interventions such as Cognitive Behavioural Therapy (CBT) (O'Leary and Torous, 2022). ED-focused mHealth apps also have the potential to enhance the quality of care and effectiveness of treatment which patients receive (Kazdin, Fitzsimmons-Craft, and Wilfley, 2016). The paucity of emerging evidence is promising. One recent Randomised Controlled Trial (RCT) of a CBT-based app for EDs found that the app effectively targeted ED symptoms and impairment due to the ED—and that these improvements were maintained over time—and was deemed helpful and satisfactory by users (Linardon et al., 2020).

The stigmatisation of EDs, and associated high levels of shame and subsequent low levels of treatment-seeking, can represent a significant barrier to recovery for individuals (Foran, O'Donnell, and Muldoon, 2020); these issues may be circumvented by the anonymity and increased ease of discreet access to treatment which an app can provide (O'Leary and Torous, 2022). However, usage and engagement with ED mHealth apps may be more irregular and complex than other treatments, which points to the need for apps to be developed in a way which fosters meaningful and sustained engagement from patients/users (Kim et al., 2021).

Jarman et al. (2022) identified a key challenge regarding apps for individuals with EDs: individuals with EDs must first recognize their symptoms of an ED, their need for treatment, and be actively seeking help in order to engage with an app; and the app must then be quickly deemed usable and credible to maintain engagement. An issue with mHealth ED apps is lack of awareness—many people with EDs do not know such apps are accessible, and therefore do not think to seek them out without clinician direction (Eikey, Chen, and Zheng, 2019)—and clinicians are unlikely to direct patients to apps which are not evidence-based. An overview of the marketplace and research trends in apps for EDs conducted by O'Leary and Taorous (2022) found that although there are a plethora of apps marketed to individuals with EDs, less than 10% had any basis in research or clinical guidance. Authors Graham and Fitzsimmons-Craft (2020) critique the gap between research development and practice implementation of evidence-based ED apps available to the public, while O'Leary and Torous (2022) suggest "research efforts should focus on offering evidenced-based apps for the marketplace."

In order to address this identified gap in both research and clinical practice, the research presented in this thesis focuses on the development of an evidence-based, PPI-informed mobile app (RecoveRiver) to support long-term recovery from EDs. There are three chapters that make up this thesis. Chapter One presents a scoping review of 12 studies which utilised mobile apps for the prevention, treatment, or recovery maintenance support for people with EDs. Chapter Two is a 'methodological paper' that discusses the methods employed in developing the RecoveRiver app, most especially the emphasis on PPI. This format (describing the development of a digital product and of research stages to implement it) is in line with similar methodological papers focusing on digital interventions for mental health (e.g., Rickard et al., 2016; Hetrick et al., 2018; Kenny et al., 2014). Chapter Three presents the findings of an interpretive phenomenological analysis that led to the development (utilising a co-production approach) of the RecoveRiver app.

Figure 1, below, shows a flowchart of the various stages of the thesis project, and which elements pertain to which of the chapters and individual papers encompassed in this thesis.

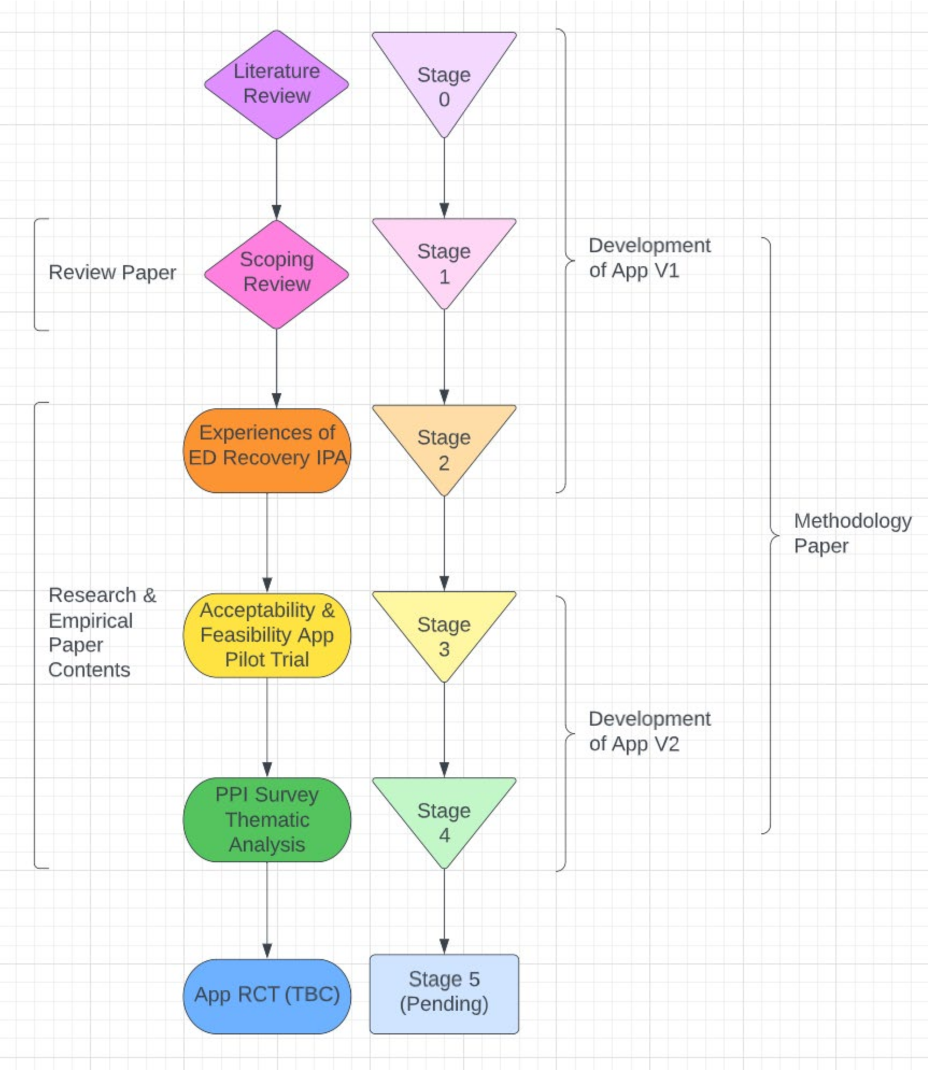


*Figure 1. Thesis Project Flowchart.*

There are two main arguments to the thesis. Firstly, app-based interventions for eating disorders are a recently emerging yet essential area to address the issue of ED relapse and recovery maintenance. They have the potential to address the dearth of post-treatment aftercare and high levels of relapse in this patient population, as well as offering an easily accessible and discreet way to access support in the recovery period.

Secondly, Patient and Public Involvement (PPI) in both ED research, and the development of digital interventions for mental health difficulties, is key to facilitate uptake and adherence to digital interventions—as well as increasing representativeness of the 'true' needs and views of service users regarding mental illness and recovery. Tomlinson and colleagues (2019) argue that although including PPI in doctoral research can be difficult due to financial and time constraints, its positive impact on research, and the research process itself, should not be discounted. PPI has been found to tangibly improve studies' methodologies, as well as improve the relevance and impact of research (Fletcher et al., 2021). Therefore, the present work will highlight the benefits and challenges of embedding PPI throughout the development of a novel mobile app for supporting ED recovery.

## Reflexive Statement

The Principal Investigator (PI) conducted the majority of this research online during the Coronavirus pandemic and lockdowns. At beginning of the project, she was in her early twenties, working as a voluntary trainee psychological therapist at a community eating disorders service for adults in the Northwest of England, while conducting this research as part of her professional doctorate of psychological therapies. The PI had recovered from an ED herself and had been in recovery for eight years.

At the time of writing, the PI is now the Clinical Lead of the same eating disorder service, supervising and managing the service's seven therapists, case managing a trainee counselling psychologist and dietitian, holding a caseload of the service's most complex patients, and meeting regularly with commissioners and NHS trust leaders to inform the further development of all ED services across the Northwest of England. She has now celebrated her 10-year anniversary of ED recovery.

It is important to acknowledge that researcher bias was present and unavoidable—from both a personal and professional perspective—however, the researcher reflected on and discussed this regularly with both her professional and academic supervisors.

From a clinical perspective, some bias was present in selecting the therapeutic modalities from which to base the app contents on. Enhanced Cognitive Behavioural Therapy (CBT-E) was selected for multiple reasons as the basis for the app. Firstly, this modality was used due to the fact that it is one of three National Institute for Health and Care Excellence (NICE)-backed approaches to eating disorders treatment in the UK. Secondly, this is the primary intervention used in the PI's eating disorder service and the primary intervention she is trained in, uses with patients, and is most familiar with in terms of contents and rationale. Thirdly, the evidence base for the efficacy of CBT-E with ED patients is more substantial than any other approach (as is typical for CBT, especially in the UK, due to its time- and cost-saving benefits when integrated in an NHS-provided service).

The integration of Compassion-Focused Therapy worksheets and ideas into the RecoveRiver prototype came primarily from the PI’s personal/professional interest in this intervention. The PI undertook a Mindful Self-Compassion course by Kristin Neff (pioneer of Self-Compassion research) during the summer of the first pandemic lockdown, at the start of her doctoral degree. Learning and implementing self-compassion skills and techniques had a profound positive impact on her overall psychological wellbeing and overall recovery stability. Choosing to use CFT in an integrative, complementary way with CBT-E came also from a combination of her professional and personal experiences and perspectives.

The PI aimed to hold all identities as ‘researcher’, ‘clinician’ and ‘individual in recovery’ in equal importance. The doctoral work was informed over the years as the PI’s understanding of recovery from both a personal and professional perspective gained more depth and nuance through facilitating communication between these aspects of identity.

# Chapter 1.

## Scoping Review of App-Based Interventions for Individuals with Eating Disorders

*Review Paper*

**Emma Elizabeth Salazar**

## Introduction

Eating disorders (EDs) are defined by the American Psychological Association as "behavioural conditions characterised by severe and persistent disturbance in eating behaviours and associated distressing thoughts and emotions" (Guarda, 2021) and include DSM-V diagnoses of Binge Eating Disorder, Bulimia Nervosa, Anorexia Nervosa, Other Specified Eating or Feeding Disorder, as well as Avoidant Restrictive Food Intake Disorder, Pica, and Rumination Disorder (Guarda, 2021). Anorexia Nervosa receives particular attention in the media and literature likely due to having the highest mortality rate of any psychiatric disorder, due to medical complications and suicide (DeNoon, 2011); however, other eating disorders are also associated with medical problems and suicide.

ED clients are notorious in the field of mental health as being one of the hardest-to-treat client groups (Abbate-Daga, 2013), with recurrent relapse being a common issue—on average, 45% of patients fully recover, 30% improve, and 25% remain chronically ill (BEAT, n.d.). Estimates for the prevalence of EDs vary greatly by the country and year in which they were measured, and the margin for error in such estimates is likely high due to how many individuals with EDs either avoid or cannot access treatment. Santomauro et al. (2021) raise a key issue: 'anorexia nervosa and bulimia nervosa are the only eating disorders included in the Global Burden of Diseases, Injuries, and Risk Factors Study (GBD) 2019, yet binge-eating disorder and other specified feeding or eating disorder (OSFED) are more prevalent.' Thus, the majority of people with EDs are missed in the GBD.

A systematic literature review on the prevalence of EDs, conducted by Galmiche et al. (2019), evaluated 94 studies published in English or French between 2000 – 2018. Findings report a mean point prevalence of 4.6% in the United States, 2.2% in Europe, and 3.5% in Asia. Global point prevalence was reported as 5.7% in women and 2.2% in men. Galmiche and colleagues' (2019) review also highlighted the steep rise—nearly doubling—prevalence of EDs between 2000 (3.5%) and 2016 (7.8%), putting estimates of the number of individuals with an ED globally around 70 million.

The Strategic Training Initiative for the Prevention of Eating Disorders (STRIPED) published a comprehensive 92-page report on the social and economic costs of EDs in the United States in June 2020, outlining not only the financial and social costs of EDs but also best practices in treatment. Some key information from this publication painted a concerning picture of the impact of EDs in the United States. Every 52 minutes a person dies as a direct result of an ED (10,200 deaths per year); 9% of Americans will have an ED at some point in their lifetime; and EDs cost hospital systems 53,918 emergency room visits and 23,560 inpatient hospitalizations (Deloitte Access Economics, 2020).

The annual financial and economic cost of EDs in the UK is £15 billion, and services are stretched thin to provide adequate support, which has led to over a dozen preventable deaths in the past seven years (Marsh and Duncan, 2020). ED inpatient admissions have been on the rise by seven percent annually since 2013 (BEAT, n.d.). Furthermore, due to the detrimental impacts of coronavirus lockdowns on overall mental health, it comes as no surprise that in the UK, ED hospital admissions increased 50% from 2019 – 2021 (Triggle, 2021). 80% of sampled individuals with EDs in the UK reported their symptoms worsening during lockdown (Branley-Bell and Talbot, 2020). The British National Health Service (NHS) stated that they had ‘run out of beds for inpatient ED referrals’ and a BBC investigation found ‘as the numbers needing help increased the early support available in the community could not cope with demand, increasing the risk of young people reaching crisis point and ending up in hospital’ (Triggle, 2021). As evidence about the impact of the pandemic on EDs emerges, it is becoming clear that the demand for help and strain on services is leading to a breaking point. Referrals for ED care in the UK have increased fourfold since the pandemic, with an average waiting time of 12 months for adults seeking therapy (Brown, 2021). There is no standard support offered whilst patients are on waitlists (Brown, 2021).

Mental health technologies such as internet-delivered or app-based self-help, psychoeducation, and therapeutic interventions hold the potential of revolutionising healthcare through increasing access, decreasing disparity, and decreasing costs (Mohr et al., 2017). Six billion people in the world own a smartphone, and since the invention of mobile applications (apps) in 2008, over 10,000 mental health apps are now available to users (Tal and Torous, 2017). However, there is little in the way of standards or practices in the research and evaluation of mental health apps (Hsin, 2019). In this regard, Mohr et al. (2017) highlight a key issue: ‘the slow pace of research methods often results in mental health technologies that are outdated and obsolete by the time they are validated’. Similarly, research on mental health technologies is often carried out with the purpose of testing products rather than proposing interventions that will benefit app users. Consequently, insufficient and/or incomplete information is often gathered from users/patients on any changes in their symptomatology that may occur as a result of their engagement with the proposed technology (Mohr et al., 2017).

Implementation of and research regarding digital interventions for EDs is still in its infancy, but with global ED prevalence increasing exponentially and many health services worldwide stretched to their limits, digital interventions are quickly gaining traction due to the low cost of delivery and wide scope of accessibility. To date, only a handful of reviews (e.g., Fairburn and Rothwell, 2015; Loucas et al., 2014) have been conducted in the area of digital health and EDs, due to the research only beginning twenty years ago, and only becoming more popularised in the last ten years. The first known study to evaluate digital health and EDs was conducted in 2000 (‘Student Bodies’, internet-delivered CBT for body image dissatisfaction, Celio et al.), with only one or two studies and publications per year in the field until 2012, when research on digital health and EDs started gaining popularity. As Tal and Torous (2017) proposed, the rapid pace of digital mental health research makes review papers essential, to synthetise the existing knowledge we have, learn what could be improved, and build advancements based on examples of good practice.

In line with this, two systematic reviews are especially important to discuss as pioneering reviews in the field, both conducted by Christopher Fairburn, the creator of Enhanced Cognitive Behaviour Therapy (CBT-E), one of the two therapeutic interventions endorsed by NICE guidelines in ED treatment. In 2014, Fairburn and colleagues, working under NICE, conducted the first review and metanalysis looking at digital health and EDs. Overall, results were scarce. Of the only 20 eligible studies included, 17 evaluated internet-delivered CBT (eight of these were based on a single intervention focused on body image), and no studies evaluated the use of app-delivered interventions. The authors stated in their discussion that no firm conclusions could be drawn from the evidence included in their work due to the scarcity of evidence and the methodological issues presented by most of the studies included in their review (e.g., low or very low confidence in effect estimates). The authors also stated that the lack of studies conducted on apps needed addressing. The following year (2015), Fairburn and Rothwell conduced a systematic clinical appraisal of apps for EDs. Of the 39 apps identified, only two were deemed clinically acceptable, and half of the apps assessed contained information and advice that the authors deemed misleading and potentially harmful.

Nevertheless, other reviews and meta-analyses conducted on digital interventions for EDs (including apps) contribute to paint a more complex picture, in which proof of effectiveness of app-delivered interventions and limitations co-exist. For example, Aardoom et al. (2013) reviewed internet-delivered ED interventions and found significant improvements in symptomatology, with some caveats (e.g., higher effectiveness was found in individuals with fewer comorbidities and in individuals with binge eating disorder as opposed to anorexia and bulimia nervosa). Barakat et al. (2017)'s review and meta-analysis concurred to indicate that CBT-based e-therapies yield promising results, as they can not only successfully help to reduce ED symptoms but also improve comorbid depression and anxiety symptoms (with results remaining stable at follow-up). In another review on randomised controlled trials (RCTs) (Linardon et al. 2020), it was found that digital interventions were more effective than control conditions both in preventing and in treating ED symptoms. However, the same review pointed out ongoing limitations affecting current digital ED interventions, such as the high drop-out rates and the presence of only a few RCTs comparing digital with face-to-face interventions.

Drawing from the recommendations emerging from the previous reviews on digital interventions and EDs, this scoping review will focus exclusively on research conducted on apps for eating disorders. Given this is a recently rapidly growing area of research, with only two reviews to date, it will address the need to update and review the literature of an up-and-coming field in treatment and research.

### Aims

The aim of this scoping review is to synthesise and understand current literature investigating how smartphone applications are used in the prevention of, treatment, and recovery maintenance of people with EDs. Thus, the review questions/objectives are as follows:

- How are apps being used for prevention, treatment, or recovery support for individuals with EDs?
- What are the app components that are deemed as most useful and effective in supporting recovery from EDs?

Arksey and O'Malley (2007) identify four key reasons why a scoping review may be conducted; of these listed reasons, this scoping review aimed to both 'examine the extent, range, and nature of research activity', and 'determine the value of undertaking a full systematic review'.

## Design & Methods

A scoping review was conducted based on the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist (Page et al., 2021), adapting Arksey and O'Malley's (2007) Methodological Framework for Scoping Reviews. A scoping review was deemed as the most appropriate option to explore the evidence on the use and effectiveness of apps for EDs, as scoping reviews aim to provide a broad overview of the available evidence on a specific topic (Sucharew and Macaluso, 2019). Scoping reviews can be used to explore existing evidence and knowledge gaps, confirm the relevance of inclusion/exclusion criteria, and refine potential questions prior to conducting more systematic literature reviews (Munn et al., 2018; Sucharew and Macaluso, 2019).

Scoping reviews, like systematic reviews, require the author(s) to search databases and review all publications related to the pre-established research question, utilise inclusion and exclusion criteria to identify relevant publications, and synthesise the findings into a cohesive summary (Sucharew and Macaluso, 2019). However, the methodology of these elements differs slightly. Firstly, the scoping research question must be broad enough to capture all relevant literature; second, inclusion and exclusion criteria as well as search terms may be altered post-hoc to identify relevant studies in an iterative, rather than linear, process (Arksey and O'Malley, 2007). Finally, data extraction occurs via 'charting' using a narrative approach.

For the current scoping review, the following stages, proposed by Arksey and O'Malley (2007) were followed:

- Stage 1: identifying the research question
- Stage 2: identifying relevant studies
- Stage 3: study selection
- Stage 4: charting the data
- Stage 5: collating, summarising and reporting the results

***Eligibility Criteria***

*Types of Studies*

Eligible articles were published in English, in peer-reviewed journals. No restrictions were initially placed on the date of publication. Nonetheless, as Loucas et al.'s (2014) systematic review on eTherapy and EDs found no studies conducted on apps for EDs before 2015, the studies included were limited to the timeframe 2015-2021. No restrictions were placed on study designs (with the only exception of literature reviews, meta-syntheses and metanalyses). Thus, eligible designs included RCTs, mixed-methods studies, quasi- and pre-experimental studies, pilot studies, and case studies.

*Types of Participants*

Studies were included if the population/sample included individuals who met some or all of the DSM-V criteria for any eating disorder (binge eating disorder, OSFED, bulimia nervosa, and/or anorexia nervosa). Studies were excluded if participants met some or all of the diagnostic criteria for feeding, rather than eating, disorders (e.g., ARFID). Studies with participants of any age or gender, in any country, were included. Both clinical and nonclinical samples were accepted, and studies were accepted regardless of control conditions.

*Types of Interventions*

Studies were included if the intervention utilised an app for the prevention, treatment, or recovery maintenance/relapse prevention from an ED. Studies were included if the app was the sole intervention or part of a multi-faceted intervention (e.g., delivered alongside therapy or guided self-help). The interventions must have included an app-based component; thus, other digital interventions (e.g., computerised therapy and online self-help) were excluded.

*Types of Outcomes*

Due to the nature of a scoping review, studies were not excluded based on nature or type of outcome reporting.

***Information Sources***

A literature search was conducted for published studies in the following electronic databases: Ovid (including MedLine), PubMed, and Google Scholar. These databases were last searched/consulted on 9th November 2021. The search was performed by the PI using the search strategy indicated below.

### ***Search Strategy***

The search strategy used the key words: (“Anorexi*” OR “Bulimi*” OR “Binge Eating” OR “OSFED” OR “EDNOS” OR “Eating Disorder*”) AND (“Digital Health” OR “Computerised Therapy” OR “App*” OR “Online Health” OR “Digital Therapy” OR “Internet Self Help” OR “Internet Therapy” OR “Online Self Help” OR “Smartphone Application*”). Keywords were intentionally broad in order to capture as many relevant studies as possible as is standard in scoping reviews, and due to the limited amount of research in this area.

Table 1, as shown below, details the initial scoping review plan. Note that some keywords were changed following this initial plan, as is common during the scoping review process in order to better capture all relevant literature. Some search terms were updated to use the asterisk function as study titles may for instance use ‘anorexic’ rather than ‘anorexia,’ etc. A large number of terms were used to identify studies that utilised apps due to some studies not using the words ‘app’ or ‘application’ in the title or abstract when the intervention was, in fact, app-based. There are many different ways to refer to health-related digital interventions and/or apps and the lack of a consistent term used in this field can be problematic to accurately searching and capturing the evidence base.

*Table 1. Scoping Review Plan: Eating Disorders and Apps*

| Stage | Details |
|---|---|
| Topic | Apps for Eating Disorders |
| Aim | Identify and synthesise current literature surrounding how apps are used in the prevention, treatment, and recovery maintenance of people with eating disorders. |
| Question | How are apps used for early intervention, treatment, or recovery support for individuals with eating disorders? |
| Search Strategy | Anorexia OR Bulimia OR Binge Eating OR OSFED OR EDNOS OR Eating Disorder OR Eating Disorders<br>AND<br>Digital Health OR Computerised Therapy OR App OR Online Health OR Digital Therapy OR Internet Self Help OR Internet Therapy OR Online Self Help OR Smartphone Application |
| Databases | OVID; PubMed; Google Scholar |
| Screening Criteria | Inclusion Criteria<br>• Diagnosis of ED<br>• App for Early Intervention, Treatment, or Recovery<br>• Published in English<br><br>Exclusion Criteria<br>• Other digital health intervention (non-app-based)<br>• ARFID/Feeding Disorders<br>• Reviews |
| Study Characteristics | Data recorded<br>• Patient population<br>o Sample size<br>o Sample demographics (primarily gender, age, and ethnicity)<br>o Country<br>o Research funding source<br>• ED<br>o ED(s) studied e.g., Anorexia, Bulimia, BED<br>• App<br>o Content (psychoeducation, self-help, or specific therapeutic intervention)<br>o For what stage of the patient journey e.g., prevention, treatment, or recovery maintenance |
| | |

### ***Selection Process***

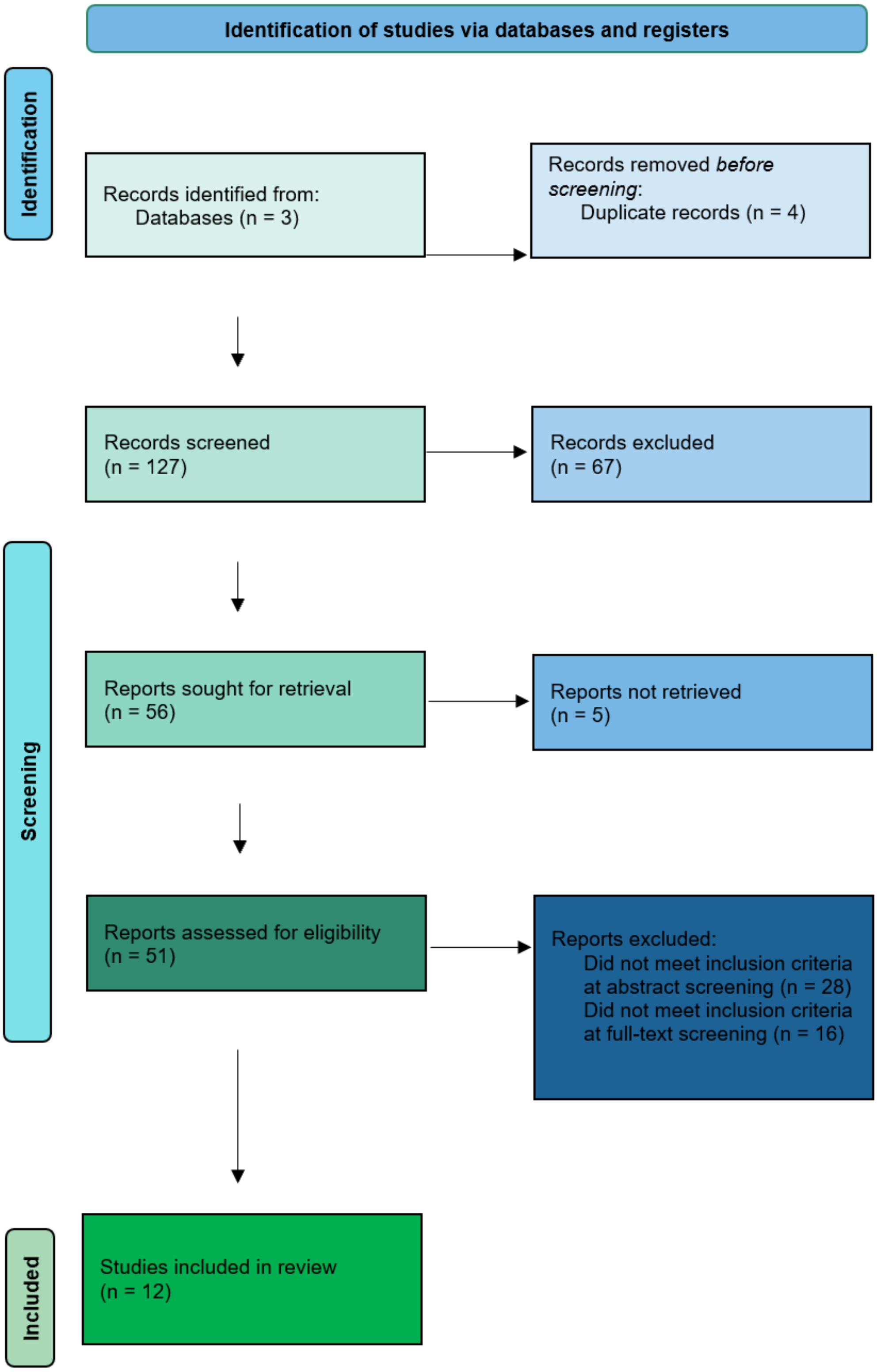
After duplicates were removed, the identified papers were screened by the author using titles and abstract to decide whether they fit the inclusion criteria. Then, the full-text was scanned to determine if each study fit the inclusion criteria. At each stage of screening, the author made a two-column table of included and excluded studies and listed the reason(s) for each excluded study. Studies were excluded for three primary reasons:

- Did not meet inclusion criteria or met exclusion criteria;
- Full-text version was unavailable;

- Duplicate record.

These tables obtained can be viewed in Appendix 1. The flowchart of the study selection process can be viewed below in Figure 1.

*Figure 1. PRISMA Flowchart of Selection Process.*



### ***Data Collection & Extraction***

Pollock and colleagues' (2023) recommendations for extraction, analysis, and presentation of results in scoping reviews note that these processes can be difficult for authors given the variety of sources included in the review, lack of clear or conflicting guidance for these processes, and questions around what is or is not relevant when trying to capture a wide range of information pertaining to a topic, in a review format more exploratory, cyclical, and broad than other literature reviews. The authors propose a simple 'PCC' (population, concept, and context) framework to guide data collection and extraction in scoping reviews. Principles informing this framework focus on transparency and rigour, as well as keeping the purpose and reasoning of the review in mind when selecting data items of interest.

Taking into consideration the PRISMA-ScR guidance as well as Pollock and colleagues' guidance regarding data collection and extraction for scoping reviews, the following data was extracted manually by the reviewer into a data chart: study title, authors and publication year, country, study population/sample (including gender, age, and symptomology/diagnosis), intervention overview, treatment stage, design, comparison group, and a summary of key results. Retrospectively, including information about the app-based intervention either being utilised as a standalone intervention or within a blended approach with clinician input would have been valuable data to include in the charting process. The data charting is detailed below in Table 2.

*Table 2. Characteristics and charting of the 12 included studies.*

| Study | Title | Country | Population | Intervention | Stage | Design | Comparison | Main results |
|---|---|---|---|---|---|---|---|---|
| Nitsch et al. (2016) | A Guided Online and Mobile Self-Help Program for Individuals With Eating Disorders: An Iterative Engagement and Usability Study | USA | 9 women aged 18-25 meeting most of the criteria for an ED. | Student Bodies-Eating Disorders: guided self-help app. 40 10-minute sessions including self-monitoring, psychoeducation, and CBT techniques. | Prevention /Early Intervention | Mixed-methods iterative usability study | None | Participants found the CBT component of the app useful. Engagement fluctuated based on symptom severity. Good usability. |
| Juarascio et al. (2021) | A Clinician-Controlled Just-in-time Adaptive Intervention System (CBT+) Designed to Promote Acquisition and Utilization of Cognitive Behavioural Therapy Skills in Bulimia Nervosa: Development and Preliminary Evaluation Study | USA | 5 (4 F and 1 M) aged 25-42 who met the primary diagnosis of bulimia. | CBT+: self-monitoring, goal-setting, and algorithm-generated CBT skills. | Treatment | Feasibility and acceptability pilot. Pre-RCT. | None | Patients and clinicians found the app useful for keeping track of goals. App was low-burden and maintained engagement. |
| Merwin et al. (2021) | An open trial of app-assisted acceptance and commitment therapy (iACT) for eating disorders in type 1 diabetes | USA | 21 women 17+ who met full diagnostic criteria for an ED. | Modified version of RecoveryRecord to include ACT exercises/coping skills and diabetes-specific feelings and behaviours. | Treatment | Feasibility and acceptability pilot. Pre-RCT. | None | Participants found the app useful. Large effects found for change in ED symptoms, diabetes self-management and diabetes distress. |
| Cerea et al. (2021) | Cognitive Behavioral Training Using a Mobile Application Reduces Body Image-Related Symptoms in | Italy | 55 female university students aged 20-25 with high body dissatisfaction and ED symptom scores. | GGBI: Based on CBT principles; uses training exercises aimed at helping individuals address maladaptive beliefs; focused | Prevention /Early Intervention | RCT with crossover design. | Delayed app-use control group | Moderate reductions in some forms of body dissatisfaction and BDD symptoms , and fewer negative thoughts in intervention |

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| | High-Risk Female University Students: A Randomized Controlled Study | | | primarily on body dissatisfaction. | | | | group. Medium effect size. |
| Tregarthen, Lock, and Darcy (2015) | Development of a Smartphone Application for Eating Disorder Self-Monitoring | USA | 108,996 users, 87.2% F / 12.8% M. Mean age was 22 (range 13-77); 67% under 25. | RecoveryRecord prototype. CBT-style self-monitoring; positive reinforcement; social support; summative feedback. | Treatment | Iterative acceptability study | None | Almost all users rated the app 4 or 5 stars. 67% used the app for more than 30 days. 46% used as a standalone intervention and 39% used alongside therapy**.** |
| Keshen et al. (2020) | Efficacy and acceptability of self-monitoring via a smartphone application versus traditional paper records in an intensive outpatient eating disorder treatment setting | Canada | 90 adults 17+ with an ED diagnosis. | RecoveryRecord | Treatment | RCT | Standard treatment (group-based and individual therapy) | No statistically significant differences between use of RecoveryRecord self-monitoring and tools and paper monitoring. |
| Linardon et al. (2020) | Efficacy of a transdiagnostic cognitive behavioral intervention for eating disorder psychopathology delivered through a smartphone app: a randomized controlled trial | Australia | 392 adults with symptoms of bulimia or binge eating. Mostly white women. | Break Binge Eating app: based on Fairburn's Transdiagnostic CBT-E model. | Treatment | RCT | Waitlist control | Statistically significant difference in EDE-Q scores with a large effect size. Changes sustained at follow-up. |

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| Neumayr et al. (2019) | Improving aftercare with technology for anorexia nervosa after intensive inpatient treatment: A pilot randomized controlled trial with a therapist-guided smartphone app | Germany | 40 women diagnosed with anorexia aged 15-36. | RecoveryRecord: with additional selected coping strategies and aftercare for recovery maintenance | Recovery Mainten-ance | RCT | Post-discharge treatment as usual | High level of adherence and acceptance of the app. Nonsignificant moderate effect for ED symptoms and small effect for BMI. |
| Lindgreen, Lomborg, & Clausen (2021) | Patient use of a self-monitoring app during eating disorder treatment: Naturalistic longitudinal cohort study | Denmark | 84 patients—41 with anorexia and 43 with bulimia. | RecoveryRecord | Treatment | Naturalistic longitudinal cohort study | None | Previous ED treatment significantly associated with decrease in active logging weeks. Time was the most significant predicting factor for app use, likely due to symptom changes. |
| Hildebrandt et al. (2020) | Randomized Controlled Trial Comparing Health Coach-Delivered Smartphone-Guided Self-Help With Standard Care for Adults With Binge Eating | USA | 114 adult patients with BMI between 18.5-40, meeting criteria for binge eating disorder or bulimia nervosa | Noom Monitor: CBT guided self-help. Customized self-monitoring for exercise, meals, compensatory behaviour, body checking, craving, and weight. | Treatment | RCT | Standard treatment | Significant reductions in objective binge eating days; higher rates of remission; reduced compensatory behaviours, eating disorder symptoms, and clinical impairment. |
| Naccache et al. (2021) | Smartphone application for adolescents with anorexia nervosa: an initial acceptability and user experience evaluation | France | 8 female inpatients meeting AN criteria, aged 12 – 18 | App prototype: unguided self-help program using CBT psychoeducation and motivational interviewing strategies. | Treatment | Acceptability evaluation | None | Patients found psychoeducation and motivational content to be of most value. Some issues were raised with aesthetics, gamification, and efficiency. |

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|---|---|---|---|---|---|---|---|---|
| Linardon et al. (2021) | Targeting dietary restraint to reduce binge eating: a randomised controlled trial of a blended internet- and smartphone app-based intervention | Australia | 403 adults with binge eating symptomology. Mostly white females. | 'Breaking the Diet Cycle': app based on CBT-E, focused on targeting dietary restraint. Digital diary with progress monitoring and graphing. | Treatment | RCT | Passive psycho-education | Objective binge-eating frequency reduction was statistically significant with a small effect size. Users found the app to be useful. |

## Results—Study Characteristics

### *Country*

The majority (five, 42%) of the studies were conducted in the United States: Nitsch et al. (2016); Juarascio et al. (2021); Merwin et al. (2021); Hildebrandt et al. (2020); and Tregarthen, Lock, and Darcy (2015) (users were global, but the majority were in North America, and the research was conducted in the US). Four (33%) of the studies were conducted in Europe: Cerea et al. (2021) (Italy); Neumayr et al. (2019) (Germany); Lindgreen, Lomborg, and Clausen (2021) (Denmark); and Naccache et al. (2021) (France). Two studies (16%) (Linardon et al., 2020 and 2021) were conducted in Australia. One study (8%) (Keshen et al., 2020) was conducted in Canada. Not all studies reported on the ethnicity of participants, but studies that did report this reported the majority of participants were white. This is also likely due to all studies being conducted in countries with a predominantly Caucasian population.

### *Sample*

#### *Diagnosis/Symptomology*

Seven (58.3%) of the studies (Juarascio et al., 2021; Merwin et al., 2021; Keshen et al., 2020; Neumayr et al., 2019; Lindgreen, Lomborg, and Clausen, 2021; Hildebrandt et al., 2020; and Naccache et al., 2021) required participants to meet DSM-5 criteria for an ED, while five (41.6%) of the studies (Nitsch et al., 2016; Cerea et al., 2021; Tregarthen, Lock, and Darcy, 2015; Linardon et al., 2020; Linardon et al., 2021) used participants expressing symptoms of an ED, but whom may have been sub-clinical threshold.

Five (41.6%) of the studies (Nitsch et al., 2016; Merwin et al., 2021; Cerea et al., 2021; Tregarthen, Lock, and Darcy, 2015; and Keshen et al., 2020) used a transdiagnostic population, with participants meeting diagnostic criteria or expressing symptomology of any ED. Three (25%) studies (Juarascio et al., 2021; Linardon et al., 2020; and Lindgreen, Lomborg, and Clausen, 2021) used participants meeting criteria or expressing symptomology of bulimia nervosa; three others (25%) (Linardon et al., 2020; Linardon et al., 2021; and Hildebrandt et al., 2020) involved participants experiencing binge eating disorder. Lastly, three (25%) studies (Neumayr et al., 2019; Lindgreen, Lomborg, and Clausen, 2021; and Naccache et al., 2021) focused on participants meeting criteria or expressing symptomology of anorexia nervosa.

#### Gender

Study populations tended to comprise mostly of women, whether the sample was chosen to be limited to women or not. Five (42%) of the studies recruited only women (Nitsch et al., 2016; Cerea et al., 2021; Neumayr et al., 2019; Merwin et al., 2021; and Naccache et al., 2021). The other seven studies (58%) (Juarascio et al., 2021; Keshen et al., 2020; Linardon et al., 2020; Linardon et al., 2021; Lindgreen, Lomborg, and Clausen, 202; and Hildebrandt et al., 2020) included participants who were both men and women (it is important to note that no data was reported on transgender, nonbinary, or intersex participants) but all of these studies reported their sample being predominantly (75% and above) women.

#### Age

The participant average age range across most studies was between late teens to mid-thirties. Tregarthen, Lock, and Darcy (2015) had the largest age range (13-77); but the mean reported age of users was 22, and 67% were under age 25. Hildebrandt et al.'s (2020) study had the oldest sample, with a mean participant age of 41.19. Naccache et al. (2021) had the youngest sample, with a mean age of 15.5 years (their intervention was specifically developed for adolescents).

### Type of Intervention – contents and underpinning principles

All of the studies' app-based intervention was directly adapted from, based on, or heavily included the use of CBT principles. Five (41.6%) of the studies (Merwin et al., 2017; Tregarthen, Lock, and Darcy, 2015; Keshen et al., 2020; Neumayk et al., 2019; and Lindgreen, Lomborg, and Clausen, 2021) used RecoveryRecord or a modified version of RecoveryRecord.

#### RecoveryRecord

Tregarthen, Lock, and Darcy developed the RecoveryRecord app in 2015. The app aimed to focus on the aspects of CBT treatment for EDs that require behavioural activation and assimilation into everyday life—namely, real-time self-monitoring of meals and the circumstances surrounding them (e.g., place, company, mood, thoughts, and compensatory behaviours). The goal was to help clients and therapists develop an evidence base of eating habits and ED behaviours and help clients become more aware of what were previously automatic behaviours. The app enabled self-monitoring to be more discrete, timelier, and less of a burden for clients. The app also features a just-in-time coping skill intervention from a library of 42 skills drawing from CBT, mindfulness, and interpersonal therapy, as well as summative feedback, presenting graphs related to disordered behaviour frequency.

Keshen et al. (2020) ran a pilot RCT with half of the participants using traditional paper-based monitoring booklets, while the other half of participants instead used RecoveryRecord for self-monitoring, all alongside standard outpatient ED treatment. Non-app participants received weekly written feedback from their psychologist and dietitian whilst app participants received feedback via comments in-app. Lindgreen, Lomborg, and Clausen (2020) evaluated patients' use of RecoveryRecord in a naturalistic setting over the course of 26 weeks. The app was used in its original form.

### *Modified RecoveryRecord*

Neumayr et al.'s (2019) intervention used RecoveryRecord as an aftercare tool post-treatment for recovery maintenance. All of the RecoveryRecord content was retained; however, a few features were added including selected coping strategies and clinical goals for each of the eight weeks of the intervention. These strategies and goals were partly selected from pre-existing content on RecoveryRecord and partly developed by the authors. Participants also received in-app feedback twice a week for the first four weeks and once a week for the last four weeks.

Merwin et al.'s (2021) intervention, iACT, was targeted towards individuals with EDs and type 1 diabetes. The intervention was based on principles of Acceptance and Commitment Therapy (ACT) using a modified version of RecoveryRecord. Standard RecoveryRecord features (self-monitoring thoughts, feelings, and behaviours) as well as coping skills and goal-setting were retained; ACT-specific coping skills, affirmation messages, and a value feature to encourage skill use were added. Due to the population, skills and messages focused on symptom management of both the ED and type 1 diabetes. The app was utilised for 12 weeks alongside weekly therapy sessions.

*CBT-Based interventions*

Linardon et al.'s (2020) 'Break Binge Eating' app was an evidence-informed, CBT-based, and transdiagnostic intervention adapted from Fairburn's CBT-E (2008). The app contained four modules, lasting 30-90 minutes each, and including audio recordings and text-based reading materials. Module one delivered psychoeducation while modules two, three, and four targeted core ED symptoms through normalising eating habits, reducing the overevaluation of control over weight and shape, and increasing emotional regulation skills. The app included a self-monitoring diary as well as auto-generated feedback on binge behaviours. Break Binge Eating was self-guided and delivered daily over eight weeks.

Linardon et al.'s (2021) 'Breaking the Diet Cycle' app was largely identical to 'Break Binge Eating', with the focus being on restrictive, rather than binge, eating behaviours as the target. The module format was the same, with the content slightly different (45-60 minutes, delivered via video tutorials, written text, and infographics) and the final session focusing on behavioural exposure to feared foods rather than emotional regulation as in 'Break Binge Eating'. The app intervention was delivered over 16 rather than 8 weeks.

Juarascio et al.'s (2021) intervention, CBT+, was an app designed to augment ongoing therapeutic treatment and included both a patient and clinician portal. The app focused on helping patients increase their acquisition and utilisation of the six key CBT skills that were taught in therapy. Key app components included self-monitoring of food, mood, and behaviours, as well as collaborative goal-setting and monitoring. The app also utilised an algorithm to auto-generate prompts for skill development suggestions at each of the participants' logs, and allowed participants a feedback option if they chose not to work on the offered skill. The app also included a repository of all the skills learned so far in-app and in therapy for the participant to access at any time.

Cerea et al.'s (2021) intervention, GGBI: Positive Body Image, a cognitive training app, focused on challenging maladaptive beliefs related to body image dissatisfaction. The authors stated the app followed CBT principles and included psychoeducation as well as addressing negative automatic thoughts and core beliefs and shifting these to become more adaptive. The app took the participants through 48 'levels' with 3 levels per belief, including levels on the importance of physical appearance and perfectionism. Dysfunctional and adaptive statements were presented on-screen, with the prompt for users to either reject or embrace these statements by swiping away from them or towards them. After each level, participants were given feedback on the time it took them to complete the level, as well as a 'Memory Boost' game to test users on how well they retained the information they had been presented and encourage attention and engagement.

Hildebrandt et al. (2020)'s intervention, CBT-GSH (Guided Self Help) plus Noom Monitor, followed the typical CBT-E steps, delivered via phone-based coaching sessions. These steps are: establishing self-monitoring and regular eating, offering alternatives and coping strategies for binge or purge behaviours, problem solving activities, reducing dietary restraint and the importance placed on shape and weight, and relapse prevention. The app-based element was Noom Monitor, a self-monitoring app which allowed participants to track exercise, meals and snacks, compensatory behaviours, body checking, cravings, and weight. Coaches could view summaries of participants' data on the app and discussed this with participants during sessions.

### *CBT & Motivational Interviewing*

Nitsch et al.'s (2016) intervention, SB-ED (Student Bodies – Eating Disorder), took the form of a guided online and mobile self-help programme. The intervention began with a web-based assessment where participants' answers sorted them into rough diagnostic categories and placed them on tailored intervention tracks. The app included forty sessions, taking around ten minutes each, over the course of eight weeks. The sessions were based on CBT and Motivational Interviewing concepts, and included daily self-monitoring of eating habits and compensatory behaviours, psychoeducation, and audio-guided and interactive tools and activities. The app also included one-on-one coaching with a clinician through a messaging service.

Naccache et al.'s (2021) (unnamed) app took the form of an unguided self-help programme using psychoeducation, CBT, and Motivational Interviewing elements. The app focused on emotional dysregulation as a key maintaining factor in anorexia. This app also included some elements targeted to its adolescent audience, including gamification (e.g., feedback on progress and trophies given for app usage) and a customizable 'companion' taking the form of an animal mascot. The companion generated automatic suggestions of text-delivered coping skills.

### *Blended Treatment Approach*

Half of the included studies implemented a blended approach in the evaluation of app-based interventions for EDs, with the digital intervention incorporated into psychotherapy as usual or, vice versa, with therapist input and guidance incorporated into the app or delivered as a supplement to the app. Table 3 below gives an overview of how blended treatment was delivered across the various studies included in the review:

Table 3. Summary of blended treatment approaches

| Study | App | Alongside (blended with) | Within/Between Group Differences |
|---|---|---|---|
| Keshen et al. (2020) | RecoveryRecord | Standard psychotherapy | Between (RCT) |
| Neumayr et al. (2019) | Modified RecoveryRecord | In-app feedback from clinician | Between (RCT) |
| Merwin et al. (2021) | Modified RecoveryRecord | Standard psychotherapy | Within (Feasibility and acceptability pilot) |
| Juarascio et al. (2021) | CBT+ | Standard psychotherapy | Within (Feasibility and acceptability pilot) |
| Hildebrandt et al. (2020) | Noom Monitor | Phone-based coaching | Between (RCT) |
| Nitsch et al.’ (2016) | SB-ED | Message-based coaching | N/A (Usability Study) |

*App-Based Intervention Only*

The other half (six) of the studies evaluated an app-based intervention on its own without clinician input; in these non-blended studies, participants used these apps without input via the app, phone calls, video calls, or in-person contact with a mental health professional. Non-blended approach studies included Tregarthen, Lock, and Darcy (2015) (RecoveryRecord, naturalistic); Lindgreen, Lomborg, and Clausen (2020) (RecoveryRecord, naturalistic); Linardon et al. (2020) (‘Break Binge Eating’, between-group); Linardon et al. (2021) (‘Breaking the Diet Cycle’, between-group); Cerea et al. (2021) (GGBI, between-group/crossover); and Naccache et al.’ (2021) (unnamed app, usability study).

### ***Treatment Stage***

Nine (75%) of the studies' interventions were intended for the treatment stage. Two studies' (16.6%) interventions (Nitsch et al., 2016 and Cerea et al., 2021) focused on early intervention/prevention and one study's (8%) intervention (Neumayk et al., 2019) was intended for recovery maintenance/'aftercare'.

### ***Design***

#### *Randomised Controlled Studies*

Six (50%) of the studies (Cerea et al., 2021; Keshen et al., 2020; Linardon et al., 2020; Neumayr et al., 2019; Hildenbrandt et al., 2020; and Linardon et al., 2021) were Randomised Controlled Trials (RCTs) that compared an intervention group using the app with a control group exposed to different 'control conditions.' Among these, only Cerea et al.'s (2021) RCT included a crossover design (the control group participants gained delayed access to the app intervention).

#### *Pilot Acceptability & Feasibility Studies*

Both Juarascio et al.'s (2021) and Merwin et al.'s (2021) studies were pilot trials to assess app feasibility and acceptability and were planned to preface a randomized controlled trial for the app.

#### *Other Designs*

Nitsch et al.'s (2016) study design was a mixed-methods iterative usability study using both thematic analysis and descriptive statistics. Similarly, Naccache et al. (2021) conducted an acceptability evaluation also reporting results via themes and descriptive statistics. Tregarthen, Lock, and Darcy (2015) conducted an iterative acceptability study by evaluating data gathered from the RecoveryRecord app in a naturalistic setting (using usage statistics and consumer ratings) and reporting descriptive statistics. Lindgreen, Lomborg, and Clausen (2021) conducted a naturalistic longitudinal cohort study, by assessing participants' use of the RecoveryRecord app over 26 weeks during ED treatment.

### ***Outcomes***

#### *ED Symptomology*

Most of the studies that reported ED symptom-related outcomes assessed symptom change using Eating Disorder Examination (EDE). Juarascio et al.'s (2021) participants saw clinically significant reductions in ED symptoms, and binge and purge incidences notably decreased. EDE scores decreased with a large effect size, but this was statistically nonsignificant. ED symptoms posttreatment were reported as within one standard deviation of community norms. Merwin et al.'s (2021) participants also saw a clinically significant reduction in ED symptoms, with a large effect size, as assessed by the EDE.

Linardon et al. (2020) found a significant reduction of ED psychopathology, ED symptoms, impairment, and distress, as assessed by the EDE, between intervention and control groups. These effects were also maintained at follow-up. Linardon et al. (2021) found that the difference of binge-eating frequency (as reported on EDE scores) between intervention and control groups was statistically significant with a small effect size, with eating concerns and psychological distress further decreasing at follow-up. Neumayr et al. (2019) found a nonsignificant small to moderate effect size favouring the intervention group for both BMI and ED symptoms (assessed via EDE scores). At follow-up, between-group differences remained nonsignificant. Hildebrandt et al. (2020) reported significant reductions in binge-eating and compensatory behaviours in the intervention group as assessed by the EDE and Clinical Impairment Assessment (CIA). The intervention group also achieved a higher remission rate through follow-up.

In Keshen et al. (2020)'s study, no significant between-group differences were found in ED symptoms as assessed using the EDE. Keshen et al.'s (2020) study is the only study of the twelve included in this review that found no benefit from using an app-based intervention. Cerea et al. (2021) found a medium effect size for the app group's reduction in body dissatisfaction symptoms, but no significant effects regarding ED symptoms. Lindgreen, Lomborg, and Clausen (2021) utilised the EDE, but due to low response rates, omitted the data gathered on ED symptomatic change, due to lack of statistical power.

### *<u>Usability & Acceptability</u>*

Nitsch et al. (2016) found that that their participants were largely satisfied with their app's usability, with the average score of usability reported as 83.1/100, and 7.9/10 participants said they would recommend the app. Regarding qualitative data, participants stated that they liked the app's CBT components, especially the focus on psychoeducation and self-awareness. Participants felt that the app was not appropriate for 'serious' EDs but was a 'good start' for those without an official diagnosis or severe symptoms. Looking at engagement and burden, participants felt that ten minutes a day was too time consuming and that there was too much text for a mobile app. Participants were also critical of the phrasing of standardised assessments, which was deemed to be written in language that was not accessible.

Juarascio et al.'s (2021) participants rated their app 5/6 on a Likert scale. Participants used the app for 86.1% of the days, with a slow decrease over time in use and a dropout rate of 40%. Participants found daily self-monitoring recording to be burdensome, but the accountability offered by this to be valuable.

Merwin et al. (2021) found that the app was acceptable to type 1 diabetes patients with ED symptoms and feasible to implement. Participants reported increased psychological flexibility and greater progress in pursuing personal values. The app also had a positive impact on diabetes management and reducing diabetes-related distress.

Tregarthen, Lock, and Darcy (2015) reported 2,503 ratings of RecoveryRecord, 84% of which were 5/5 stars, 13.3% 4/5 stars, 1.7% 3/5 stars, and 1% 2/5 stars. 108,996 people used the app and 67% used RecoveryRecord for at least one month. Overall, results indicated that the RecoveryRecord users found it to be both feasible and acceptable.

Keshen et al. (2020) also evaluated app acceptability and found that RecoveryRecord was not significantly more acceptable than traditional paper-based monitoring. However, participants reported a positive experience of the app and 76% stated they would recommend RecoveryRecord.

Lindgreen, Lomborg, and Clausen (2021) found no significant association between ED diagnosis and app use activity levels. Higher participant age was associated with greater app use while previous ED treatment was associated with less time of app use. App use peaked within the first four weeks of use with a gradual decrease in use culminating in the highest dropout at week thirteen. Long-term use of RecoveryRecord was not found to be feasible or acceptable due to engagement issues.

92% of Linardon et al.'s (2020) participants stated they would recommend their app to others. The daily food diary was rated as the most helpful app component. Similarly, 90% of Linardon et al.'s (2021) participants stated they would recommend the app and, 66% were satisfied with the intervention. Video tutorials were rated as the most engaging app component. However, attrition rates for both studies were high over time.

Neumayr et al.'s (2019) app users rated the usability and design of their app as 'good'. 29.4% found the app 'very helpful', 52.9% 'helpful', and 17.6% 'moderately helpful'. The majority of the participants stated that the app was a little time consuming. 43.8% of participants felt that the app was a positive addition to their experience of outpatient therapy, but only 35.3% stated they would use the app without regular input from a therapist.

Participants using Naccache et al.'s (2021) app-based intervention rated the app as attractive and effective. The psychoeducation feature was deemed most valuable, and participants found the gamification of the app to be acceptable, though some issues with aesthetics were noted.

## Discussion

Twelve studies met the inclusion and exclusion criteria for this review. In all of them, the majority of the participants were young white women. All 12 studies used apps based on the principles of Cognitive Behaviour Therapy (CBT). RecoveryRecord, or adaptations of it, was the most commonly used app intervention. In usability studies, app-based interventions were, on the whole, found to be acceptable by participants. Studies that reported outcomes on ED symptomology found that the app-based interventions reduced symptomology, but effect sizes and significance varied largely.

Since the present scoping review was conducted, in the summer/autumn of 2021, new research has emerged on the topic of apps for EDs, which may enable the possibility of a future systematic review to be conducted on the topic of apps used in prevention, treatment, and aftercare for people with EDs. So far, findings, however, remain limited.

In February 2022, O'Leary and Torous (2022) published 'Smartphone apps for eating disorders: An overview of the marketplace and research trends', synthesising the data on apps intended to assist with the management of EDs. Findings were not dissimilar to this scoping review—the authors found only 13 articles deemed suitable to analyse, which revealed that only four different apps were used for individuals with EDs. Graham and Fitzsimmons-Craft later published a commentary on O'Leary and Torous's overview, stating: "The lack of publicly available evidence-based apps is problematic for society and reflects a gap in the research-to-practice translation of the advances that have been made through academic research in this area… the effective translation of eating disorder apps, and other digital approaches, from research to practice will require new approaches," an argument echoed in the present scoping review (which also ties into Normalisation Process Theory—see Methods Paper).

Later, in November 2022, Dofour and colleagues conducted a scoping review on technology use in ED treatment in young people (it is important to note that this review looked at any technology, e.g., online self-help, videoconference therapy, as well as apps). Qualitative studies included in the review overall found that young people with EDs deemed virtual interventions acceptable, while quantitative studies overall found that virtual interventions reduced ED symptomology with medium-to-large effect sizes. The authors note that there was too limited a number of studies included in the review to draw any firm conclusions about the use of technology in general for the treatment of EDs in young people, but that preliminary findings were promising.

Around a similar time in October 2022, Jarman and colleagues published guidance around developing mHealth and web-based ED interventions with an emphasis on including lived-experience (e.g., PPI) as well as 'design thinking approaches' (e.g., implementation science). The authors' key findings point to the importance of identifying what symptoms to target, and recovery practices to implement, which will be pertinent to the app user.

Though research and subsequent reviews are emerging in the field of apps for EDs at an ever-increasing pace, further research is needed to determine the effectiveness and usability of app-based interventions for people with eating disorders. The evaluation of the clinical utility of ED apps also needs to be pursued via more rigorous, globally standardised methods. Additionally, patient and public involvement should be consistently implemented for integration of patient views and needs in digital products.

### ***Limitations of Evidence***

Regarding participant demographics, no studies used a population of only men or reported including nonbinary or transgender participants. Although EDs are more common in women (Galmiche et al., 2019), it is essential for interventions to be developed to be acceptable and relevant for all genders. The lack of involvement of transgender and nonbinary individuals in ED research overall is a social justice issue that must be recognised and addressed. The age range of participants also skewed young. EDs can affect individuals of any age and including perspectives from older people is essential to ensure app-based interventions are accessible and acceptable to middle- and older-aged individuals. All included studies were conducted in 'Western' cultures (e.g., North America, Australia, and Western Europe). Due to all of the app-based interventions included in this scoping review being produced within, and marketed towards, white western cultures/individuals, these interventions and subsequent findings about their acceptability, feasibility, and effectiveness may not be generalisable or transferrable to non-white and/or-non-western individuals or cultures. To assume generalisability or transferability would be reductive and not take into consideration the powerful interplay between eating disorders, culture, and social norms—for example, how would a user interface with RecoveryRecord's daily food diary format of three meals and three snacks, if the cultural norm for their social world was two large communal meals daily? Acle and colleagues' (2021) systematic review of cultural considerations in the treatment of EDs points to key themes including the importance of considering individual and societal cultural contexts, acculturation and related stress, implementing culturally sensitive interventions, and addressing barriers to treatment, to name a few. How these cultural competency recommendations would apply to app-based interventions for EDs is yet to be studied or reviewed which presents a large gap in the literature. Studies about EDs and app-based interventions, both separately and together, in the South and Central Americas, Eastern Europe, the Middle East, Asia, Africa, and Oceania, are needed; research in these continents and countries tends to be rare in the field. However, research conducted and published in these countries may also be missed and excluded from reviews due to these studies not being published in or translated to English.

Much like the population of participants, the app-delivered interventions themselves were largely homogenous as well, with a self-monitoring diary for food and mood the key (sometimes only) component in each app and a heavy overall focus on CBT principles. Though self-monitoring may be effective and appropriate in early intervention and treatment conditions, the burden it is associated with may mean it is not as valuable an element in recovery maintenance, but only one study to date was found addressing this treatment stage.

In regard to the evaluation of the apps themselves, no standardised measures yet exist, which means evaluating these interventions accurately and reliably is difficult. Most of the studies that reported statistic-based outcomes on ED symptoms found clinical significance in symptom reduction, but statistical significance was sometimes lacking. Studies that assessed acceptability and feasibility found that participants, on the whole, found the various app-based interventions to be valuable, engaging, and helpful. However, attrition rates were high, and a high dropout of app use after one month occurred in multiple studies, indicating issues with maintaining engagement.

### ***Strengths of Review***

To the author's knowledge, this is the first review to look at the existing literature on apps and EDs. This scoping review paints a multifaceted picture of the existing evidence in the field, taking a broad approach in assessing the literature and including studies of various designs, countries of origin, and outcome/results reporting. This review also identifies some key issues in the existing literature, including homogenous population demographics and interventions, and comprehensively summarises the features of the existing app-based interventions for EDs. This review draws together the fragments of what is known so far in the field into a coherent synthesis.

### ***Limitations of Review***

A limited number of studies have been conducted on apps and EDs, which meant that this scoping review was limited in its ability to review a broader range of literature. As stated above, reviews that are conducted only in the English language risk missing valuable publications from non-Western or English-speaking countries. The use of grey literature and manual searching was not performed due to time constraints but may have produced more literature for the review.

### ***Implications for Future Research***

Implications only for future research are discussed, due to the fact that implications for practice and policy may be far-fetched at this stage due to the scarcity and heterogeneity of relevant studies, and the need to develop a strong base of evidence in the area topic. With a growing number of studies focusing on app-delivered interventions for EDs, a systematic literature review and meta-analysis of published RCTs may be an appropriate direction to pursue, drawing from the key findings of the current work. Moreover, more qualitative studies are needed to capture app users' experiences and feedback on their engagement with app-based interventions. This may help both researchers and clinicians to better assess and improve app-based interventions and develop more products for the early intervention and recovery maintenance treatment stages.

This review excluded studies assessing clinician perspectives of apps for EDs, which is an equally important domain to assess and synthesise. A scoping review of the literature surrounding clinician experiences of apps for EDs may be useful to gather their perspective and to address issues (e.g., ensuring users' engagement) that may affect the effectiveness and usability of apps for EDs.

## Conclusion

This scoping review offers a synthesis of the available literature about how apps are being used in prevention, treatment, and recovery maintenance for individuals with eating disorders. Twelve studies from 2015-2021 were reviewed and data on studies' countries of origin, sample populations, app-based interventions, treatment stage, designs, comparison groups, and results were extracted into a data chart. The review found that most existing apps for EDs are targeted towards the treatment stage, with few addressing prevention or recovery maintenance; current use of app-based interventions is split fifty-fifty between stand-alone use or blended-use with clinician input; and most apps for EDs draw their content base from principles of CBT.

The findings point to the need to develop or modify more variation in app-based interventions to support people with EDs, given the lack of options available which may not be acceptable/generalisable to all individuals, cultures, and contexts. Further efforts are needed to improve the usability and feasibility of these digital interventions, including developing apps that are designed with and for individuals who are not white western women, or for contexts in which blended treatment is not accessible. Standardised approaches must also be developed to evaluate the effectiveness of these tools.

In conclusion, the results of this work suggest that in the near future, researchers, clinicians and PPI representatives should collaborate to the creation and systematic evaluation of apps to support ED recovery, so that they will gradually become part of routinely offered support in ED services.

## Additional Information

### *Registration and Protocol*

This review is not registered. The protocol for this review is displayed in Table 1.

### *Support*

There are no sponsors nor funding associated with this review.

### *Competing Interests*

There are no competing interests to report.

# Chapter 2:

## Developing a Smartphone App to Support Eating Disorder Recovery Maintenance Using Patient and Public Involvement

## *Methodology Paper*

**Emma Elizabeth Salazar**

### Background

Over 700,000 people have an eating disorder (ED) in the UK (NICE, 2019). All published estimates of the prevalence of EDs note that numbers are underestimated due to a large proportion of individuals with EDs not presenting to healthcare services (NICE, 2019). This is a difficult patient group to engage not only in treatment, but also research. High levels of dropout from therapy and attrition from research are a known issue in furthering developments in ED research and treatments (Hoste et al., 2007; Mahon, 2007). Reviews of current treatments for EDs concur that there is need for improvement in the outcomes of ED therapies (Smink, Hoeken and Hoek, 2013; Steinhausen and Weber, 2009). Despite being the most widely used intervention, Cognitive Behaviour Therapy (CBT), only produces significant improvement in approximately 50% of ED patients (Fairburn et al., 2009). Additionally, there is substantial evidence of high relapse rates, and an average of 20% of patients remain chronically ill (Noordenbos et al., 2002; Reay, 2022). Exploring how best to engage individuals with EDs in treatment and subsequently to achieve and maintain recovery is vital, in order to inform further research and clinical practice, as well as lessen the burden on sufferers and services.

In recent years, there has been an increased interest in the use of smartphone applications (apps) to support individuals in their recovery process from numerous physical and mental health problems. Health-related apps (sometimes referred to as mHealth, mobile health) can be used as a supplementary tool during treatment (Luxton et al., 2011) and can offer beneficial assistance in tracking progress, making homework assignments more convenient to complete, opening up more communication between patient and practitioner, and supporting relapse prevention by maintaining follow-up (Tregarthen, Lock and Darcy, 2015). Mobile apps are also discreet, offering an accessible avenue for higher engagement. This can potentially help overcome some of the significant shame and stigma associated with EDs, and related barriers to treatment-seeking and access to services (Doley et al., 2017).

Apps developed specifically for individuals with EDs are gaining traction as mHealth apps continue to gather interest (Juarascio et al., 2014; Fairburn and Rothwell, 2015). To date, two published reviews specific to apps for people with EDs have been conducted, by Juarascio et al. (2014) and Fairburn and Rothwell (2015). Both reviews found only two apps deemed by the authors to be of an acceptable quality: Recovery Record and Rise Up, both of which are CBT-based apps that act as companions during active treatment to aid clients in the early stages of ED recovery (Juarascio et al., 2014; Fairburn and Rothwell, 2015). The RecoveryRecord app is the only current ED app with a substantial evidence base (see Chapter One: 'Scoping Review of App-Based Interventions for Individuals with Eating Disorders'). It is used by over 10,000 clinicians and one million people living with eating disorders (Recovery Record Inc, n.d.) worldwide, and has been successfully incorporated into routine treatment for EDs in many services in the US and UK.

In order to develop a product that is used in routine clinical practice, app development and dissemination must take implementation science and Normalisation Process Theory into consideration (Murray et al., 2020; Keenan and Lionarons, 2018). Using theory in intervention design is considered 'best practice' (Gillison et al., 2019) and it follows that this applies to all interventions, including those of digital nature. In a 2014 review, Prestwich and colleagues found that theory, however, is yet to be regularly incorporated into intervention design due to various obstacles (e.g., attractiveness to professionals and service users, as discussed by Keenan and Lionarons, 2018). Gillison and colleagues argue that Self-Determination Theory (SDT) can ‘provide a framework for intervention development by setting out the necessary mechanisms that underpin changes in long term health behaviour’; this notion is also supported by Keenan and Lionarons (2018). Implementation science spans a wide range of theories and methods, and can be summarised as focused efforts to support the systematic adoption of research findings into routine clinical practice in order to promote more effective healthcare (Bauer et al., 2015). More succinctly, implementation science is concerned with taking research to the real-world. The Normalisation Process Theory (May et al., 2006; 2009) is a framework through which factors—such as contextual integration (Keenan, Rahman, and Hudson, 2021)—influencing the implementation potential of an intervention can be assessed (Murray et al., 2010).

There is implementation potential for apps to support ED treatment and recovery across the care spectrum, from prevention and early intervention, to guided self-help and treatment, to relapse prevention and maintenance support (Bauer, 2013). Though there are several digital interventions targeting various stages of the ED recovery process, very few have been evaluated with an appropriately vigorous methodology (Bauer, 2013), incorporate evidence-based principles, or have been developed in collaboration with individuals with EDs (e.g., Juarascio et al., 2015; Kim et al., 2018). Collaboration between researchers and the public has become a hallmark of meaningful, impactful research over the past few decades and is now an NHS research requirement (NHS HRA, 2022; Ocloo et al., 2021).

Patient and public involvement (PPI) is defined as “an activity that is done ‘with’ or ‘by’ patients or members of the public rather than ‘to’, ‘about’ or ‘for’ them,” (NHS HRA, 2022; Ocloo et al., 2021). The NHS Health Research Authority (2022) state: “People have the right to be involved in all health and social care research. Excellent public involvement is an essential part of health and social care research and has been shown to improve its quality and impact. People’s lived experiences should be a key driver for health and social care research.”

Although an emphasis has been placed on PPI in research in recent years, the question of how to best implement PPI is yet to be answered. Ocloo, Garfield, Franklin and Dawson, who conducted a 2021 overview of reviews exploring the theory, barriers and enablers for patient and public involvement across health, social care and patient safety, state that their review found theoretical challenges due to inconsistent conceptualisations and definitions of PPI, ultimately leading to a lack of theory in approaches. Ocloo and colleagues' review found that across the literature, there is no clear consensus on what constitutes PPI in research, and no guidance on any criteria that must be met for a researcher to use this newly popularised term. Critiques of current PPI in research include limited diversity in individuals involved, and the lack of genuine empowerment of said patients and public (Gibson et al., 2012) with both faults leading to tokenism—defeating the intended purpose of PPI altogether (Ocloo et al., 2021).

Regarding PPI in digital interventions and mHealth, Bjerkan et al. (2019) suggest multiple avenues of including the public in development and design, such as including the public in identifying needs as well as testing and evaluation of prototypes and finished products. In their guidelines for PPI implementation, Aguayo and colleagues (2020) recommend including PPI in the early stages and the entire duration of the research, and encourage methods be combined to encourage the generation of new ideas. Bjerkan et al. (2019) suggest taking a pragmatic approach to PPI in mHealth—which is, by its nature, reliant on the public's desire and ability to use currently available apps. Therefore, not only does PPI in mHealth research fulfil researchers' moral duties and policy requirements, but will likely significantly contribute to the success and impact of the digital product itself. Relevant theory must also be considered to frame and guide the process of incorporating the PPI input into app development.

High attrition from research studies, high levels of dropout from treatment, and high relapse rates after treatment suggest that the complex psychological, social, and physical health needs of patients with eating disorders are not being adequately met. This disparity between needs and service/intervention availability may best be critically considered through a theoretical needs-based framework. This approach has been applied in the fields of palliative care (Keenan, Rahman, and Hudson, 2021) and dementia care (de Poli et al., 2020), both fields which mirror the complex relationships between psychological, social, and physical health care as seen in eating disorders care. De Poli et al.'s (2020) need-based, multi-level, cross-sectional framework—blending candidacy and discrepancy theories—can be particularly relevant when considering the multitude of needs identified by patients with EDs yet various individual, service, and system-level barriers to access to appropriate support.

An acceptable app-based intervention to support individuals in ED recovery should be grounded in theories of acceptance of technology and behaviour change, developed with a needs-based framework and the principles of co-production and PPI. Thus, all of these foundational elements were incorporated with intention and will be detailed in this methods paper, pertaining to the development of this novel mobile app designed to support ED recovery maintenance.

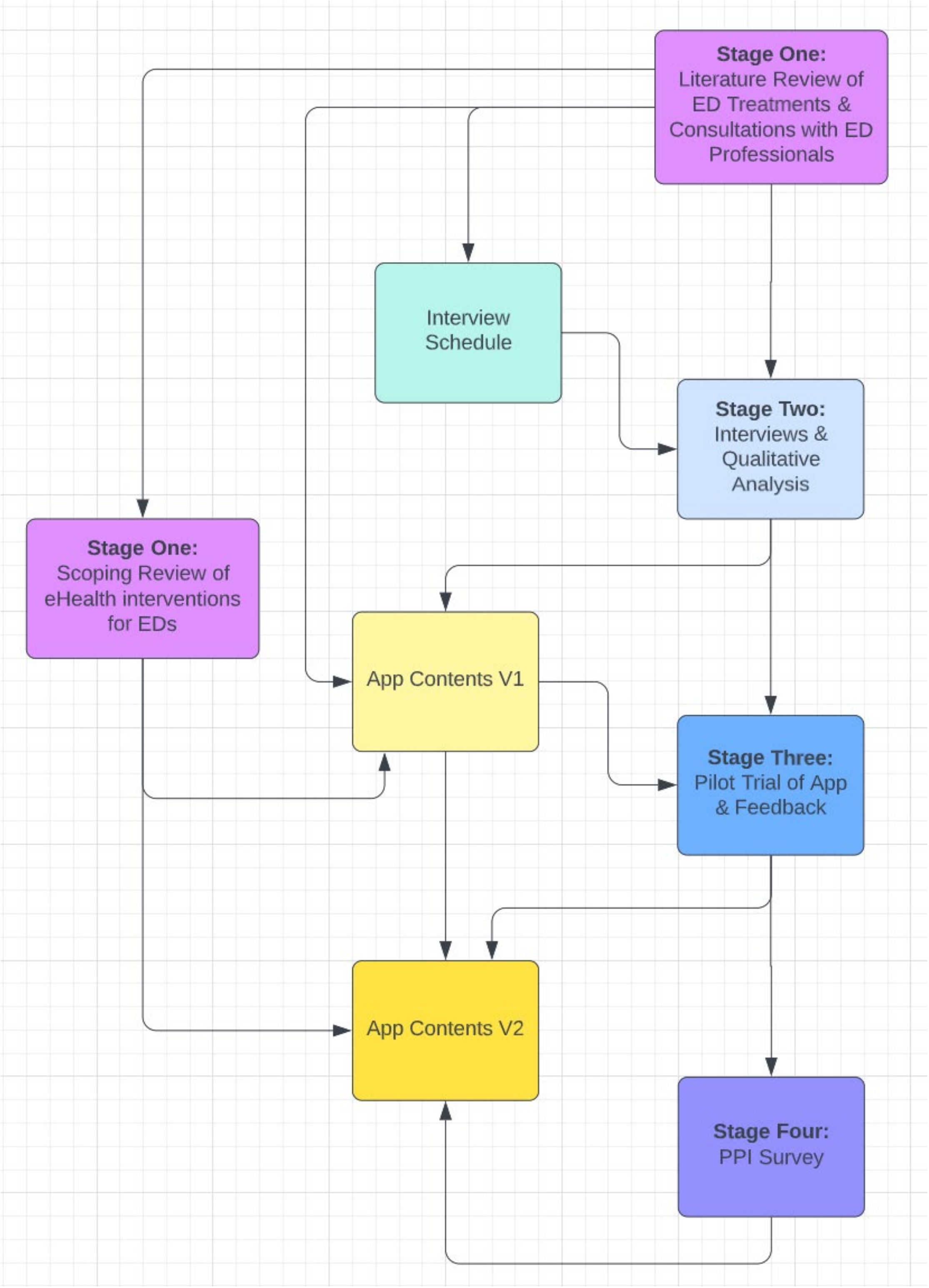
## Aim

This methodology paper aims to describe how co-production was implemented throughout the development process of RecoveRiver, an app for people in recovery from eating disorders grounded in theory and grown from the evidence base.

## Methods of Product Development and Theoretical Underpinnings

A cornerstone of the app development process was PPI, which is not yet widely employed in the development or appraisal of ED treatments (Newton, 2001). A recent systematic review evaluating ED interventions which involved people with lived experience (Lewis and Foye, 2021) found only ten studies which met inclusion criteria. Emphasis was placed on co-production of the RecoveRiver app between individuals in ED recovery and the researcher from the inception of the project, through all stages of development. There was a multi-layered, iterative approach to the creation of the app, as shown in Figure 1 below.

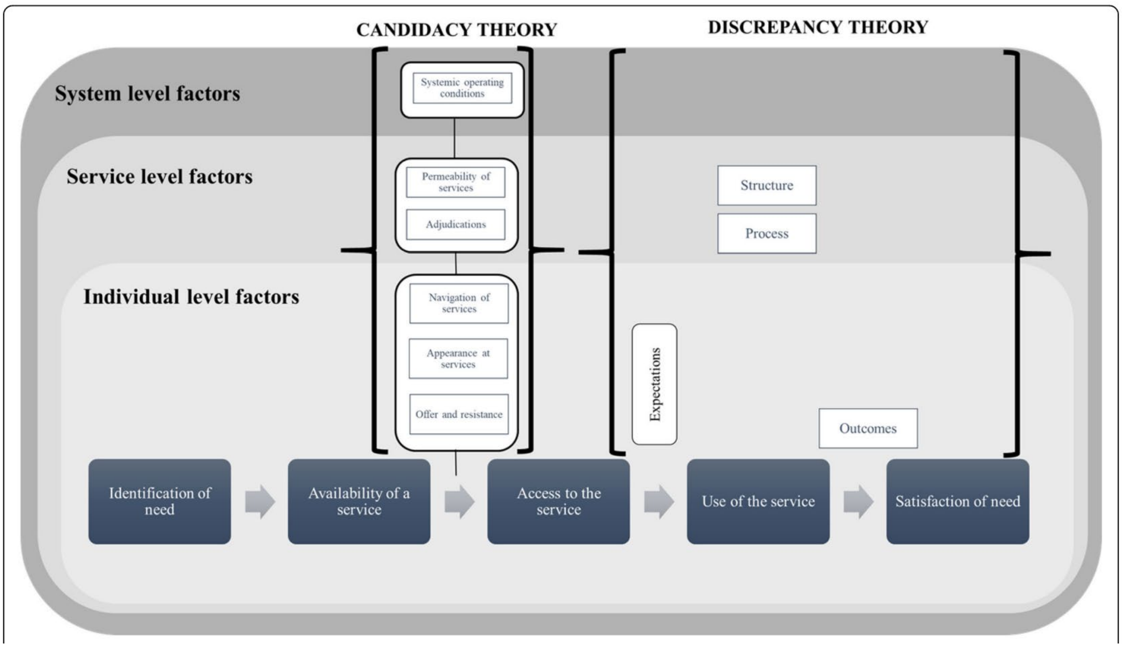
*Figure 1. App development process flowchart*



Multiple theoretical underpinnings informed the co-production process in relation to the feasibility, acceptability, and uptake of the RecoveRiver app. A theoretical needs-based framework was adopted to understand and apply the feedback and suggestions gathered from PPI to the app contents and design. De Poli et al.'s (2020) framework is structured around the care delivery process which comprises five stages:

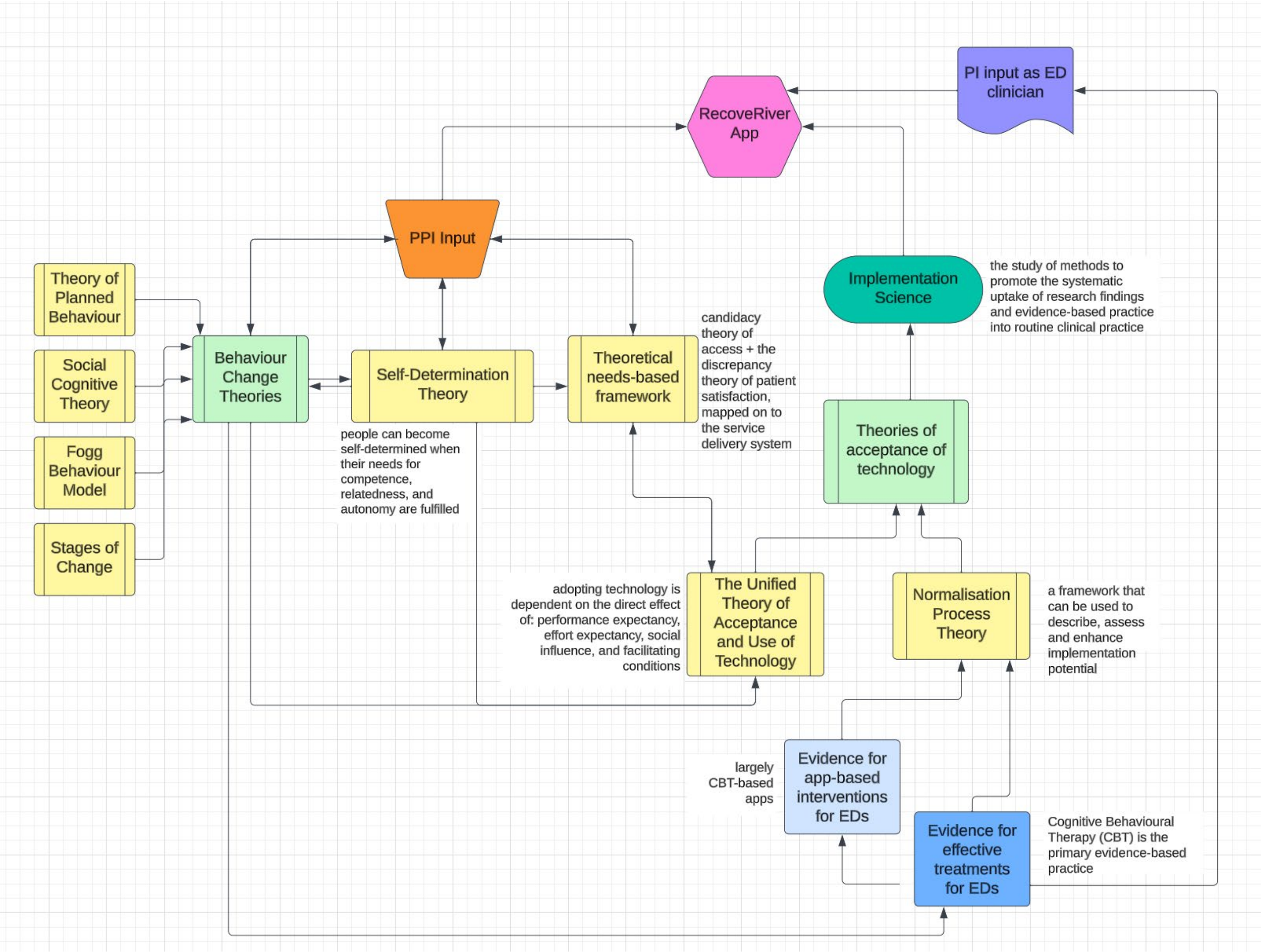
1. Identification of a need
2. Availability of a service which could satisfy the identified need
3. Access to the identified service
4. Utilisation of the accessed service
5. Satisfaction of the need identified

The framework further considers individual, service, and system factors which impact processes of seeking, accessing, and using care. The framework integrates both candidacy theory (pertaining to patients' conceptualisations of their eligibility for a service as socially constructed) and discrepancy theory (understanding satisfaction with a service through the difference between expectation and experience) with an emphasis on addressing the gap between service availability and access (candidacy) and service use and satisfaction (discrepancy).



A thorough engagement with the evidence base on the effectiveness of app-based interventions for EDs was then viewed through the lenses of the Unified Theory of Acceptance and Use of Technology (Venkatesh et al., 2003)—which incorporates and streamlines all previous theories of technology acceptance as outlined by Momani and colleagues in their 2017 review—as well as normalisation process theory. The theories informing the development of the RecoveRiver app are demonstrated in Figure 2, below.

*Figure 2. Theoretical underpinnings of the development of the RecoveRiver app.*


PI input as ED clinician
RecoveRiver App
PPI Input
Implementation Science
the study of methods to promote the systematic uptake of research findings and evidence-based practice into routine clinical practice
Theory of Planned Behaviour
Social Cognitive Theory
Fogg Behaviour Model
Stages of Change
Behaviour Change Theories
Self-Determination Theory
people can become self-determined when their needs for competence, relatedness, and autonomy are fulfilled
Theoretical needs-based framework
candidacy theory of access + the discrepancy theory of patient satisfaction, mapped on to the service delivery system
Theories of acceptance of technology
adopting technology is dependent on the direct effect of: performance expectancy, effort expectancy, social influence, and facilitating conditions
The Unified Theory of Acceptance and Use of Technology
Normalisation Process Theory
a framework that can be used to describe, assess and enhance implementation potential
largely CBT-based apps
Evidence for app-based interventions for EDs
Evidence for effective treatments for EDs
Cognitive Behavioural Therapy (CBT) is the primary evidence-based practice

## Design and Development of the RecoveRiver App

### *Stage One: Literature & Scoping Review*

#### *Aim*

The aim of this stage of app development was to review current treatments and app-based interventions for EDs to help inform the selection of therapeutic modalities and clinical contents of the app.

#### *Method*

Before commencing development of the RecoveRiver app, a robust scoping phase was employed. Stage One comprised a preliminary literature review on existing treatments for EDs and a subsequent scoping review of literature on the effectiveness, usability, feasibility, and safety of using digital interventions with individuals with EDs. The full scoping review is detailed in 'Scoping Review of App-Based Interventions for Individuals with Eating Disorders.'

#### *Results*

CBT-based apps for people with EDs, most especially RecoveryRecord, had, by far, the largest evidence base. This, combined with ED clinician input, formed the rationale for the therapy modality the app contents would primarily draw from.

### *Stage Two: Preliminary PPI (Preceding the App Prototype)*

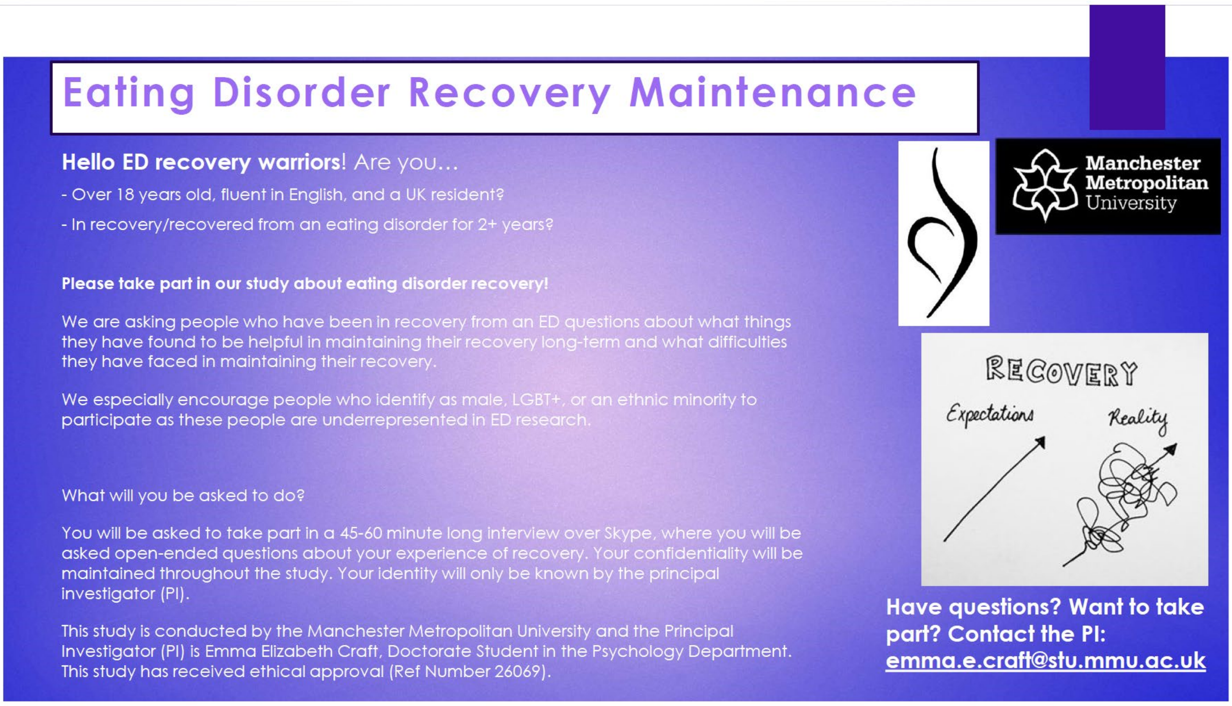
#### *Aim*

Stage Two of the research project utilised a qualitative methodology to collect input from a key and essential resource: individuals with lived experience of ED recovery. The aim of this stage was to gather and interpret this lived experience to develop an understanding of protective factors which may help individuals maintain recovery, with the goal of incorporating identified themes to inform the app contents.

#### *Recruitment*

Recruitment took the form of a poster promoted in ED recovery groups on Facebook, with the aim of accessibility and inclusivity. Social media is accessible and not limited to individuals within a specific geographical location. Constraints of recruitment at the time due to the COVID-19 pandemic also meant digital working was the only feasible recruitment and interview method. The recruitment poster can be viewed below in Image 1.

*Image 1. Stage Two Recruitment Flyer*



**Eating Disorder Recovery Maintenance**

**Hello ED recovery warriors**! Are you…

- Over 18 years old, fluent in English, and a UK resident?
- In recovery/recovered from an eating disorder for 2+ years?

**Please take part in our study about eating disorder recovery!**

We are asking people who have been in recovery from an ED questions about what things they have found to be helpful in maintaining their recovery long-term and what difficulties they have faced in maintaining their recovery.

We especially encourage people who identify as male, LGBT+, or an ethnic minority to participate as these people are underrepresented in ED research.

What will you be asked to do?

You will be asked to take part in a 45-60 minute long interview over Skype, where you will be asked open-ended questions about your experience of recovery. Your confidentiality will be maintained throughout the study. Your identity will only be known by the principal investigator (PI).

This study is conducted by the Manchester Metropolitan University and the Principal Investigator (PI) is Emma Elizabeth Craft, Doctorate Student in the Psychology Department. This study has received ethical approval (Ref Number 26069).

**Have questions? Want to take part? Contact the PI: emma.e.craft@stu.mmu.ac.uk**

## Design

Six people who self-reported being in recovery from an ED for at least two years took part in 45–60-minute interviews. These participants, of all patients/public involved in the project, were the farthest temporal distance from the acute stage of their ED (having the longest time in recovery). With evidence suggesting that relapse is most common in the first two years post-recovery (Berends et. al, 2016), these participants were deemed to be at low risk of triggering, which facilitated the ability for in-depth questions about personal experiences of recovery due to less emotional proximity to the acute ED phase. Participants were asked to not partake in interviews if they may be at risk of experiencing high levels of psychological distress when asked to recall/discuss events or any other element related to their ED, to ensure their safety. Full inclusion/exclusion criteria are detailed in the companion empirical paper.

Interviewees were asked questions focused on their personal experiences of ED recovery with the aim of better understanding what goals individuals set for their recovery, what factors facilitated recovery maintenance, what coping skills and resources were most helpful, and what strategies were used for relapse prevention. Questions were designed to best elicit depth in consideration and answers from the participant about their personal experiences and meaning making of these.

Example questions from the interview schedule include: “Can you tell me about the goals you set for yourself when you started your recovery journey?” and “What are the strategies that you currently use to prevent relapse?”. The full interview schedule can be viewed in Appendix 1.

The interviewees were made aware that their answers would be used to inform the development of an app to support people to maintain ED recovery. Thus, some participants offered their own specific suggestions for contents and features outright, which were considered in conjunction with the emerged themes.

### *Methods*

Participants’ responses were analysed via Interpretative Phenomenological Analysis (detailed in the empirical paper in Chapter Three). Themes, as well as specific codes and quotes from the interviewees in Stage Two informed the contents of the first iteration of the app. This data was integrated with findings from the literature as well input from the research team members, who had clinical expertise in supporting patients with EDs. Theories of behaviour change and theories of acceptance of technology were used as frameworks to translate and apply the results into app contents and design.

There is established evidence for the increased effectiveness of interventions which have been developed using behaviour change theories (Prestwich et al., 2014). Goal-Setting Theory, the Theory of Planned Behaviour, Social Cognitive Theory, the Fogg Behaviour Model, and Self-Determination Theory served as frameworks through which to understand PPI input and inform the contents development and app design.

### *Results*

Overall, four main sections/functions of the app were developed from this combined data and theory: worksheets and safety plans, journals, guided meditations, and activity planning. Drawing from theories of behaviour change, the RecoveRiver app was designed to send push notifications for reminders for engagement, track progress towards goals set by the user, and encourage reflection (through journal prompts and worksheets) about barriers to and motivation about change.

The themes and subthemes generated from Stage Two of the research are presented below in Table 1, alongside the correlating app contents they informed.

*Table 1. Themes and App Contents*

| Themes | Subthemes | App Contents Informed |
|---|---|---|
| Recovery is for Life | 1. Accepting the illness<br>2. Finding the right pace<br>3. Building a therapy toolbox<br>4. Setting boundaries | 1. Safety plans<br>2. App design<br>3. Worksheets<br>4. Journals |
| Recovery Doesn't Happen Alone | 1. Building a network<br>2. Finding acceptance<br>3. Exploring identity | 1. Activity planning<br>2. Guided meditations<br>3. Journals |
| Recovery Means Getting a Life | 1. Finding new interests<br>2. Developing healthy habits and routine<br>3. Seeking purpose | 1. Activity planning<br>2. Activity planning<br>3. Journals |

The results of a recent systematic review of the design of digital interventions for EDs (Barakat et al., 2019) found that better treatment outcomes were associated with the use of "multiple channels of therapeutic content delivery" (e.g., utilising apps' inherent multimedia functions to include audio, images, graphics, etc. in a dynamic way). The RecoveRiver app used audio, images, and text to deliver information and employed various methods of gathering user input such as free text-entry, goal/task setting trackers, and ratings.

### *App Element 1. Worksheets and Safety Plans*

Worksheets and safety plans are a core component of Enhanced Cognitive Behaviour Therapy (CBT-E) for EDs (Fairburn and Bohn, 2008). The subthemes 'accepting the illness' and 'building a therapy toolbox' which emerged from interviewees also heavily informed this content creation. Digital worksheets implemented in the app drew from CBT techniques for anxiety, depression, and eating disorders.

### *App Element 2. Journals*

Journals and thought diaries are often featured in CBT-based mental health apps to facilitate cognitive restructuring (Denecke, Schmid, and Nüssli, 2022). Interviewees spoke of the importance of developing a better understanding of themselves during their recovery process in the themes of exploring identity, setting boundaries, and seeking purpose. One participant directly expressed the benefits of journaling: "I've kept a diary for nearly 4 years…it has been a big pivotal moment for me to have all those thoughts written on a piece of paper and realizing, you know what, these are just patterns that I can see." Thus, journal prompts encouraging reflection and perspective-shifting were a natural app component to include.

#### *App Element 3. Activity Planning*

Activity planning is key to behavioural activation in CBT and another common feature of CBT-based apps (Denecke, Schmid, and Nüssli, 2022). The benefits of activity planning were discussed by every interviewee, for example: “For me, recovery happened when you start to get everything else in life rolling…routines, support, and having activities…more focus on like getting friends, you know, and having hobbies and being passionate about something.” The subthemes ‘building a network’ and ‘finding new interests’ derived from the Stage Two data complimented this and facilitated activity scheduling and monitoring as an app feature.

#### *App Element 4. Guided Meditations*

Dozens of Randomized Controlled Trials (RCTs) have now demonstrated that mindfulness training delivered via apps such as Headspace, which employs brief guided meditations, can increase psychological wellbeing and reduce stress (e.g., Bostock et al., 2019; Champion, Economides, and Chandler 2018; Flett et al., 2019). One of the participants spoke directly of the importance of mindfulness in her recovery journey: “I definitely see myself trying to practice mindfulness every day in different ways.” The subtheme ‘finding acceptance’ incorporated participants’ sense of mindfulness in the recovery journey and supported the inclusion of app-based mindfulness training.

### ***Stage Three: Testing of the App Prototype***

#### *Aim*

The aim of Stage Three was to conduct an acceptability and feasibility trial of the RecoveRiver app.

#### ***Design***

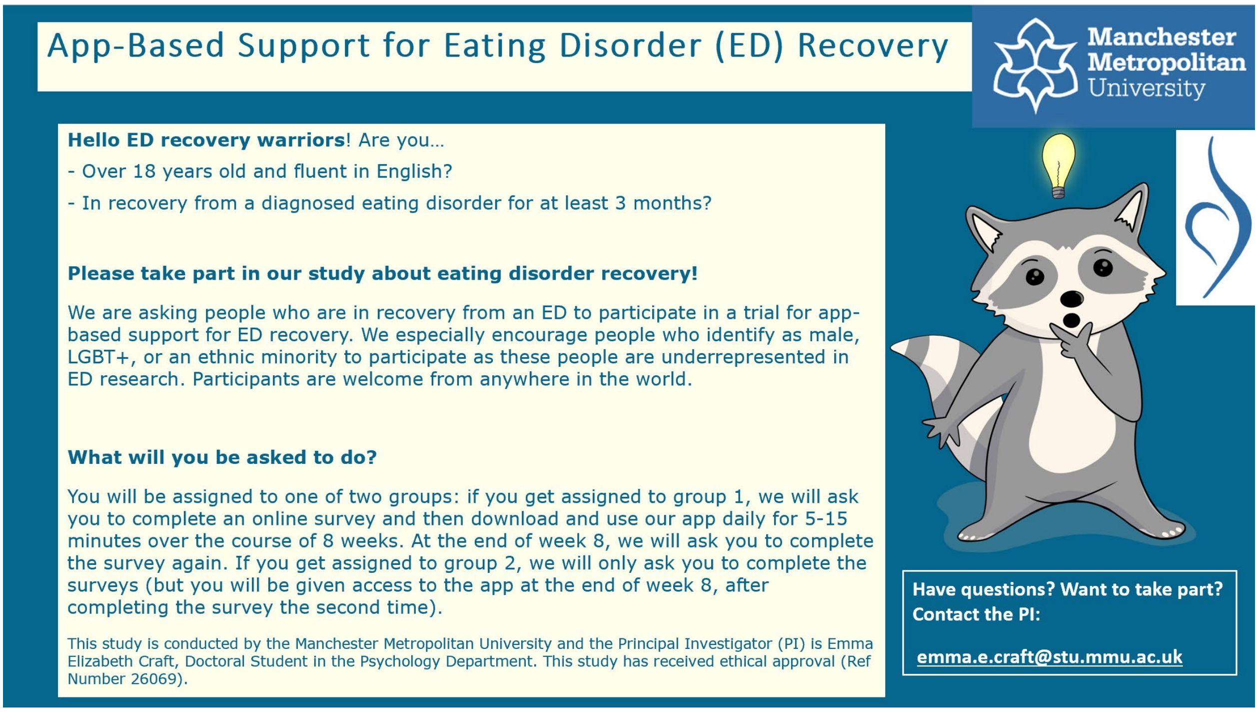
In Stage Three, 20 people who self-reported being in recovery from an ED (3+ months) were asked to pilot the first version of the RecoveRiver app. Participants were asked to complete psychometric questionnaires at baseline online using Qualtrics, then use the app every day for 8 weeks, then complete the same questionnaires followed by five app feedback questions (viewable in Appendix 2) at the end of the Qualtrics survey. Open-ended text-entry questions were used to best obtain essential information while also encouraging depth of answers. Example questions included: “Please tell me what type of app activity you found most helpful?” and “Please tell me if the app influenced any aspect of your mental/physical/emotional health? Why or why not and how?”.

Data gathered from these feedback questions was then used to start developing Version Two of the app, keeping co-production and PPI at the heart of the methodology of building this digital intervention.

*Recruitment*

The recruitment for Stage Three took the form of a poster promoted in ED recovery groups on Facebook—again, due to the constraints of the COVID-19 pandemic and the benefits of recruitment via social media (e.g., larger and more diverse pools of people). The recruitment poster can be viewed in Image 2.

*Image 2. Stage Three Recruitment Poster.*



App-Based Support for Eating Disorder (ED) Recovery

Manchester Metropolitan University

**Hello ED recovery warriors**! Are you…

- Over 18 years old and fluent in English?
- In recovery from a diagnosed eating disorder for at least 3 months?

**Please take part in our study about eating disorder recovery!**

We are asking people who are in recovery from an ED to participate in a trial for app-based support for ED recovery. We especially encourage people who identify as male, LGBT+, or an ethnic minority to participate as these people are underrepresented in ED research. Participants are welcome from anywhere in the world.

**What will you be asked to do?**

You will be assigned to one of two groups: if you get assigned to group 1, we will ask you to complete an online survey and then download and use our app daily for 5-15 minutes over the course of 8 weeks. At the end of week 8, we will ask you to complete the survey again. If you get assigned to group 2, we will only ask you to complete the surveys (but you will be given access to the app at the end of week 8, after completing the survey the second time).

This study is conducted by the Manchester Metropolitan University and the Principal Investigator (PI) is Emma Elizabeth Craft, Doctoral Student in the Psychology Department. This study has received ethical approval (Ref Number 26069).

**Have questions? Want to take part? Contact the PI:**

emma.e.craft@stu.mmu.ac.uk

*Results*

In line with previous ED-app-related research (e.g., Kim et al., 2018), high attrition rates were encountered. Of the 20 participants for Stage Three, only six completed the post-app-based-intervention psychometrics questionnaires and only two people completed the subsequent feedback questions about the app. A key feedback point from users was that journals and CBT worksheets were deemed the most useful and enjoyable app activity. A feedback quote from one user said: “I felt listened to and understood in a way when I did the daily activities. The journaling didn't feel forced like group therapy type activities sometimes can." Another feedback suggestion for app improvement was to include an inspirational quote of the day.

Due to the high level of attrition and subsequent limited data gathered in Stage Three, details of results have been omitted from write-up as they do not offer a meaningful contribution to the project. The research team decided to employ further PPI to continuously inform the development of version two of the app, especially considering the limited amount of data and feedback gathered from the pilot trial.

### ***Stage Four: PPI Data Collection to Inform the Second Version of the App***

#### *Aim*

To ensure the next version of the app incorporated PPI in its development, Stage Four aimed to gather qualitative input about the RecoveRiver app via an online survey disseminated to patients who had just completed treatment at a community outpatient ED therapy service for adults. The primary research aims were to gather input from people with lived experience of an eating disorder (ED) as to what they would like to see in an ED recovery maintenance support app, as well as evaluate current features of RecoveRiver in order to facilitate coproduction.

#### *Design*

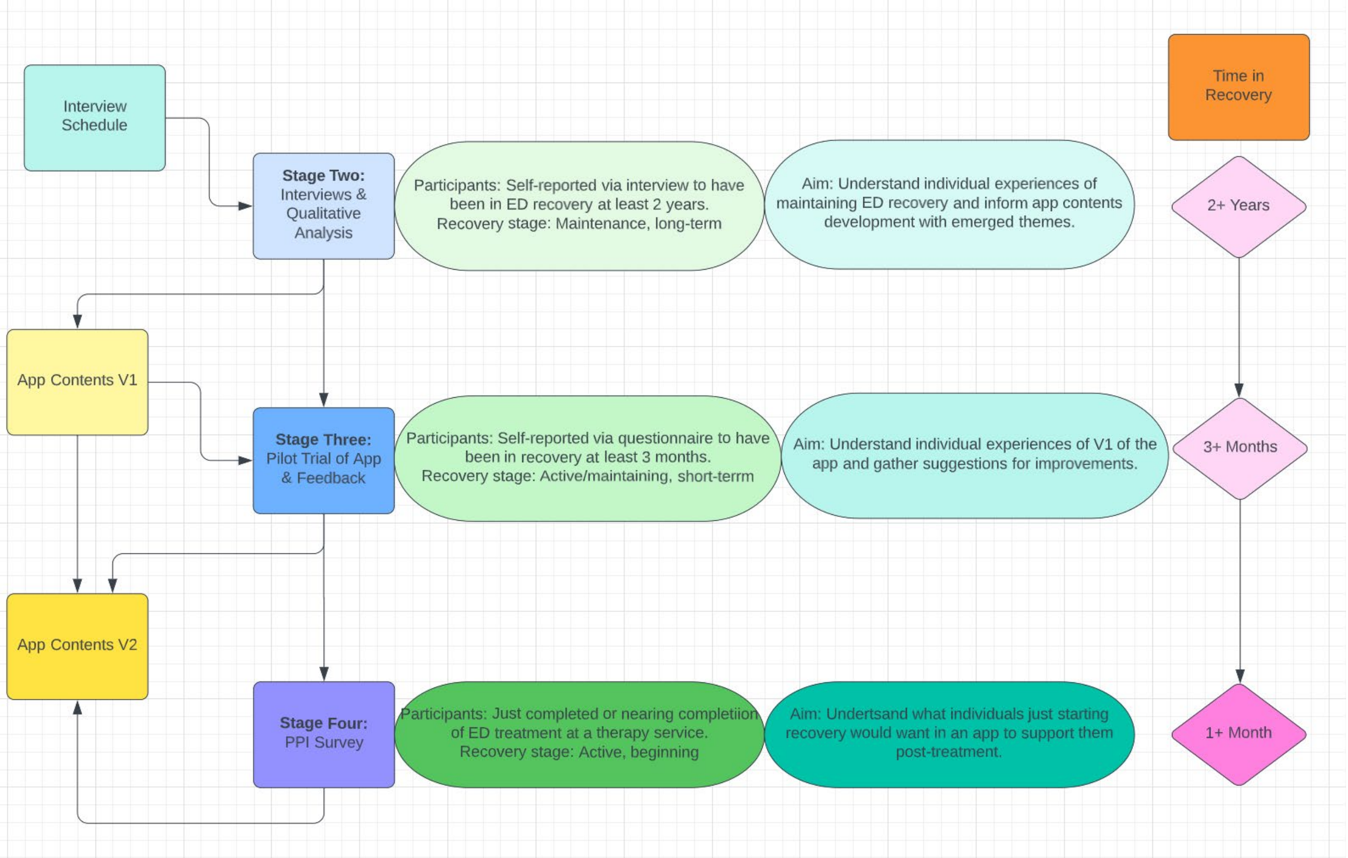
The research design of Stage Two employed a qualitative methodology, using an online survey to obtain feedback and suggestions about the RecoveRiver app. The survey was open for entry between September and November 2022. Participants were asked to fill in the survey using the online software Qualtrics. The online survey used a combination of open and closed questions, as well as multiple choice answers, about a hypothetical ED recovery app and RecoveRiver specifically. Closed questions asked the person to provide more information if they would be willing to. Some examples of the Stage Four PPI Survey questions included: "Imagine a mobile app that helps people who are in recovery from EDs. What would be the three types of contents (for example, body image/mood tracking, thought diaries, worksheets, guided meditations, etc.) that you think could be most useful to include?" and "What is a 'helpful habit' that supports you to stay in recovery, that you think we could include in our app? This could be anything that works for you." The survey asked for participants' input on what elements they would or would not want to see in an eating disorder recovery app. Examples were provided about the app's contents and some screenshots of visual elements were included to help guide participants' feedback.

*Participants & Recruitment*

Recruiting for Stage Four, via a survey shared with recent service users of an ED clinic, meant that new perspectives were included—those of individuals just starting recovery. These individuals were asked to think about how app-based support might help them in the future following treatment, and to evaluate existing domains of the RecoveRiver app.

From an ethical perspective, the PPI stages shifted from consulting the least to the most vulnerable individuals (in regard to potential triggers and distress) due to each stage building on the previous stage's techniques and data, and requiring less in-depth personal questions about the individual's experience of their ED recovery. The different participant characteristics and aims of their involvement are displayed in Figure 2.

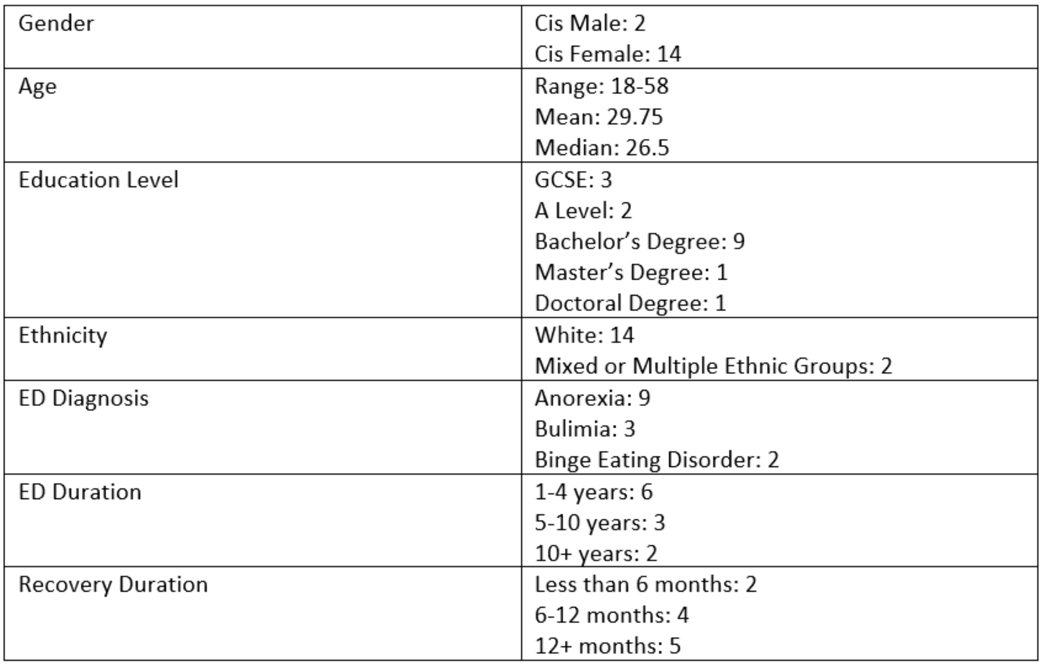
*Figure 2. Participants' perspectives and recovery stages per PPI/research stage.*



Participants for the PPI survey were recruited via an email sent to current and recently discharged patients of the community adult eating disorder service in which the PI practices. Appropriate patients were identified by therapist discretion on the basis that the patient was mostly in symptom remission from their ED. Thus, participants for Stage Four were individuals who had recently finished, or were nearly finishing ED treatment and who had started managing their recovery on their own.

The participants of the PPI survey were less homogeneous than the participants in the other stages of the research project and included men, middle-aged people, and non-white people. ED diagnosis, length of illness, and length of recovery varied across participants. Table 1 details the demographics of the participants of the PPI survey.

*Table 1. Participant demographics and characteristics*



| | |
|---|---|
| Gender | Cis Male: 2<br>Cis Female: 14 |
| Age | Range: 18-58<br>Mean: 29.75<br>Median: 26.5 |
| Education Level | GCSE: 3<br>A Level: 2<br>Bachelor's Degree: 9<br>Master's Degree: 1<br>Doctoral Degree: 1 |
| Ethnicity | White: 14<br>Mixed or Multiple Ethnic Groups: 2 |
| ED Diagnosis | Anorexia: 9<br>Bulimia: 3<br>Binge Eating Disorder: 2 |
| ED Duration | 1-4 years: 6<br>5-10 years: 3<br>10+ years: 2 |
| Recovery Duration | Less than 6 months: 2<br>6-12 months: 4<br>12+ months: 5 |

### _Analysis_

The data was analysed using Reflexive Thematic Analysis (rTA) (Braun and Clarke, 2019). RTA was selected as the most appropriate approach for this PPI survey due to its flexible nature (essential for the survey format, without the direction offered by semi-structured interviews) and ability to generate clear, cohesive themes (key to the aim of the survey to determine objectives for app contents/design). Braun and Clarke (2019) stress that rTA has no 'standardised' approach but must be applied in a way that best suits the type of data (given that qualitative data can vary greatly depending on source, e.g., surveys versus interviews or focus groups), the researcher's positionality, and method of theme conceptualisation (Braun and Clarke, 2022). Therefore, rTA assumes subjectivity in analysis and embraces a level of inaccuracy in codes (Braun and Clarke, 2022). The original analysis process of Thematic Analysis (Braun and Clarke, 2014) was applied using the six-step method:

1. familiarization with the data
2. generating initial codes
3. searching for themes
4. reviewing themes
5. naming themes
6. producing the report

This process was conducted keeping the more interpretive, subjective nature of rTA as an overarching analysis framework.

## Results

### *I. There are clear dos and don'ts regarding ED recovery app contents.*

#### *Include mood tracking, thought diaries, and guided meditations.*

Participants had many suggestions for app contents, with suggestions largely consistent across participants. The three primary themes were mood tracking, thought diaries, and guided meditations as key components of the app. Seven participants suggested "mood tracking", six participants suggested "thought diaries" or "journals", six participants suggested "guided meditations", five participants suggested "affirmations" and recovery reminders, three participants suggested psychoeducation (e.g., "ways to improve social relationships; nutrition education and recipes; getting enough sleep; managing strong emotions"), three participants suggested a calendar function (e.g., "daily routine reminders for showering, making your bed, general self-care reminders or checklist… or a timetable") two participants suggested "worksheets", and two participants suggested "body image diaries/check-ins."

#### *Avoid any food-related content or diet culture.*

Five participants advised avoiding any content related to food (e.g., "meal plans", "labelling food as 'good' or 'bad'", or "pictures of food"). Two participants suggested excluding any contents related to weight or BMI. Two participants advised avoiding "reminders" or "advice" pertaining to exercise. Other suggestions included avoiding body image reflections directly after a meal, "patronising wording", or "images of slim young pretty white women."

Participants had clear boundaries about what they thought potentially triggering contents in the app would be unacceptable. Eight participants identified any diet culture language (e.g., "anything to do with diets, beauty, exercise, too oriented towards 'healthy'") as dangerous for an ED recovery app. Three participants felt that any content regarding weight or body-talk would be inappropriate. Two participants felt that pressuring language, especially "the word 'should'", would be problematic. Two participants felt that comparisons (to others, or old habits) would be triggering for users.

### *Some risks may be present in using an ED recovery app.*

Participants were asked if they might foresee any risks to using an ED recovery app. Five participants felt the app might entail some risks to the user, while four said 'maybe' and four said 'no'.  to this question. Three participants spoke of the risk of the app putting too much "pressure" on the user, potentially leading to guilt, stress, or dropping out. Two participants questioned the danger of the app becoming a crutch and hindering a full recovery (e.g., "using an app could help someone stay in quasi recovery as they are comfortable and feel safe not challenging themselves") Other risks participants identified included users becoming perfectionistic or obsessive around the app, or becoming overwhelmed or confused with too much content. Participants suggested signposting and keeping the format simple and quick to fill in as potential avenues for managing these risks.

## II. The way in which the app is presented is also important.

### *Warm, soft colours are the best aesthetic for an ED recovery app.*

There was some conflict in participants' suggestions when it came to the visual aspects of the app. Four participants suggested warm, soothing, soft colours. Two participants suggested avoiding anything overly happy or childlike, while two participants suggested "bright colours". Two participants suggested an animated animal widget (e.g., "animal widgets perhaps to bring some happiness"). One participant suggested using the ED recovery symbol while conversely, another participant advised to keep the app discreet and not allude to it being an ED recovery app.

### *Reddy the raccoon is a welcome companion.*

Participants were presented with an image of 'Reddy', the digital art raccoon that acts as the user's guide throughout the app; this was mostly met with positive reactions. Nine of the participants expressed liking Reddy and preferring an animal companion to a human for the app (e.g., “I like Reddy! Made me smile soon as I saw it! I quite like that it isn’t a human”). Two participants suggested that Reddy have different facial expressions and share ‘thoughts’ with the user. Two participants found Reddy to be “too young.”

### ***III. People in ED recovery have similar important habits and goals.***

#### *Mindfulness and accountability are essential healthy habits to maintaining recovery.*

Participants identified a range of healthy habits that supported their recovery, but many had tools and strategies in common. Five participants spoke of various mindfulness practices as healthy habits. Four participants spoke of the importance of “accountability” in recovery—through the self, others, or resources like an app or podcasts. Three participants spoke of the importance of reflecting on the gains of recovery and remembering the reasons they chose to recover. Three participants named understanding and challenging their ED as a helpful habit. Three participants listed regular eating as a healthy habit, and three participants spoke of having a routine as a healthy habit. Other healthy habits included mood monitoring, avoiding compensatory behaviours, and thought tracking.

#### *Key recovery goals are enjoying life and spending time with loved ones again.*

The last question participants were asked pertained to the goals they set for themselves at the beginning of their recovery. The two most common recovery goals were being able to enjoy and actively participate in life again (e.g., “being able to take part in life/activities”) which five participants spoke about in relation to studying, work, travel, and activities, as well as being able to spend time with family and friends. Four participants spoke of wanting to eliminate ED behaviours (e.g., “not to go back to old, safety behaviours that led to a downward spiral, not to compensate or do something damaging when feeling out of control or emotional”), while three participants directly mentioned wanting to restore their physical health. Three participants had a recovery goal around finding happiness and peace (e.g., “feel gratitude and peace in myself”), and two participants specifically wanted to improve their body image.

## **Discussion**

Research and development of apps to support people in recovery from EDs is in its infancy, with PPI in this field only recently being considered or implemented. Participatory research was conducted by Milton et al. (2021), which succinctly explained issues with PPI in ED mHealth: “Engagement with the eating disorders community to co-design, build, and evaluate these much-needed technology solutions through participatory design processes has been lacking and, until recently, under-resourced.” Evidence from the literature (as well as themes from Stage Two of this research) points to individuals with EDs benefitting from having control over the process and pace of their recovery (Bell, 2003)—which apps can easily allow for. App-based interventions are continuing to gain popularity and credibility as a viable treatment option as well as an excellent resource for aftercare post-treatment. Patients and members of the public consulted during the various stages of this project expressed, overall, a sense of excitement and hope when thinking of the potential benefits an ED recovery support app could offer, especially if developed in partnership with people with lived experience of an ED.

Evidence from the literature, project conceptualisation and contents design from the ED clinicians involved, and suggestions and feedback from PPI all dovetailed together in a complimentary way that made identifying and implementing app components a fairly intuitive (albeit iterative) process. The mutual confirmation of ideas meant that the app components were universally supported from previous research, practitioner experience, and lived experience of people in recovery from EDs. Thus, the layered, multi-stage process with an emphasis on PPI utilised in the development of this mHealth app led to high levels of acceptability and usability, two key areas of early app evaluation. To view a small sample of the app contents for Version One, please see Appendix 4.

The themes generated from the PPI survey lend themselves well to implementing changes in the RecoveRiver app to make the app more appealing and acceptable to future users. Results from this study will directly influence development of version two of the app, which will then be evaluated via Randomised Controlled Trial (RCT) in 2023. Results of this RCT will be published to begin forming the evidence base to implement RecoveRiver in clinical practice.

## Conclusions

### *Strengths of Approach*

Using PPI in the development of the RecoveRiver app helped inform content creation in a practical, grounded way that no theory or research could. Given that mHealth apps aim to offer an engaging product that the public will want to use, no one can better provide guidance on what that should look like than people with lived experience. RecoveRiver is the first app developed for people with EDs that has employed PPI throughout every stage of its development; the approach to PPI taken in this project was rigorous and intentional. The discussion of the benefits of using PPI in mHealth research and design in this paper may encourage other researchers and developers to consider using PPI throughout the process of designing and testing their mHealth products.

### ***Limitations of Approach***

Although recruitment through all stages specifically encouraged individuals of marginalised groups in ED research, nearly all participants across all stages were young, white women. One potential factor for the lack of representation of other genders besides cis women may be that the Facebook groups accessed by the PI comprised of predominantly female users. Because the PI was female, asking for permission to join ‘closed’ or ‘private’ groups specifically for trans, nonbinary, or male individuals with EDs was deemed not appropriate as this could be perceived as an invasion of a protected space. Another limitation was sample sizes in the earlier stages of the study due to issues with recruitment and retention, largely due to the Covid-19 lockdowns limiting recruitment to only taking place via social media.

Both issues with sample size and heterogeneity pertaining to participants in ED research have been well documented for decades across the literature. Researchers in the ED field must develop further strategies to engage individuals with lived experience of EDs in research and product design, particularly those of minority backgrounds and other genders. It is also well-documented that many clinicians working in the field of EDs are white cisgender women. Perhaps through encouraging more professionals from a diverse range of genders and ethnicities to join the field of ED research and treatment, this representation may then encourage individuals from non-white, non-cis-female identities to participate in research.

### ***Next Steps***

The development of Version Two of the RecoveRiver app is currently underway at the time of writing, with an RCT of the app planned as future Stage Five of this ongoing research and app development project (spanning past this thesis project). More contents will be developed so that the app is useable for more than its original eight weeks of contents, in light of evidence from research (e.g., Kim et al., 2021) which found that the longer a user engages with an ED recovery app, the greater its efficacy in maintaining symptom remission. Future researchers might consider using PPI to evaluate and improve the two currently well-established ED recovery apps, Recovery Record and Rise Up. As more research demonstrates the value and importance of PPI in mental health app development, it will ideally become a central component rather than a ‘helpful extra’. Future researchers may encounter conflicts between clinical guidance and PPI suggestions/feedback, and devising a standard practice for how to overcome this in a realistic and fair way would be beneficial.

# Chapter 3.

## Exploring Lived Experiences of Eating Disorder Recovery Maintenance

*Empirical Paper*

**Emma Elizabeth Salazar**

## Introduction

### *Ontology & Epistemology*

Critical realism was used to inform the ontological and epistemological frameworks of all the research projects within the thesis. Critical realism creates a blended midpoint between social constructivism and positivism in order to provide a way to contextualise scientific knowledge, gathered within social constructs, within an independent reality (Yucel, 2018). The critical realist perspective acknowledges that scientists' understandings of reality are concurrently naïve and sophisticated (Yucel, 2018), and that reality can be likened to an iceberg, in that most of it is hidden and must be identified through inference (Stutchbury, 2021).

Potterton and colleagues (2021) applied a critical realist perspective to their research study of the FREED early intervention pathway for EDs and noted, "Critical realism is particularly well-suited to studies related to clinical interventions, as increased understanding of both experiences and their construction can suggest targets for intervention development". This considered, the author of the studies presented in the following sections identified critical realism as an appropriate stance, due to its ability to explore individual experiences of phenomena while keeping social contexts at the centre of forming an understanding of the constructs of individuals' realities (Potterton et al., 2021).

### *Ethical Considerations*

The studies received ethical approval from the Manchester Metropolitan University Ethics Committee, and a copy of the approval may be viewed in Appendix 9. UK GDPR (2018) principles, principles of ethics in research, and BACP Guidelines for Research in Counselling Professions (2018) were adhered to throughout the research process.

### Aims

The first aim of this study was to conduct a qualitative exploration of the factors representing barriers and facilitators of long-term recovery for individuals who had recovered from a diagnosed eating disorder (ED). This was motivated by the need to capture the complexity of the experiences of individuals in recovery from EDs, which was a key step in the process of creating the RecoveRiver app. The secondary aim of the research was therefore to identify themes in protective factors of recovery which could inform the contents development of RecoveRiver.

### Methods

#### *Design*

The research design of Stage Two employed a qualitative methodology, using semi-structured interviews to gather data about participants' perspectives and lived experiences of ED recovery maintenance. Qualitative methods are used "to answer questions about experience, meaning and perspective, most often from the standpoint of the participant" (Hammarberg and de Lacey, 2016) and thus a qualitative methodology lent itself best to the aims of this research.

*Semi-Structured Interviews*

The semi-structured interviews were conducted by the PI between January and February 2021 using Skype, an online platform that is increasingly used in research as a way to conduct online interviews (Iacono et al., 2016). Moreover, due to the COVID-19 restrictions, face-to-face interviews were not allowed. Skype interviews also allowed for inclusivity and reduced barriers to participation regarding participants' ability to attend an in-person interview (time, location, transportation, childcare, etc.)

The interviews lasted between 45 and 80 minutes. The beginning of the interview gathered a brief narrative of the participants' experience of living with an ED before moving to exploring what prompted them to seek help, what factors influenced their recovery, and how they stayed safe or navigated relapse. The full interview schedule can be viewed in Appendix 1. Interviews were recorded on Skype and the audio file was saved in an encrypted folder on the PI's computer; the Skype recording auto-deleted after 24 hours and this was confirmed to have occurred after each interview.

Participants were made aware that interview questions would touch on sensitive and potentially distressing topics related to their ED in the Participant Information Sheets (PIS) (see Appendix 2), and were provided with a Debrief Sheet (DS) (see Appendix 3) after participation. Interviews were transcribed verbatim and listened through thrice each to ensure transcription was accurate throughout. A sample interview transcript is viewable in Appendix 4. Any personally identifiable information was removed during the transcription process. Identification of transcripts used only pseudonyms assigned to participants by the PI; participants consented to direct quotes being used from their interviews.

*Participants*

The participants were six individuals who self-reported having been diagnosed with an ED and had been in recovery for a minimum of two years. Inclusion criteria were: aged over 18, any gender, fluent in English, have received a past diagnosis of ED(s) from a health professional, and in the recovery stage and not having had any relapse for at least two years. Exclusion criteria were: self-reportedly currently meeting the diagnostic criteria for an ED, or at risk of experiencing high levels of psychological distress when asked to recall/discuss events or any element related to their ED. The participants were asked in the PIS not to take part in the study if they thought these criteria may apply to them.

Participants were recruited via an e-advert (viewable in Appendix 5) posted in private and public social media groups on Facebook for people in ED recovery. No financial compensation was offered for participation. Recruitment took place solely online due to the pandemic. Individuals of any age, gender, or ED diagnosis were asked to participate; men, members of the LGBT+ community, and ethnic minorities were especially encouraged to participate due to being underrepresented in ED research. The e-advert posted in relevant groups contained the PI's academic email address and participants interested in the study were invited to contact the PI directly to have more information on the study and receive a copy of the PIS. If they agreed to participate, an interview date and time was arranged. Consent was obtained verbally at the beginning of each interview and saved in a separate recording file to the interview itself. Following the completion of the interview, participants were emailed the DS and informed they could contact the PI, her supervisor, or the Faculty Head of Ethics if they needed support post-interview or wished to report complaints.

*Participant Characteristics*

The participants originated from a wide range of countries but were all white and mostly women. No men expressed interest in the study; one participant identified as nonbinary. The age range of the total six participants was 20-37. Participant characteristics can be viewed in Table 1, below.

Table 1. Participant characteristics and pseudonyms

| Participant | Nationality | Eating Disorder | Age | Age of Onset of ED | Years in Recovery |
|---|---|---|---|---|---|
| Sophia | Spanish | Anorexia | 31 | 15 | 10 |
| Natalie | English | Anorexia | 25 | 12 | 3 |
| Gianna | Italian | Binge Eating | 25 | 20 | 4 |
| Alice | Swedish | OSFED | 20 | 13 | 2 |
| Imogen | English | Anorexia | 27 | 18 | 5 |
| Cheryl | American | Bulimia | 37 | 14 | 16 |

**Analysis**

The data was analysed using Interpretive Phenomenological Analysis (IPA; Smith, 2009). IPA was deemed most suitable for the study due to its exploratory nature, lending itself well to complex and emotionally-laden topics (Smith and Osborn, 2014). Given that the research topic of ED recovery maintenance has little existing literature, the open-ended, flexible nature of IPA, and its focus on gathering a large amount of rich data (Smith, 2009) fit well. Additionally, the study's aim of exploring individual lived experiences in detail also naturally fit best with IPA, compared with other qualitative approaches. Other qualitative approaches were ruled out through process of elimination. For example, grounded theory was not appropriate as the study did not have an aim of theory generation and already drew from a theoretical basis. Thematic analysis was not appropriate as the authors (Braun and Clarke, 2014) suggest it is most appropriately used to identify patterns in a data set, but “is less suited for examining unique meanings or experiences from a single person” (Kiger and Varpio, 2020).

Three key theories and principles inform IPA, namely phenomenology (identifying unique elements of experience), hermeneutics (acknowledging the role of interpretations of the context of experience), and idiograpy (exploring perspectives on a deep individual basis before attempting to draw any comparisons) (Pietkiewicz and Smith, 2014). How these domains were considered during the analysis process will be discussed first before detailing the analysis process and steps.

The PI engaged with the analysis process from the overall perspective that individuals interpret themselves, their experiences, life events, and relationships in an ongoing, dynamic process unique to them. Particular care was taken to honour the individuality and uniqueness of each participant’s expression and understanding the nuanced detail of their own lived experience. The PI aimed to keep intersectionality at the forefront of how phenomenology applied to each participant, for example considering how culture, gender, age, and neurodiversity might influence how a participant spoke of particular phenomena. The PI endeavoured to take the perspective of each participants, in an attempt to understand how they see the world through their eyes, and translate their experiences into the PI’s understanding and interpretation of their experiences.

In their 2012 publication, ‘Inclusive Research Design: Unravelling the double hermeneutic spiral’ McKemmish and colleagues discuss the complexity of double hermeneutics in community partnership research. Some complexities include blurred boundaries between the ‘observer’ and the ‘observed’, with a shared meaning-making of community identity. The authors add, ‘inclusive research design is in turn associated with another manifestation of the double hermeneutic – the interaction between the inclusive approaches involved in designing the research and in doing the research, between the principles and processes involved in negotiating the research design, and the experience of implementing the research design.’ Thus, with so many factors contributing cyclically to the double hermeneutics of this type of research, the authors refer to the process as having a spiralling effect. For this research project, there was an additional component contributing to the double-hermeneutic process—the PI’s own experience and meaning-making of ED recovery from both a personal and professional perspective.

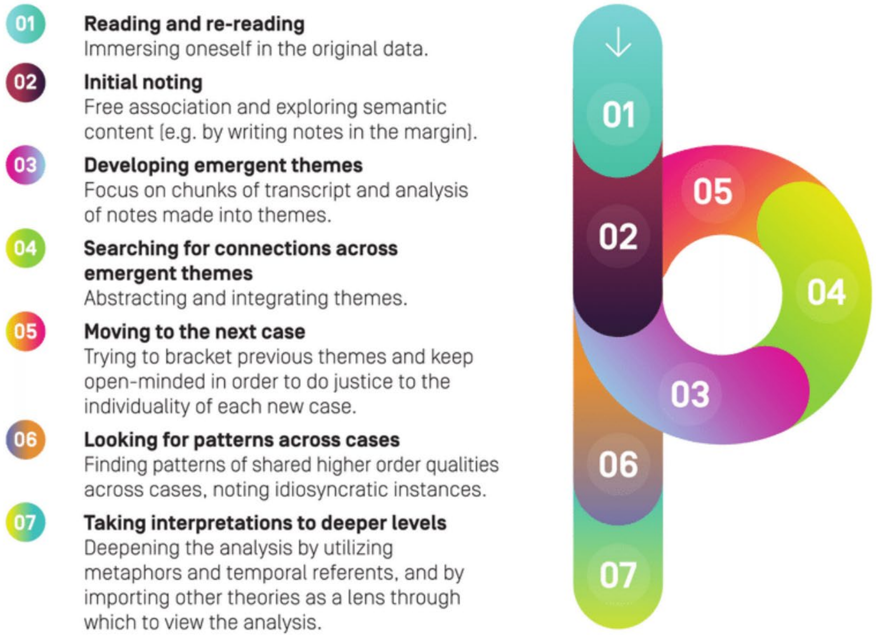
The researcher’s initial attempt to engage in ‘bracketing’ (setting aside preconceptions to let the phenomena ‘speak for itself’), as outlined in Smith et al.’s (2009) description of IPA, consequently limited genuine engagement with the overall analytic process. Given the research project's large focus on PPI, as well as the researcher's wariness of 'contaminating' the analysis with her own professional or personal perspectives of factors contributing to recovery maintenance, there was an initial overemphasis on letting the participant voices speak for themselves which resulted in the IPA focusing much more on the 'PA' than the 'I'. A consequent result was an overemphasis on the PI's recognition that true understanding of an individual's lived experience is never truly possible, stunting the essential double-hermeneutic aspect of the IPA.

LeVasseur (2003) discusses issues with the conflict of bracketing in phenomenology and hermeneutic principles, acknowledging the pressure to demonstrate scientific rigour on qualitative researchers in social science fields and clinical applications. Dunn et al. (2019) conceptualise this problem in clinical psychology science as 'throwing out the innovation baby with the research credibility bath water', arguing that there is a risk of rigid research rigour principles and processes limiting innovation and creativity. Acknowledging and accepting that qualitative methods of research, most especially IPA, are not and will never be comparable to quantitative methodologies seems obvious, but in practice, is not so straightforward. The same is true for understanding the difference between the relationship of methods and philosophical orientations in natural science compared to social science. To do this we must repeatedly return to the basic questions: *what* are the aims of the research, *why* is the research being conducted, *who* is the research being conducted with and about, and *where* is the context of the research—within the literature, as well as perspective of the researcher and participants. Only then can we proceed with *how* the research is conducted in a meaningful and genuine way that attends to the intention of addressing questions of meaning, through 'persistent curiosity' as proposed by LeVasseur (2003).

The data was analysed through a cyclical process of engaging with the transcripts, paying particular attention to nuances in participants' interpretations of their experiences along with meanings attributed to these. After transcripts were each read through thrice, the PI made notes of codes going line by line through each of the transcripts. Then, manual inductive coding was used to develop shared types of experiences and meaning making between participants. The PI kept reflective notes on this process which were brought regularly to both academic and professional supervision. Codes then transformed into emerging themes by grouping, drawing semantic and thematic links, and identifying patterns. Finally, initial codes were cross-referenced with emerged themes, and the relationships between these were carefully considered to develop a framework leading to the superordinate themes of the data. Smith et al.'s (2009) seven steps of IPA were followed. The seven steps of IPA analysis which were followed are illustrated in Figure 1 (Charlick et al., 2015) below.

The IPA process was revisited a second time with the considerations above in mind to accept that the expectation that bracketing in this research process was unrealistic and likely impossible, and limited deep engagement with the double-hermeneutic process. Transparency about 'fumblings' in the research process is a key element of inclusive research design and omission of learnings and mistakes can stunt understandings of the phenomenon in question (McKemmish et al., 2012). The ethos of the project centres upon inclusive research design and community partnership, thus openness about initial issues navigating the double hermeneutics in analysis is key.

*Figure 1. IPA Analysis Steps*



01 **Reading and re-reading**
Immersing oneself in the original data.

02 **Initial noting**
Free association and exploring semantic content [e.g. by writing notes in the margin].

03 **Developing emergent themes**
Focus on chunks of transcript and analysis of notes made into themes.

04 **Searching for connections across emergent themes**
Abstracting and integrating themes.

05 **Moving to the next case**
Trying to bracket previous themes and keep open-minded in order to do justice to the individuality of each new case.

06 **Looking for patterns across cases**
Finding patterns of shared higher order qualities across cases, noting idiosyncratic instances.

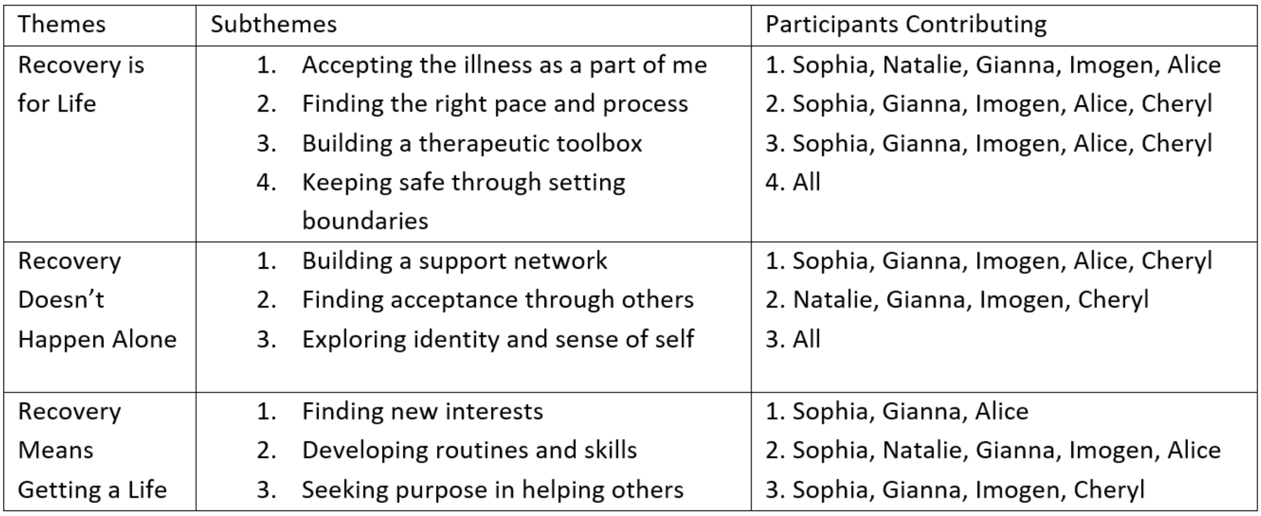
07 **Taking interpretations to deeper levels**
Deepening the analysis by utilizing metaphors and temporal referents, and by importing other theories as a lens through which to view the analysis.

The seven-steps of IPA data analysis (Charlick, McKellar, Fielder, & Pincombe, 2015 adapted from Smith et al., 2009)

## Findings

Three superordinate themes emerged from the analytic process, each with three or four subthemes. The initial themes and their contributing participants can be viewed in Table 2. The amended super- and sub-ordinate themes adjusted after the second iteration of the analysis can be viewed in Table 3.

Table 2. Main themes and subthemes



| Themes | Subthemes | Participants Contributing |
|---|---|---|
| Recovery is for Life | 1. Accepting the illness as a part of me<br>2. Finding the right pace and process<br>3. Building a therapeutic toolbox<br>4. Keeping safe through setting boundaries | 1. Sophia, Natalie, Gianna, Imogen, Alice<br>2. Sophia, Gianna, Imogen, Alice, Cheryl<br>3. Sophia, Gianna, Imogen, Alice, Cheryl<br>4. All |
| Recovery Doesn't Happen Alone | 1. Building a support network<br>2. Finding acceptance through others<br>3. Exploring identity and sense of self | 1. Sophia, Gianna, Imogen, Alice, Cheryl<br>2. Natalie, Gianna, Imogen, Cheryl<br>3. All |
| Recovery Means Getting a Life | 1. Finding new interests<br>2. Developing routines and skills<br>3. Seeking purpose in helping others | 1. Sophia, Gianna, Alice<br>2. Sophia, Natalie, Gianna, Imogen, Alice<br>3. Sophia, Gianna, Imogen, Cheryl |

Table 3. Revised themes and subthemes

| Themes | Subthemes | Participants Contributing |
|---|---|---|
| Recovery is a Lifelong Process | 1. Accepting the illness as a part of me<br>2. Finding the right pace and process | 1. Sophia, Natalie, Gianna, Imogen, Alice<br>2. Sophia, Gianna, Imogen, Alice, Cheryl |
| Recovery Requires Tools and Supports | 1. Building a therapeutic toolbox<br>2. Keeping safe through boundaries<br>3. Building a support network | 1. Sophia, Gianna, Imogen, Alice, Cheryl<br>2. All<br>3. All |
| Recovery is a Journey of Self-Discovery | 1. Exploring identity and sense of self<br>2. Finding new hobbies, routines, and skills<br>3. Seeking purpose in helping others | 1. All<br>2. All<br>3. All |

### *I. Recovery is a Lifelong Process*

When asked to define what 'recovery' meant to them, all six participants spoke of recovery as a life-long journey, and identified as 'in recovery' as opposed to 'recovered'. Recovery was experienced as an ongoing state and ever-evolving process, rather than an event with a discrete start and end.

> "I think recovery is always ongoing in the sense that it needs to be maintained. It needs to be nurtured." (Imogen, lines 293-294)

Imogen’s perspective of recovery encompassed not only her own personal experience of it, but what she had seen with her patients as a clinician working with individuals with EDs. The conceptualisation of recovery as a living thing captures the fragility of recovery identified by participants—and echoes meta-theory ideas behind Self-Determination Theory (SDT), which proposes that humans’ natural developmental tendencies towards growth require ongoing ‘nutrients’ of support (Ryan and Deci, 2000).

Two subordinate themes emerged from the analytic process which developed this superordinate theme, namely: *Accepting the Illness as a Part of Me, and Finding the Right Pace and Process.*

### *Accepting the Illness as a Part of Me*

Many patients demonstrated practicing radical acceptance when talking about their ED living within themselves in a fluid, fluctuating state of full symptom remission and occasional lapses. Radical acceptance is a core component of Dialectical Behaviour Therapy, developed by Marsha Linehan in 1993, who states: “Radical acceptance rests on letting go the illusion of control and a willingness to notice and accept things as they are right now, without judging.” Theoretical links between overevaluation of perceived control and eating disorders are well-established in the literature and form a key foundation of the transdiagnostic theory of eating disorders in CBT-E (Fairburn, 2008). Participants expressed a willingness to ‘let go’ of control, including controlling the process of recovery, and practice acceptance.

> “Recovery is acceptance. And I think that’s really important... It’s not a state, it’s a process as well... I accepted that this illness is going to be with me for the rest of my life.” (Sophia, lines 275 & 278)

Sophia had lived with anorexia for half her life at the time of interview, with just over half this time (10 years) spent in what she defined as recovery, though she acknowledged that defining the start of her period of recovery was difficult due to the fluid nature of her understanding of what recovery meant. Eating disorders are often characterised by black-and-white or all-or-nothing thinking; Sophia's mere conceptualisation of recovery as a fluid, semi-grey area, in itself demonstrates a recovery mindset. While at first glance, her notion of accepting she would always live with anorexia could be interpreted as bleak or hopeless, Sophia's interpretation of this experience was expressed with a self-compassionate tone and could be a demonstration of putting radical acceptance into practice.

Many participants conceptualised staying in recovery as an active choice, and a sense of personal responsibility to manage lapses was expressed. Imogen viewed recovery as a daily decision to move towards:

> "I actively choose not to be anorexic every day I think... Not that I'm always tempted, but it's a conscious choice because it's always an option." (Imogen, lines 302-304)

An emphasis on personal responsibility and developing autonomy and competence in managing eating disorder symptoms is central to any ED treatment (Steiger et al., 2017) and logically follows within a framework of SDT. Multiple participants spoke of recovery also encompassing periods in which their symptoms were no longer in full remission, regarding these lapses as a natural part of the recovery process, and not letting this discourage them from identifying as still 'in recovery.' Alice for instance, spoke about the intention behind actions being important:

> "Of course there's like harder days, easier days, and thoughts like feelings that you had can come back. But it's like, how you react to them." (Alice, lines 95-96)

Although Alice was the participant newest to the recovery process, she expressed her sense of autonomy and personal responsibility just as much as any other participant. Enhanced autonomy is a key factor for the internalisation of motivation within Organismic Integration Theory, which informs SDT. The power of this internalised motivation to move towards the ongoing goal of recovery allowed participants like Alice and Gianna to not be discouraged when obstacles to recovery appeared.

> "Some days are worse than others but it's not a big fight any more like it used to be... It's quite normal that even after I've been trying to recover for 4 years … some patterns will come back up. Because I have been in my eating disorder phase way longer than I have been in my recovery phase, and even then, it will still probably feel sometimes like the most automatic thing to go to." (Gianna, lines 129-136)

While Gianna and most participants approached the concept of life-long recovery with a sense of resilience, using lenses of radical acceptance and self-compassion to set the expectation that lapses would be a part of this process, Natalie conceptualised this with more fear and fragility.

> "Just like... with addiction, you never fully recover. It's like you live your life perpetually scared that one thing will push you down a dark road." (Natalie, lines 291-292)

Of all the participants, Natalie was the only participant who spoke of a recent lapse (a return to restrictive eating) which may have influenced their sense-making of recovery at the time of interview. Natalie was also the only participant who openly spoke of having struggled with addiction, and thus was attempting to hold two separate but undeniably interlinked concepts of recovery. Definitions of recovery from addiction tend to centre more around 'abstinence' (Dodge et al., 2010), a concept which can conflict with radical acceptance of the 'grey-area' of ED recovery expressed by participants. Abstinence was especially pertinent for Cheryl, who viewed recovery as a complete detachment from the ED, rather than an acceptance of ebbs and flows in remission.

> "For me, it certainly is the absence of the desire to have any symptoms or behaviours… not even just controlling them, but literally not feeling like it. Never having an urge to do any of that garbage." (Cheryl, lines 300-302)

There are multiple factors that may have influenced Cheryl's different conceptualisation of recovery. Cheryl was older than the other participants and had spent at least 6 more years in recovery—giving her more time to experience full symptom remission. Cheryl also expressed an early and persistent autonomous motivation to recover from her ED which has been cited as an indicator of treatment outcomes in patients with bulimia (Mansour et al., 2012) as framed by the authors through SDT. However, Petersson and colleagues (2021) found that the only significant predictor of full ED symptom remission at nine-year follow-up was initial levels of self-blame, and suggest development of self-compassion skills as key to sustained recovery. Cheryl spoke of compassion at multiple points in her interview.

Each participant's unique experience of their recovery process was in many ways expressed in their meaning-making of what 'recovery' is. Ultimately, most participants did agree that recovery is a self-determined dynamic state requiring ongoing support and work to sustain, in-line with SDT.

### *Finding the Right Pace and Process*

All participants spoke of a difficult start to their recovery journey in which they were initially ambivalent about treatment or recovery itself. Not one of the participants classed the start of their 'recovery' as their first episode of accessing treatment. Participants instead classed the start of their recovery as when they set the intention for themselves to recover. Alice spoke of the importance of intention and self-pacing the process:

> "Take it at your own pace. Cus I don't think recovery is like—real recovery—is possible until you want to recover." (Alice, lines 168-169)

Alice's emphasis on an individual's own internal desire for recovery as the key determinant of its success can be understood as intrinsic motivation, as is outlined in the 'mini-theories' which inform SDT (e.g., Cognitive Evaluation Theory and Organismic Integration Theory) (Ryan and Deci, 2000). Along with internal motivation, personal willingness to commit to recovery and manage this independently was also discussed as a key predictor of its success. The participants' emphasis on finding autonomy in managing their own recovery journey can also be understood through SDT, in which autonomy is one of three key elements for motivation and engagement in activities pertaining to health behaviours (Ryan and Deci, 2000).

Autonomously creating and following a personalised recovery path was an important part of this process for participants.

> "I found my own way. I've been able to listen to myself which I think is the key, and to be honest with myself." (Sophia, lines 256-258)

Sophia had been through multiple inpatient admissions under detention processes which she had experienced overall as unhelpful and traumatic. Being pushed—or forced—into recovery by external factors was deemed by participants as unsustainable; only when there was intrinsic motivation for self-actualising towards recovery did Sophia's true recovery begin.

Multiple participants spoke of the importance of patience with the process of recovery—which was not a straightforward, consistent experience, but one with ups and downs. Cheryl spoke of compassion towards the self, process, and body many times throughout her interview.

> "Have patience, have compassion for things not going as planned...be forgiving of yourself... like just trust your body... And, and it's a messy process, but just trust the process." (Cheryl, lines 358-363)

Self-compassion appeared to be integral to navigating the not-so-straightforward road of recovery. Kristin Neff's (2023) theoretical model of self-compassion comprises six elements, namely: self-kindness, common humanity, and mindfulness as well as reduced self-judgment, isolation, and overidentification. These elements align closely with the model of psychological wellbeing by Ryff (1989) which also consists of six elements, including self-acceptance, autonomy, mastery, purpose, and meaning. The participants weaved their own threads of key elements of self-compassion and psychological wellbeing throughout their discussions of the pace and process of the recovery journey—from Cheryl's compassion, to Alice's autonomy, and Sophia's self-acceptance.

Imogen's emphasis on curiosity and determination link back to intrinsic motivation and autonomy as discussed earlier.

> "It was topsy-turvy, it was definitely not how I wanted recovery to go. But I started to get curious... Curiosity, fascination, determination, and learning were such big parts of my recovery." (Imogen, lines 246-253)

Imogen's reflections on the 'topsy-turvy' experience of her early recovery reflect the non-linearity of the process alluded to by all participants. Her expression of the importance of determination links to findings from Duncan and Lee (2015) who found empowerment and self-management as two important recovery criteria for EDs often missed by other consensus studies exploring definitions from ED practitioners and patients.

### *II. Recovery Requires Tools and Supports*

As well as autonomy, SDT also places particular emphasis on competence and relatedness, and incorporates external factors (which also become internalised), such as context and social support, into its overall model of individuals' motivation towards health-related behaviours (Ryan and Deci, 2000). Social support, relatedness, and competence in safely managing the ED as an ongoing endeavour also comprised the aforementioned 'nutrients of support' towards long-term recovery maintenance for participants.

> "Don't do it on your own... I think having a good network is the key." (Sophia, lines 291-292)

Sophia spoke highly of the variety of support she had received whilst in residential treatment for her ED after hospitalisation, and had mapped key elements of this experience to her life in recovery maintenance in the long-term, including using therapeutic tools and skills and developing supportive friendships.

Three subordinate themes led to the creation of this superordinate theme: Building a Therapeutic Toolbox, Keeping Safe through Setting Boundaries, and Building a Support Network.

### *Building a Therapeutic Toolbox*

Although participants' experiences of treatment or self-help for their ED differed greatly, most identified the importance of finding tools, techniques, and coping skills to manage their illness. These fit within the 'toolbox' idea of many therapeutic modalities—skills for life, which made sense given the participants' sense-making of recovery as a lifelong process. Sophia expressed this concept very clearly in her definition of recovery:

> "I will define…recovery is a process of gathering tools to help you fight when dark times come again... And awareness as well is an important thing." (Sophia, lines 276-277)

Sophia's empowerment to use her own curated skillset links back to the self-management discussed by Duncan and Lee (2015) key to the process of recovery from anorexia. Cognitive-behavioural tools and techniques were employed by multiple participants, although none of the participants had received formal CBT treatment—in fact, Sophia and Imogen were the only participants who had received ED-specific treatment (both had spent time in Specialist Eating Disorder Inpatient Units). Cheryl reported that she had learned CBT techniques from books and podcasts she'd sought out herself, and used these tools in all aspects of her life. Alice and Gianna both explained they had used initial professional guidance (a psychiatrist and counsellor, respectively) as a baseline for support into recovery, then self-discovered CBT techniques (such as goal setting, activity planning, and thought diaries) and implemented these in their day-to-day lives.

There was no clear distinction between using these therapeutic tools for domains specific to the ED and overall psychological wellbeing. For example, Gianna spoke of the benefit of keeping a diary to manage both her ED thoughts and behaviours as well as self-harm urges and relationship difficulties—areas technically outside of the management of her ED in the long-term, but also closely linked to long-term psychological wellbeing.

> "I've kept a diary for nearly 4 years... to have all those thoughts written on a piece of paper and realizing, you know what, these are just patterns that I can see... I was able

> to categorize it, and be like okay, I can deal with one thing at a time." (Gianna, lines 189-196)

Emanuelli and colleagues (2012) determined that ED recovery encompasses both specific ED criteria as well as general social, emotional, and psychological criteria, where overlap naturally occurs between all domains. While Gianna may have initially used CBT skills with the aim of managing ED symptoms, these skills later became an integral part of managing her overall social, emotional, and mental health. Using structured problem-solving skills to work with one difficulty at a time across all domains of life was also echoed by Imogen.

> “I seek support when I need it. I don’t look at things as a whole all the time. If I’m struggling with a particular aspect of my mental health or my daily life, I focus on that.” (Imogen, lines 333-335)

Imogen and four other participants had accessed treatment or self-help materials to recover from their ED, which made sense as to why they spoke of the importance of using therapeutic tools. Natalie, who had not used any formal therapeutic resources in their recovery, did not speak of these. Of all the participants, Natalie was the participant who expressed the least security in their recovery. One might question if the lack of therapeutic tools, which may have enhanced Natalie’s self-adaptability and resilience as they did for the other participants, may have played a role in this.

### *Keeping Safe through Setting Boundaries*

Each participant identified certain boundaries they had set with themselves to protect their recovery and buffer themselves from relapse triggers. Avoiding scales and weighing was a common boundary, spoken about by four of the participants, including Gianna.

> “After many, many more relapses of me trying to weigh myself, I literally dumped my scale.” (Gianna, lines 79-80)

Gianna spoke not only of the importance of getting rid of her scale for her own recovery, but this was also her first point of advice for others starting recovery—something she repeated a few times with conviction, which can be interpreted as critically important to her. Reduction or elimination of weight-controlling behaviours and over-evaluation of appearance, shape, and weight are discussed as one of the key definitions of ED recovery throughout the literature (Emaneuelli et al., 2012) and are also central to CBT-E (Fairburn, 2008).

While moving away from all-or-nothing thinking is generally important in ED recovery, there were a few exceptions understood by participants of where this may be helpful—where the ‘grey area’ tends to turn into a slippery slope and can lead to a lapse or relapse. Multiple participants had removed scales from their homes, citing an inability to maintain a balanced or unharmful relationship with them.

> "I don’t weigh myself... I wouldn’t have scales in the house because it’s too tempting to do that.” (Natalie, lines 93-95)

As discussed by Natalie, this decision was viewed as practical self-management, with a level of mindful self-compassion and acceptance that developing a neutral relationship with scales may never be possible (‘recovery is a lifelong process’). For all participants, there was an importance of making the decision to set their own boundaries with the scale, and this autonomous decision was expressed, on the whole, as empowering. For Imogen and Sophia, who had experienced regular weighing imposed on them in inpatient units, stepping away from the scale altogether perhaps carried even more gravity in the sense of autonomy and empowerment this gave them.

Strict boundaries around body-checking behaviours and exercise were two further areas discussed by participants pertaining to the central theme of elimination of weight-control behaviours running through many studies exploring ED recovery. When discussing recovery maintenance, CBT-E (Fairburn, 2008) conceptualises these types of behaviours as ‘relapse signatures’ and places great importance on prevention, early detection, and self-management. Natalie expressed this early detection and prevention clearly in their explanation of their relationship with the gym.

> “I don’t want to join a gym. Because joining a gym for me, you know, always signifies me being in a really bad place... it’s almost like the first domino.” (Natalie, lines 61-64)

Thus, even though they had not received formal treatment, Natalie had autonomously identified going to the gym as one of their key relapse signatures, and a behaviour around which to put a clear boundary in place. Imogen, too, had also ‘banned’ herself from the gym.

> “I ban myself from exercise outside a very specific exercise. I have banned myself from ever having a gym membership. I have banned myself from any kind of gym class. I will not do any kind of dedicated exercise that isn’t otherwise meaningful to me.” (Imogen, lines 349-354)

Imogen expressed what many participants did—a level of compromise that whilst certain forms or settings of exercise may have been strictly ‘banned,’ developing a personally meaningful and recovery-focused relationship with exercise was valuable. Indeed, participants’ views of the relationship with exercise in recovery as not all-or-nothing echoes treatment advice in Fairburn’s (2008) CBT-E and guidance (e.g., Medical Emergencies in Eating Disorders Guidance, 2022) that suggests that practicing complete abstinence from exercise is unhelpful or unrealistic, even in the early stages of recovery.

What a ‘healthy’ relationship with exercise looked like was different for each participant—while Imogen and Natalie abstained from gyms, Alice and Sophia identified going to the gym as a beneficial part of their regular routines. Though participants all had their own individual relationships with exercise in recovery, they all expressed the importance of letting go of perfectionism and achievement and focusing instead on wellbeing.

> “I do exercise, but... I've set my bar for exercise very low, and it's for my mental health more than anything... Not feeling like, I'm gonna ever try to control my size, shape, whatever, again.” (Cheryl, lines 308-311)

For Cheryl, boundaries around exercise had a relational link to the ‘letting go’ of overevaluation of control as postulated by Fairburn (2008) in the transdiagnostic theory of eating disorders.

Participants also established boundaries for themselves regarding diet—largely avoiding any restriction and focusing on honouring hunger. A move away from all-or-nothing thinking was also expressed in participants’ sense making of letting go of control over diet. Alice focused on letting go of rules and restrictions:

> “Basically recovery is no ‘musts’ or ‘can’ts’—I can’t have this or I must have this.” (Alice, lines 147-148)

Overall, participants expressed the importance of clear, self-determined boundaries around key areas pertaining to ED behaviours and cognitions, including weighing, exercise, and restrictive eating—dimensions of control which all relate to ED behaviours and have also been linked to obsessive-compulsive symptoms (Froreich et al., 2016). Autonomy, mindfulness, radical acceptance, intrinsic motivation, and empowerment were all key parts of this boundary-setting process. Thus, boundary-setting around risk for ED behaviours in recovery can be understood through the lenses of Self-Determination Theory, the Transdiagnostic Theory of Eating Disorders, and the theoretical models of self-compassion and psychological wellbeing.

### *Building a Support Network*

Participants identified having a support network as a key element of maintaining recovery. SDT argues that relatedness is one of the key three foundations (alongside autonomy and competence) that forms the basis of an individual’s motivation towards wellbeing; the social context in which these foundational needs are or are not met, therefore, determines the individual’s tendencies of development (Deci and Ryan, 2000). Social support was indeed identified as an essential factor for recovery maintenance by multiple participants, including Imogen:

> “I attribute it to a really good friendship/family support network. No matter what state I got myself in, they were still there for me.” (Imogen, lines 312-313)

Imogen had not had the support of family or friends at the beginning of her treatment for her ED, and struggled immensely to maintain any treatment gains before finding a ‘chosen family’ she spoke fondly of. Making sense of this through SDT, her ability and motivation to move towards wellbeing was thwarted due to the lack of social support and relatedness she had access to at the start of her recovery, but once her psychological need for relatedness was met, and the nutrients of support in place, she was more motivated—and more able—to grow towards and maintain wellness.

Gianna explicitly identified herself as a product of her environment, (‘I’m like a mirror’) expressing early issues with family members and friends who she did not relate to in a recovery-focused way, which she made sense of as hindering her recovery process.

> “I tried to build around myself a group of people that are understanding and they have healthy habits because that helped massively the way I was being with myself." (Gianna, lines 167-168)

Once she oriented herself away from those holding values and beliefs relating to diet-culture, and towards those holding values and beliefs relating to overall wellbeing, Gianna seemed to have established more solidity in her recovery, demonstrating not only the importance of social connectedness and relatedness in its own right, but within a context of shared principles.

This need for connection and shared perspectives might be explored through Neff’s (2023) conceptualisation of ‘common humanity’, one of the three central components of the theoretical model of self-compassion. Reduced isolation through the understanding that one’s experience is not unique, but one that many other humans are suffering with, too, can be a deep form of relatedness. For Cheryl, this was key to navigating recovery in a cultural world that felt geared towards the opposite—diet culture.

> “They just help ground me, you know... We do swim in diet culture, and it could be very easy if you didn't have the reinforcements, I imagine, easy to kind of get persuaded back to what the rest of our world believes. So I kind of have those little communities that I think are very important because it's not the norm.” (Cheryl, lines 217-220)

Cheryl’s support network took the form of fellow members of online ED recovery groups, but this community was just as valuable and recovery-supporting as in-person counterparts for other participants. In this way, Cheryl’s need for relatedness as understood through SDT was met through a sense of belonging in this group.

Relatedness pertains to the development and maintenance of social relationships including belonging to a group, close friendships, and romantic partnerships; Relationships Motivation Theory (another theory which informs SDT) proposes that these relationships are essential to wellbeing (Ryan and Deci, 2000). The unconditional love and acceptance of a romantic partner was identified as a key part of three participants’ recovery. Using the acceptance of another as a springboard for developing self-acceptance was a theme amongst participants including Natalie:

> “It’s a lot easier when you find someone who does accept you for like, whoever you are... Over time I’ve become more and more comfortable with who I am—and I’m not saying necessarily that you have to find a partner in order to recover—it helped me in a way because like, it’s somebody who looks at you with love and is really attracted to you but also just loves you as a person. And that helps you to think that you’re sort of like, okay.” (Natalie, lines 234-239)

Natalie’s experience of their partner’s impact on their recovery maintenance was a powerfully deep acceptance and understanding of who they were—most especially for their identity as a non-binary person. They made sense of a lack of self-acceptance not just through the perspective of a difficult relationship with their body due to their ED but also gender dysphoria, with these difficulties entangled in a complex relationship. For Natalie, being loved and accepted as a whole person—inside and out—was something they had never been able to consider for themselves, but receiving this from another brought an awareness and hope of the possibility of self-acceptance.

The positive components identified in partners mirrored some of the core conditions of a person-centred therapist—e.g., unconditional positive regard and non-judgementality. Cheryl interpreted the expression of these elements by her partner at the time as key fuel for the start of her ‘true’ recovery (which she seemed to define as the time in which her intrinsic motivation towards full symptom remission was present).

> “He was the first person that I ever felt truly loved me unconditionally. And I really think that helped me get to that point. Cus I was like, no matter what I do, no matter where I end up, I know he's going to love me and accept me no matter what, even when I couldn't do it myself.” (Cheryl, lines 174-178)

Participants spoke clearly of the importance of relatedness in the context of romantic relationships and the modelling opportunity for acceptance that this provided. However, those who identified a romantic partner as an essential ingredient to their recovery also expressed a level of discomfort in admitting that they had had to model their own self-acceptance from another, rather than having the intrinsic motivation or autonomous ability to find this for themselves. Dichotomously, these participants used foundational concepts of self-compassion (modelling compassion of the self on compassion for or from others), while interpreting this process through self-criticism, using descriptive words such as “weird” or “ass-backwards.”

### ***III. Recovery is a Journey of Self-Discovery***

Participants spoke in a variety of ways about the importance of developing, nurturing, and maintaining a sense of self outside of the ED in recovery. Farchaus Stein and Corte (2006) used the cognitive model of the self-concept to evaluate the theoretical links between disturbances in identity and eating disorder symptomology and suggest that the exploration and development of self-concept is a recovery factor not to be overlooked. Sophia spoke of the difference between her self-understanding and view of the world before and after recovery:

> "When the anorexia is so inside of you, you cannot see anything else... you don't think of happiness, it is not a part of you at that time... you need some kind of normality to come back to your life." (Sophia, lines 70-76)

Moving back to a life of 'normality' was a common topic of discussion for participants when thinking about factors facilitating their recovery maintenance. Three subordinate themes contributed to the creation of this final theme: Exploring Identity and Sense of Self, Developing Hobbies, Routines, Interests, and Skills, and Seeking Purpose in Helping Others.

### *Exploring Identity and Sense of Self*

Three participants spoke of how their ED, and subsequent recovery, had facilitated more awareness of personal identity within a critical understanding of social constructs. Participants spoke of a development of their sense of self as well as worldview through the recovery process. For Gianna, socio-cultural expectations placed on women was pertinent to explore through the lens of feminism:

> "You become more aware that these are just like, constructs, and not things set in stone, that these don't really matter at the end of the day or at the end of your life." (Gianna, lines 266-268)

The links Gianna drew between feminism, ED development, and recovery tie into Orbach's Developmental Theory of Embodiment (1986) which applies a feminist framework to the psychodynamic understanding of EDs as a struggle with developing an autonomous self. Orbach conceptualises this within the understanding of social roles and expectations of women to define themselves in relations to others and address others' needs as a priority—resulting in a lack of an autonomous self.

Participants spoke of a better developed sense of self through the recovery journey. An important part of Sophia's recovery process was rediscovering her autonomous self, with the ED having absorbed a large part of her identity for many years.

> "I just didn't know who I was, what I wanted, or why I was even acting like this... I feel like I found myself a little bit better. The tiny Sophia that is there still inside of me, it's just growing now, and discovering herself." (Sophia, lines 240-242)

Developing identity and sense of self was described as an ongoing process by Sophia as well as other participants, including Imogen, where eschewing social norms and expectations was integral to authenticity and congruence.

> "I feel like I'm more myself than I ever have been, even before the anorexia. Because I've now learnt the skills one way or another to manage life. I do my own thing." (Imogen, lines 379-381)

The topic of feminism was brought up by four of the six participants when discussing the intersection between identity and recovery, linking into Orbach's (1986) theory which considers the relationships between gender roles, autonomy, sense of self, and EDs.

### *Developing Hobbies, Routines, Interests, and Skills*

Some participants drew comparisons between their mental and physical occupations when ill with their ED versus in recovery, and noted a shift from their attention being on weight, food, and exercise, moving to a focus on hobbies and relationships. The three key themes which lay the theoretical foundations of occupational therapy are relevant when considering participants' sense-making of occupation and recovery. These themes are outlined by McColl and include: occupation is a basic human feature essential to health; occupation shifts to meet internal and external demands; and occupation can be used to remediate occupational dysfunction.

Alice expresses this shift directly from focusing on ED thoughts to focusing on her more adaptive, recovery-oriented occupations:

> "More focus on… like getting friends, and having hobbies and being passionate about something. Cus you know you miss that, because your focus was so on food... You wanted your brain to be at peace, you wanted to be happy and have the life you had before like as a kid, just enjoying things.” (Alice, lines 68-72)

Seeking and finding happiness went hand-in-hand with developing interests outside the ED, and self-determined routines, interests, hobbies and skills also link back to concepts of autonomy and competence as framed within SDT. Alice correlated these domains with happiness and a sense of reconnecting with her inner child. Participants overall attributed their hobbies as having a direct, positive influence on their recovery and overall psychological wellbeing. Gianna linked her involvement in hobbies to intrinsic motivation and competence in managing ED and self-harm urges:

> “Starting to focus my energy on something completely unrelated to food. So I got into climbing... It’s such a beautiful moment to be able to have the physical confirmation, in a way, that no matter how many times I had to try that I would eventually get there. So I just translated that into my real life and other issues like recovering, or you know, stopping self-harming.” (Gianna, lines 209-216)

Although participants spoke of the importance of shifting their mental occupation away from food into more recovery-focused domains such as hobbies, developing cooking skills specifically was spoken about by most participants as important for recovery. Gianna, Sophia, and Natalie all spoke of how developing skills in the kitchen had a positive impact on their relationships with food.

> “I’m a much better cook than I ever was, which has helped me have such a better relationship with food.” (Natalie, lines 273-274)

Natalie spoke of the importance of a return to ‘normality’ in her interactions with food, helped by working in the hospitality industry. Participants also attributed their personal routines to helping maintain recovery and discussed the importance of using structure, especially during times of struggle or distress. Alice spoke of the importance of routine many times throughout the course of her interview, tying it into many discussion points, underscoring the value she placed on routine.

> "The eating disorder gets a lot less—if any—space because I have my routine. Leaving the house, going for a walk, talking to friends over the phone... I think it's a lot about routine, like having like a life that you enjoy." (Alice, lines 86-88)

Alice, as well as Gianna, linked the importance of routine into the psychological need for relatedness and social support:

> "I'm a big fan of routines. I need to have a very minimal baseline routine. Like for example I need to have one fixed place, maybe I will need to have a couple of very important people in my life that are always there." (Gianna, lines 285-287)

Routine and structure can, during the acute phase of an ED, maintain the disorder, whilst also being an essential component of successfully maintaining recovery. The intention behind the use of structure and routine was clear from the participants that it was used with a self-compassionate motive, rather than a rigid or punitive one as may have been the case before recovery.

#### *Seeking Purpose in Helping Others*

All six participants were working in, or training to go into, caring professions (e.g., nurses, teachers, social workers, ED clinicians). Altruistic behaviour is often listed as one of the key domains of psychological wellbeing (for instance, 'connect' and 'give' as proposed by the NHS 'Five Ways to Wellbeing'). Being able to help others was identified by all participants as a driving force behind their recovery maintenance. Gianna spoke of this desire to help others through ED recovery as very motivating for her own recovery:

"I need to get better because I want to raise awareness about this. And I need to be stronger, or feel stronger, or feel more comfortable around this matter if I want to do this. So it was almost like the helping hand that I saw that I was gonna give to other people in the future if I recovered, was definitely my own helping hand in a way." (Gianna, lines 183-185)

Helping others with EDs specifically was seen as personally healing for three participants, by further solidifying their own recovery. Using personal experiences helped participants guide others towards recovery, which was a motivator to stay well. Imogen spoke of a shift in defining and developing a sense of self and identity outside the ED:

"Because I work as an eating disorders professional, it's a very motivating reason to stay well... I think I've displaced the anorexic identity with the recovered or in recovery identity... My work is really meaningful and I find it really motivating to support others and I don't think it comes from a bad place. It's not like 'I want to rip away your anorexic identity', it's like, 'I want you to come and join me over in this camp because it feels so much better.'" (Imogen, lines 386-393)

Imogen and Cheryl discussed how staying involved in recovery resources and practices for others also kept them engaged in these tools for themselves.

"I do my own intuitive eating coaching... It's the whole, like, walk the walk, talk the talk. I feel like I have a passion like, a mission, you know... turn your mess into your message... And since I want to be an eating disorder therapist, that also keeps me focused and grounded... that just reinforces the importance of staying in recovery too." (Cheryl, lines 222-230)

Research into recovered individuals pursuing a career in eating disorder clinical practice is in its infancy, but emerging literature suggests this may be fairly common (Bowlby et al., 2008); a survey by Bloomgarden et al. (2003) found nearly a quarter (24%) of ED therapists has a past history of an ED, and believed this was an underestimation due to stigma about this. Bowlby and colleagues investigated how recovery is viewed by professionals who themselves had recovered from an ED and found six key themes about the process of recovery: 'it is nonlinear, it is comprehensive, it involves changing attitudes toward the self, it requires de-identification with the illness, developing a sense of purpose, and acquiring meaningful relationships' – themes which very closely align with themes in this research. Pursuing work in supporting others with EDs linked into the importance of finding identity, meaning, and purpose for participants in both Bowlby and colleagues' study and the present study.

## Discussion

### Summary of Findings

Three primary superordinate themes were identified from people in long-term ED recovery maintenance, namely: 'Recovery is a Lifelong Process', 'Recovery Requires Tools and Supports' and 'Recovery is a Journey of Self-Discovery'. Each subtheme generated was generated from codes from at least four out of six of participants. The subthemes developed from this research project align extremely closely with the subthemes in "Recovery as a process: Exploring definitions of recovery in the context of eating-disorder-related social media forums" by Bohrer et al., 2020, as well as other studies around definitions and criteria of recovery such as Bolby et al. (2008) and de Vos et al. (2017).

The protective factors identified in the research closely mirror the domains of psychological wellbeing deemed fundamental criteria for ED recovery in a systematic review and meta-analysis conducted by de Vos and colleagues in 2017. Key recovery criteria identified in their research included self-acceptance, positive relationships, personal growth, decreased ED behaviours/cognitions, resilience, and autonomy. Themes in this study echo these criteria.

On the whole, participants conceptualised recovery as a lifelong process, with the individual in recovery needing to set their own pace, be patient with the journey, and be prepared to cope with lapses. Conceptualisations of recovery as a process and the journey as non-linear are echoed in subthemes from Bohrer et al. (2020). Participants were clear that this journey of recovery does not happen in a vacuum, but in the wider social setting of the individual. For recovery to both begin and be maintained, a support network, the unconditional acceptance of a partner, and/or a further developed sense of self were critical areas of the individual's interpersonal world to explore. Social connectedness and finding one's identity as cornerstones of recovery was also a key finding of Bohrer et al. (2020).

Two key methods of navigating the sometimes-turbulent path of recovery were collecting and implementing therapeutic tools and setting boundaries to keep safe. Similar cognitive and affective factors are outlined in Bohrer et al.'s (2020) subthemes. Developing interests and a life outside the ED, as well as finding hobbies, building healthy routines, and developing new skills were identified by all participants as essential. Similar behavioural and physical factors are also outlined in Bohrer et al. (2020). Finding passion in a helping profession which helped participants stay in recovery was a unique result to this research. Overall, themes of this research around protective factors around recovery maintenance mirror criteria for what defines ED recovery and meanings of recovery in other types of recovered individuals (e.g., recovered clinicians as compared to individuals in long-term recovery).

### *Strengths*

This research is, to the author's knowledge, the first of its kind to investigate the lived experiences of individuals maintaining long-term recovery from an ED. Data saturation was reached within the participant pool, with clear, cohesive themes emerging from the data. The themes identified in this research translated efficiently to developing contents for the app-based intervention, RecoveRiver, which was the secondary aim of the study.

### *Limitations*

The participant pool was somewhat homogenous; thus, themes identified from these participants' experiences of long-term recovery may not be generalisable. As with most other literature in the field of EDs, the perspectives of men and transgender people was not captured in this research. Perspectives from older adults and non-white individuals were also missed. Lack of diversity and representation in ED research populations is an ongoing and widely-acknowledged issue in the field (Goel et al., 2022; Halbeisen et al., 2022).

### *Implications for Future Research & Clinical Practice*

Future researchers exploring lived experiences of ED recovery maintenance should endeavour to include perspectives of non-white individuals, other genders besides cisgender women, and older adults. Clinicians should keep in mind that protective factors for recovery maintenance may differ for people of different demographics (gender, age, culture, and ethnicity). Gathering information about socioeconomic status may also be salient for future research; in clinical practice, socioeconomic status may also play an important role in recovery maintenance and should be considered in treatment and discharge planning.

## Summary of Thesis Project

### Overall Findings and Contributions

#### *Summary of Overall Findings*

#### *PPI as a Key Novel Aspect of the Research*

As has been discussed, the key novel aspect to the research project in its entirety is the incorporation of PPI throughout the process of intervention development which has not yet, to the author's knowledge, been conducted in the field of apps for EDs. The emphasis on including, listening to, and honouring the lived experience of people who have had EDs led to the creation of a product that I truly hope reflects the wants and needs of its user base as accurately as possible. With 'experts by experience' joining clinical forums to offer essential input and guidance in service provision and development within the NHS, their involvement in the research informing these treatment offers from services is a must. Much like the literature encourages PPI from the start to end of the development process of a product, PPI logically goes hand-in-hand with implementation science.

#### *Real Clinical Utility*

Having worked now for three years in a community adult eating disorders service, hearing experiences and input from my own patients, as well as analysing the service's patient overall feedback and liaising with other ED professionals and services (community, children's, inpatient) nationally, it has only become clearer the desire and need patients in recovery from EDs have for post-treatment aftercare. Waitlists for treatment in some services remain over a year long, with treatment offers becoming shorter in an attempt to address wait times. More patients are given a 'revolving door' label as a consequence of unsatisfactory treatment outcomes leading to the need to re-access ED services repeatedly (Marzola et al., 2021). The experts by experience who inform the NHS-Led Provider Collaborative for Adult Eating Disorders I attend recently proposed app-based support for people on waitlists and people who have finished treatment but need further support. App-based support for people with eating disorders across the treatment spectrum is not only a promising area of research, but an essential area for practice to develop in order to better meet the needs of this population who present with particular complexity and risk.

## Challenges

### *App Development*

Prior to the start of the project, the PI had no experience or knowledge in the field of app development or mHealth. As this was a thesis project with no associated funding, the coding and creation of the RecoveRiver app itself was conducted by other students within the University. The app had two developers, both who unfortunately abandoned the project without notice.

The app's first developer was a MSc conversion student and the RecoveRiver app was the first app they had ever developed. This lack of experience, as well as a mutual language barrier (both spoken language and jargon from respective fields), made the process of taking the contents developed by the PI and adapting them into an app within the extreme time constraints on the coder and the PI difficult. The PI worked closely with the coder to ensure the contents were incorporated as intended, however due to both parties remote working, the level of oversight needed for the detail of this was not possible. The first coder of the app suffered various difficult personal circumstances which limited their availability and time, and ultimately led to them leaving the project suddenly.

Due to these issues, the prototype of the app that was tested in 'Stage Three' was not ultimately useable. A lack of available screenshots or videos of the app itself limited recruitment opportunities and promotion to potential participants. Participants frequently emailed the PI about bugs preventing logging in, viewing, or engaging with the app contents. These factors likely contributed significantly to the difficulties with recruitment and high level of attrition from the pilot trial.

The app's second developer was part of an internship project and also worked at a company which focuses on app development. Again, the PI worked closely with this developer, re-creating the entire app from scratch due to buggy/lost code, but issues of remote-working and time constraints persisted. This coder also left the project suddenly due to a change in personal circumstances, and handed it off to a colleague associated with their external employer. The coder who the project was handed to acknowledged the potential of the app to be monetised and consequently attempted to blackmail the PI and larger research team to re-gain access to the code and contents. Ultimately the research team accepted this piece of work was lost and opted to start V3 of the app from scratch, using funding secured for the post-thesis trial of the app to pay a coder as an RA to partake in the process.

### *Integration vs. separation of personal, professional, and researcher identities*

My initial concerns of 'muddying' the research waters with my own lived experience both as a person in ED recovery and clinician who has worked with dozens of individuals with EDs initially limited the depth of my engagement with some aspects of the research and analysis. Not wanting my own personal or professional opinions or bias to influence the research project, I initially took a 'bracketing' approach too firmly in the first stages of the IPA analysis. So firmly wanting to put PPI front and centre of the whole project left my voice—as researcher, but also ED therapist, clinical lead, and person maintaining long-term recovery—somewhat weak. Going through the second iteration of the IPA process, and engaging more deeply with the theory and principles underpinning it, most especially the double hermeneutic process, revealed the importance of my own interpretations and meaning-making—not just of the data, or results, but entire research project.

I can draw comparisons from the research process of this thesis project to my own clinical practice (which span a similar timeframe) through which an example about self-disclosure seems particularly relevant. At the start of my career working therapeutically with patients with EDs, I did not engage in self-disclosure for fear of this being inappropriate. Then, the BACP published an article about the potential benefits of self-disclosure in their 'Therapy Today' magazine and I started bringing this topic more often to supervision. When I started using self-disclosure on occasion to patients who felt especially ashamed and alien for having an ED, I was taken aback at how quickly and deeply we could establish rapport, understanding, and trust in the room. Just saying 'I've recovered from an ED and I know the process is scary and gruelling. I'm not saying I know what it's like for you, but I've been through it and know how it can feel' led to patients filtering their words and experiences less and being more willing to engage in the treatment.

Perhaps similarly, including more of myself in the research has led to a more meaningful and reflective connection with the project—a mirror to including more of my genuine and congruent self in the therapy room, leading to more honest and deep connections with my patients. This research project is about humans, for humans, and adopting a humanistic approach is a natural fit with the underlay of Self-Determination Theory, Self-Compassion, and the appreciation of the unique experiences of individuals woven throughout the project.

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## Chapter One: Appendix 1.

### Study Selection Process

| **Included from Title (56/127 results)** |
|---|
| Web-Based Fully Automated Self-Help With Different Levels of Therapist Support for Individuals With Eating Disorder Symptoms: A Randomized Controlled Trial. |
| Self-help and guided self-help for eating disorders. |
| Computerised psychoeducation for patients with eating disorders. |
| Annual Research Review: Digital health interventions for children and young people with mental health problems - a systematic and meta-review. |
| Exploring Participants' Experiences of a Web-Based Program for Bulimia and Binge Eating Disorder: Qualitative Study. |
| Demographic and clinical characteristics of individuals utilizing an internet-based digital coaching program for recovering from binge eating. |
| Perspectives of e-health interventions for treating and preventing eating disorders: descriptive study of perceived advantages and barriers, help-seeking intentions, and preferred functionality. |
| The relationship between working alliance with peer mentors and eating psychopathology in a digital 6-week guided self-help intervention for anorexia nervosa. |
| Translating evidence-based treatment for digital health delivery: a protocol for family-based treatment for anorexia nervosa using telemedicine. |
| Network intervention analysis to assess the trajectory of change and treatment effects associated with the use of online guided self-help for anorexia nervosa. |
| The Role of Regular Eating and Self-Monitoring in the Treatment of Bulimia Nervosa: A Pilot Study of an Online Guided Self-Help CBT Program. |
| Moving online: young people and parents' experiences of adolescent eating disorder day programme treatment during the COVID-19 pandemic. |
| Does personalized feedback improve the outcome of cognitive-behavioural guided self-care in bulimia nervosa? A preliminary randomized controlled trial. |
| Efficacy and acceptability of self-monitoring via a smartphone application versus traditional paper records in an intensive outpatient eating disorder treatment setting. |
| Apps and Eating Disorders: A Systematic Clinical Appraisal. |
| Development of a Smartphone Application for Eating Disorder Self-Monitoring. |
| Views on online self-help programmes from people with eating disorders and their carers in UK. |
| Patient use of a self-monitoring app during eating disorder treatment: Naturalistic longitudinal cohort study. |
| A smartphone application for semi-controlled collection of objective eating behavior data from multiple subjects. |
| Cognitive Behavioral Training Using a Mobile Application Reduces Body Image-Related Symptoms in High-Risk Female University Students: A Randomized Controlled Study. |
| Binge eating predicts adherence to digital self-monitoring during behavioral weight loss. |

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|---|
| Randomized Controlled Trial Comparing Health Coach-Delivered Smartphone-Guided Self-Help With Standard Care for Adults With Binge Eating. |
| Efficacy and acceptability of self-monitoring via a smartphone application versus traditional paper records in an intensive outpatient eating disorder treatment setting. |
| Improving aftercare with technology for anorexia nervosa after intensive inpatient treatment: A pilot randomized controlled trial with a therapist-guided smartphone app. |
| Mobile Health Adoption in Mental Health: User Experience of a Mobile Health App for Patients With an Eating Disorder. |
| The Use of General Health Apps Among Users with Specific Conditions: Why College Women with Disordered Eating Adopt Food Diary Apps. |
| Just-in-time adaptive interventions: A novel approach for enhancing skill utilization and acquisition in cognitive behavioral therapy for eating disorders. |
| Clinicians' perspective on an app for patient self-monitoring in eating disorder treatment. |
| Subgrouping the users of a specialized app for eating disorders. |
| Annual Research Review: Digital health interventions for children and young people with mental health problems - a systematic and meta-review. [Review] |
| An evidence-based gamified mHealth intervention for overweight young adults with maladaptive eating habits: study protocol for a randomized controlled trial. |
| Smartphone-Enhanced Low-Threshold Intervention for adolescents with Anorexia Nervosa (SELTIAN) waiting for outpatient psychotherapy: study protocol of a randomised controlled trial. |
| An app-based blended intervention to reduce body dissatisfaction: A randomized controlled pilot study. |
| A Guided Online and Mobile Self-Help Program for Individuals With Eating Disorders: An Iterative Engagement and Usability Study. |
| A Survey of Attitudes towards Computerized Self-Help for Eating Disorders within a Community-Based Sample. |
| Development of a smartphone application for eating disorder self-monitoring. |
| Perceptions of the feasibility and acceptability of a smartphone application for the treatment of binge eating disorders: Qualitative feedback from a user population and clinicians. |
| Apps and eating disorders: A systematic clinical appraisal. |
| An Internet-based intervention for eating disorders consisting of automated computer-tailored feedback with or without supplemented frequent or infrequent support from a coach: study protocol for a randomized controlled trial. |
| Online cognitive behavioral therapy for bulimic type disorders, delivered in the community by a nonclinician: qualitative study. |
| The abrupt transition from face-to-face to online treatment for eating disorders: a pilot examination of patients' perspectives during the COVID-19 lockdown. |
| Randomised controlled trial of a guided self-help treatment on the Internet for binge eating disorder. |
| Internet-based cognitive-behavioral therapy for bulimia nervosa: a controlled study. |

| |
|---|
| An open trial of app-assisted acceptance and commitment therapy (iACT) for eating disorders in type 1 diabetes. |
| Introducing Dietary Self-Monitoring to Undergraduate Women via a Calorie Counting App Has No Effect on Mental Health or Health Behaviors: Results From a Randomized Controlled Trial. |
| Virtual Reality App for Treating Eating Behavior in Eating Disorders: Development and Usability Study. |
| Targeting dietary restraint to reduce binge eating: a randomised controlled trial of a blended internet- and smartphone app-based intervention. |
| Patient use of a self-monitoring app during eating disorder treatment: Naturalistic longitudinal cohort study. |
| Parental consent: A potential barrier for underage teens' participation in an mHealth mental health intervention. |
| Usability Evaluation of a Cognitive-Behavioral App-Based Intervention for Binge Eating and Related Psychopathology: A Qualitative Study. |
| Smartphone-Based Self-Monitoring, Treatment, and Automatically Generated Data in Children, Adolescents, and Young Adults With Psychiatric Disorders: Systematic Review. [Review] |
| Efficacy of a transdiagnostic cognitive-behavioral intervention for eating disorder psychopathology delivered through a smartphone app: a randomized controlled trial. |
| Smartphone application for adolescents with anorexia nervosa: an initial acceptability and user experience evaluation. |
| Smartphone apps for eating disorders: A systematic review of evidence-based content and application of user-adjusted analyses. |
| A Clinician-Controlled Just-in-time Adaptive Intervention System (CBT+) Designed to Promote Acquisition and Utilization of Cognitive Behavioral Therapy Skills in Bulimia Nervosa: Development and Preliminary Evaluation Study. |
| Virtual Online Home-Based Treatment During the COVID-19 Pandemic for Ultra-Orthodox Young Women With Eating Disorders. |
| Integrating User-Centered Design and Behavioral Science to Design a Mobile Intervention for Obesity and Binge Eating: Mixed Methods Analysis. |

| Included from Abstract (28) | Excluded from Abstract (28) |
|---|---|
| A Clinician-Controlled Just-in-time Adaptive Intervention System (CBT+) Designed to Promote Acquisition and Utilization of Cognitive Behavioral Therapy Skills in Bulimia Nervosa: Development and Preliminary Evaluation Study. | Smartphone apps for eating disorders: A systematic review of evidence-based content and application of user-adjusted analyses. (Review) |
| A Guided Online and Mobile Self-Help Program for Individuals With Eating Disorders: An Iterative Engagement and Usability Study. | Apps and eating disorders: A systematic clinical appraisal. (Duplicate) |

| | |
|---|---|
| An app-based blended intervention to reduce body dissatisfaction: A randomized controlled pilot study. | Randomised controlled trial of a guided self-help treatment on the Internet for binge eating disorder. (Not app) |
| An evidence-based gamified mHealth intervention for overweight young adults with maladaptive eating habits: study protocol for a randomized controlled trial. | Smartphone-Based Self-Monitoring, Treatment, and Automatically Generated Data in Children, Adolescents, and Young Adults With Psychiatric Disorders: Systematic Review. (Review) |
| An open trial of app-assisted acceptance and commitment therapy (iACT) for eating disorders in type 1 diabetes. | An Internet-based intervention for eating disorders consisting of automated computer-tailored feedback with or without supplemented frequent or infrequent support from a coach: study protocol for a randomized controlled trial. (Protocol) |
| Binge eating predicts adherence to digital self-monitoring during behavioral weight loss. | Internet-based cognitive-behavioral therapy for bulimia nervosa: a controlled study. (Full text unavailable) |
| Clinicians' perspective on an app for patient self-monitoring in eating disorder treatment. | Introducing Dietary Self-Monitoring to Undergraduate Women via a Calorie Counting App Has No Effect on Mental Health or Health Behaviors: Results From a Randomized Controlled Trial. (Full text unavailable) |
| Cognitive Behavioral Training Using a Mobile Application Reduces Body Image-Related Symptoms in High-Risk Female University Students: A Randomized Controlled Study. | Smartphone-Enhanced Low-Threshold Intervention for adolescents with Anorexia Nervosa (SELTIAN) waiting for outpatient psychotherapy: study protocol of a randomised controlled trial. (Protocol) |
| Demographic and clinical characteristics of individuals utilizing an internet-based digital coaching program for recovering from binge eating. | Computerised psychoeducation for patients with eating disorders (Full Text Unavailable) |
| Development of a Smartphone Application for Eating Disorder Self-Monitoring. | The Use of General Health Apps Among Users with Specific Conditions: Why College Women with Disordered Eating Adopt Food Diary Apps. (Not intervention) |
| Does personalized feedback improve the outcome of cognitive-behavioural guided self-care in bulimia nervosa? A preliminary randomized controlled trial. | Apps and Eating Disorders: A Systematic Clinical Appraisal. (Review) |

| | |
|---|---|
| Efficacy and acceptability of self-monitoring via a smartphone application versus traditional paper records in an intensive outpatient eating disorder treatment setting. | Efficacy and acceptability of self-monitoring via a smartphone application versus traditional paper records in an intensive outpatient eating disorder treatment setting. (Duplicate) |
| Efficacy of a transdiagnostic cognitive-behavioral intervention for eating disorder psychopathology delivered through a smartphone app: a randomized controlled trial. | Virtual Online Home-Based Treatment During the COVID-19 Pandemic for Ultra-Orthodox Young Women With Eating Disorders. (Not app) |
| Exploring Participants' Experiences of a Web-Based Program for Bulimia and Binge Eating Disorder: Qualitative Study. | Self-Help and Guided Self-Help Treatments for Bulimia Nervosa and Binge Eating Disorder (Not Digital Intervention) |
| Improving aftercare with technology for anorexia nervosa after intensive inpatient treatment: A pilot randomized controlled trial with a therapist-guided smartphone app. | Online cognitive behavioral therapy for bulimic type disorders, delivered in the community by a nonclinician: qualitative study. (Not app) |
| Just-in-time adaptive interventions: A novel approach for enhancing skill utilization and acquisition in cognitive behavioral therapy for eating disorders. | The abrupt transition from face-to-face to online treatment for eating disorders: a pilot examination of patients' perspectives during the COVID-19 lockdown. (Not app) |
| Mobile Health Adoption in Mental Health: User Experience of a Mobile Health App for Patients With an Eating Disorder. | Smartphone-Based Self-Monitoring, Treatment, and Automatically Generated Data in Children, Adolescents, and Young Adults With Psychiatric Disorders: Systematic Review. (Review) |
| Moving online: young people and parents' experiences of adolescent eating disorder day programme treatment during the COVID-19 pandemic. | A smartphone application for semi-controlled collection of objective eating behavior data from multiple subjects. (Full text unavailable) |
| Patient use of a self-monitoring app during eating disorder treatment: Naturalistic longitudinal cohort study. | Annual Research Review: Digital health interventions for children and young people with mental health problems - a systematic and meta-review. (Review) |
| Perspectives of e-health interventions for treating and preventing eating disorders: descriptive study of perceived advantages and barriers, help-seeking intentions, and preferred functionality. | Annual Research Review: Digital health interventions for children and young people with mental health problems - a systematic and meta-review. (Review) |
| Randomized Controlled Trial Comparing Health Coach-Delivered Smartphone-Guided Self-Help With Standard Care for Adults With Binge Eating. | A Survey of Attitudes towards Computerized Self-Help for Eating Disorders within a Community-Based Sample. (Not app) |

| | |
|---|---|
| Smartphone application for adolescents with anorexia nervosa: an initial acceptability and user experience evaluation. | Integrating User-Centered Design and Behavioral Science to Design a Mobile Intervention for Obesity and Binge Eating: Mixed Methods Analysis. (Not intervention) |
| Subgrouping the users of a specialized app for eating disorders. | Development of a smartphone application for eating disorder self-monitoring. (Duplicate) |
| Targeting dietary restraint to reduce binge eating: a randomised controlled trial of a blended internet- and smartphone app-based intervention. | Parental consent: A potential barrier for underage teens' participation in an mHealth mental health intervention. (Not intervention) |
| The relationship between working alliance with peer mentors and eating psychopathology in a digital 6-week guided self-help intervention for anorexia nervosa. | Translating evidence-based treatment for digital health delivery: a protocol for family-based treatment for anorexia nervosa using telemedicine. (Protocol) |
| The Role of Regular Eating and Self-Monitoring in the Treatment of Bulimia Nervosa: A Pilot Study of an Online Guided Self-Help CBT Program. | Views on online self-help programmes from people with eating disorders and their carers in UK. (Full text unavailable) |
| Virtual Reality App for Treating Eating Behavior in Eating Disorders: Development and Usability Study. | Patient use of a self-monitoring app during eating disorder treatment: Naturalistic longitudinal cohort study. (Duplicate) |
| Web-Based Fully Automated Self-Help With Different Levels of Therapist Support for Individuals With Eating Disorder Symptoms: A Randomized Controlled Trial. | Self-help and guided self-help for eating disorders. (Review) |

| Included from Full Text (12) | Excluded from Full Text (16) |
|---|---|
| A Clinician-Controlled Just-in-time Adaptive Intervention System (CBT+) Designed to Promote Acquisition and Utilization of Cognitive Behavioral Therapy Skills in Bulimia Nervosa: Development and Preliminary Evaluation Study. | An evidence-based gamified mHealth intervention for overweight young adults with maladaptive eating habits: study protocol for a randomized controlled trial. (Protocol not intervention) |
| A Guided Online and Mobile Self-Help Program for Individuals With Eating Disorders: An Iterative Engagement and Usability Study. | Binge eating predicts adherence to digital self-monitoring during behavioral weight loss. (Not app-based) |
| Virtual Reality App for Treating Eating Behavior in Eating Disorders: Development and Usability Study. | Demographic and clinical characteristics of individuals utilizing an internet-based digital coaching program for recovering from binge eating. (Not app-based) |

| | |
|---|---|
| An open trial of app-assisted acceptance and commitment therapy (iACT) for eating disorders in type 1 diabetes. | Does personalized feedback improve the outcome of cognitive-behavioural guided self-care in bulimia nervosa? A preliminary randomized controlled trial. (Not app-based) |
| Targeting dietary restraint to reduce binge eating: a randomised controlled trial of a blended internet- and smartphone app-based intervention. | Exploring Participants' Experiences of a Web-Based Program for Bulimia and Binge Eating Disorder: Qualitative Study. (Not app-based) |
| Cognitive Behavioral Training Using a Mobile Application Reduces Body Image-Related Symptoms in High-Risk Female University Students: A Randomized Controlled Study. | Moving online: young people and parents' experiences of adolescent eating disorder day programme treatment during the COVID-19 pandemic. (Not app-based) |
| Development of a Smartphone Application for Eating Disorder Self-Monitoring. | Perspectives of e-health interventions for treating and preventing eating disorders: descriptive study of perceived advantages and barriers, help-seeking intentions, and preferred functionality. (Does not evaluate apps) |
| Efficacy and acceptability of self-monitoring via a smartphone application versus traditional paper records in an intensive outpatient eating disorder treatment setting. | Subgrouping the users of a specialized app for eating disorders. (Not app-based) |
| Efficacy of a transdiagnostic cognitive-behavioral intervention for eating disorder psychopathology delivered through a smartphone app: a randomized controlled trial. | The relationship between working alliance with peer mentors and eating psychopathology in a digital 6-week guided self-help intervention for anorexia nervosa. (Not app-based) |
| Improving aftercare with technology for anorexia nervosa after intensive inpatient treatment: A pilot randomized controlled trial with a therapist-guided smartphone app. | The Role of Regular Eating and Self-Monitoring in the Treatment of Bulimia Nervosa: A Pilot Study of an Online Guided Self-Help CBT Program. (Not app-based) |
| Smartphone application for adolescents with anorexia nervosa: an initial acceptability and user experience evaluation. | Virtual Reality App for Treating Eating Behavior in Eating Disorders: Development and Usability Study. (Not app-based) |
| Randomized Controlled Trial Comparing Health Coach-Delivered Smartphone-Guided Self-Help With Standard Care for Adults With Binge Eating. | Web-Based Fully Automated Self-Help With Different Levels of Therapist Support for Individuals With Eating Disorder Symptoms: A Randomized Controlled Trial. (Not app-based) |

| | |
|---|---|
| Patient use of a self-monitoring app during eating disorder treatment: Naturalistic longitudinal cohort study. | An app-based blended intervention to reduce body dissatisfaction: A randomized controlled pilot study. (Not ED diagnosis; full text unavailable) |
| | Just-in-time adaptive interventions: A novel approach for enhancing skill utilization and acquisition in cognitive behavioral therapy for eating disorders. (Not app-based intervention) |
| | Mobile Health Adoption in Mental Health: User Experience of a Mobile Health App for Patients With an Eating Disorder. (Population professionals, not ED patients) |
| | Clinicians' perspective on an app for patient self-monitoring in eating disorder treatment. (Population professionals, not ED patients) |

## Chapter Two: Appendix 1. Stage Two Interview Schedule

1. Can you tell me about how you started your ED recovery journey?

2. What prompted you to seek help?

3. Can you tell me about the goals you set for yourself when you started your recovery journey?

4. What were the main challenges you faced, or are facing, if any, during your recovery journey?

5. What are the main resources (personal and/or external—for example, people or services), that you feel are/were most useful to you during your recovery process?

6. What do you attribute your long-term recovery to the most?

7. If you have received therapeutic support, which aspects were the most helpful to you?

8. What are the strategies that you currently use to prevent relapse?

9. If you have experienced relapse, recently or in the past, can you tell me how you coped with it?

10. How do you feel you have changed, if you have changed, throughout your recovery journey?

11. Can you tell me a bit more about the areas in your life (e.g., relationships with your loved ones, work, hobbies, etc.) that you feel have changed the most since you have started your recovery?

12. What does recovery mean to you/how do you define it?

13. Is this different from how others (your GP, your friends and family, other people in recovery) define it?

14 What advice would you give to people starting recovery? What about people maintaining it?

15. Is there anything you would like to add?

## Chapter Two: Appendix 2. Stage Two Participant Information Sheet

**Eating Disorder Recovery Maintenance:**

**A Mixed-Methods Exploration of Protective Factors and Relapse Buffers**

### 1. Invitation to research

We would like to invite you to take part in in a research study about eating disorder (ED) recovery. My name is Emma Craft and I am the principal investigator for this project, which I am conducting as part of my doctoral studies at Manchester Metropolitan University.

This is the first of two stages of our research project. This stage will involve asking people who have been in recovery from an ED questions about what things they have found to be helpful in maintaining their recovery and what difficulties they have faced in maintaining their recovery. We will use the information from the interviews in this first stage to then create an app, with the aim of supporting individuals with EDs in their recovery.

### 2. Why have I been invited?

You have been invited to take part in this study because you are a member of an ED recovery-focused Facebook group. For this stage of the study, I am interviewing people who have been in recovery for at least two years because I am interested in finding out more about long-term eating disorder recovery, and the risk of relapsing is highest in the first 1.5 years of recovery. I am keen to hear about your lived experiences—your perspective and voice is important to be heard. Adults of all ages, genders, and ethnicities are welcome to participate, and we especially encourage participants who identify as male, LGBT+, or an ethnic minority to participate as these people are underrepresented in eating disorder research. Approximately 10 participants will be interviewed for this stage of the study.

### 3. Do I have to take part?

It is up to you to decide after reading through this information sheet. I will be available to contact via email for any questions you have about the information presented here. I will then ask you to express your consent to take part in the study by selecting ‘I agree’ on the consent form (CF) that you can find in the email that contained this form. Again, you are free to email me with any questions you may have about the consent form. You are free to withdraw from the research study at any time, without giving a reason.

### 4. What will I be asked to do?

You will be asked to take part in a 45-60 minute long interview via Skype. We will arrange a date and time that best suits you; however, the interview will need to take place during November 2020, December 2020, or January 2021. During the interview, you will be asked a series of open-ended questions about your experience of eating disorder recovery—looking specifically at what has been helpful, what has increased your resilience, what barriers you have faced, how you have prevented relapse, and what resources you have used in the past, are currently using, or would like to access in the future. Our Skype interview will be audio-recorded using the in-app recording tool so that I can type up a transcription of the interview and use your data along with the other participants' data to inform the app development.

### 5. Are there any risks if I participate?

Although unlikely, the contents of the app may trigger unpleasant thoughts and feelings connected to your body image, eating disorder, and/or elicit distress. If this happens, you will be able to contact me (using my email address, at the bottom of this sheet), my research supervisor, or other organisations for support such as B-eat or Samaritans. You will be emailed a Debrief Sheet reminding you of this at the end of the study, which will include all the contact information. If you are currently experiencing ED symptoms, or feel you are at risk of experiencing distress when asked to discuss/recall events or any element related to your ED, we kindly ask for you to not participate, to avoid triggering you.

### 6. Are there any advantages if I participate?

There is no direct advantage of participating, though you may find the interview to be an interesting opportunity to reflect on your recovery journey. Your participation will help to contribute to research about eating disorder recovery and will improve current knowledge about what can promote recovery maintenance over time. If the app created from the second stage of the study is successful and participants find it helpful, it will be made available to the public for other people to benefit from its use.

### 8. What will happen with the data I provide?

When you agree to participate in this research, we will collect from you personally-identifiable information.

The Manchester Metropolitan University (‘the University’) is the Data Controller in respect of this research and any personal data that you provide as a research participant.

The University is registered with the Information Commissioner’s Office (ICO), and manages personal data in accordance with the General Data Protection Regulation (GDPR) and the University’s Data Protection Policy.

We collect personal data as part of this research (such as your age). As a public authority acting in the public interest we rely upon the ‘public task’ lawful basis. When we collect special category data (such as medical information or ethnicity) we rely upon the research and archiving purposes in the public interest lawful basis.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained.

We will not share your personal data collected in this form with any third parties.

If your data is shared this will be under the terms of a Research Collaboration Agreement which defines use, and agrees confidentiality and information security provisions. It is the University’s policy to only publish anonymised data unless you have given your explicit written consent to be identified in the research. **The University never sells personal data to third parties.**

We will only retain your personal data for as long as is necessary to achieve the research purpose. Your anonymity and the confidentiality of your data will be protected by asking you to create a unique identification code, that you will use to access the app. You will be prompted to create the code after having consented to participation and when accessing the app for the first time. Your data will only be identified by using this code. Besides me, only my supervisors will have access to the data, as well as authorised representatives from MMU to permit study-related monitoring, audits and inspections. The anonymised data and the research records will be stored for up to ten years on the University server.

For further information about use of your personal data and your data protection rights please see the University’s Data Protection Pages (https://www2.mmu.ac.uk/data-protection/).

### 9. What will happen to the results of the research study?

The data collected as part of this study will be analysed and discussed as part of my doctoral dissertation. They will also be published in academic journals and may also be discussed in national and international conferences on the themes of mental health, eating disorders, and mental health-related mobile apps. Any publications or discussions about the research will maintain your anonymity. You are welcome to contact me after the study is complete in January 2022 if you would like to receive a summary of the findings via email.

**10. Who has reviewed this research project?**

This research project has been reviewed by my director of studies (Dr Daniela Di Basilio), research supervisors (Dr Maria Livanou and Dr Amuda Agneswaran), field supervisors (Dr Hannah Wilson and Dr Caroline Vermes) and the MMU Ethics Committee.

**11. Who do I contact if I have concerns about this study or I wish to complain?**

Primary Investigator: Emma Elizabeth Craft, Doctorate Student, Psychology Department
emma.e.craft@stu.mmu.ac.uk
Dr Daniela di Basilio, Director of Studies (DoS): Psychology Lecturer, Psychology Department
d.di-basilio@mmu.ac.uk / 0161 247 2593
Dr Maria Livanou, 1st Supervisor: Senior Lecturer, Psychology Department
m.livanou@mmu.ac.uk / 0161 247 5463
Dr Amuda Agneswaran, 2nd Supervisor: Lecturer, Psychology Department
a.agneswaran@mmu.ac.uk / 0161 247 2547
Prof Khatidja Chantler, Faculty Head of Ethics Department of Psychology
k.chantler@mmu.ac.uk / 0161 247 1316

If you have any concerns regarding the personal data collected from you, our Data Protection Officer can be contacted using the legal@mmu.ac.uk e-mail address, by calling 0161 247 3331 or in writing to: Data Protection Officer, Legal Services, All Saints Building, Manchester Metropolitan University, Manchester, M15 6BH. You also have a right to lodge a complaint regarding the processing of your personal data with the Information Commissioner's Office as the supervisory authority. Please see: https://ico.org.uk/global/contact-us/

**THANK YOU FOR CONSIDERING PARTICIPATING IN THIS PROJECT.**

## Chapter Two: Appendix 3. Stage Two Participant Debrief Sheet

## Eating Disorder Recovery Maintenance:

## A Mixed-Methods Exploration of Protective Factors and Relapse Buffers

Thank you for participating in our study about eating disorder recovery, and for the contributions of your interview. We hope that you have found it interesting and have not been upset by any of the topics discussed. However, if you have found any part of this experience to be distressing and you wish to speak to one of the researchers, please contact:

Emma Elizabeth Craft, Primary Investigator, Doctorate Student, Psychology Department, emma.e.craft@stu.mmu.ac.uk
or
Dr Daniela di Basilio, Director of Studies (DoS): Psychology Lecturer, Psychology Department
d.di-basilio@mmu.ac.uk / 0161 247 2593

You can also contact the following organisations:

**B-eat Eating Disorders**
https://www.beateatingdisorders.org.uk/support-services
0808 801 0677 (9am–8pm during the week, and 4pm–8pm on weekends and bank holidays)
One-on-one Help Chat also available on website

**Samaritans**
https://www.samaritans.org/
116 123 (Available 24/7)
Jo@samaritans.org (response within 24 hours)
Self-Help App also available in the App Store

## Chapter Two: Appendix 4. Stage Two Sample Transcript

I: So my first question for you is if you could just give me a little bit of an overview into how you started your recovery journey?

P: So like, background, when I was eight was the first time I felt like, self-conscious about my body. And then I like, forgot about it because I got interested in swimming. But when I turned thirteen, I developed my eating disorder. Cus you know, appearance is more important when you're thirteen. And erm, I had a very intense six-month period where I lost a lot of weight, and that's where the eating disorder started. And then I didn't really get any treatment the first year or so, so then my parents would force feed me—or like, force me to eat. And then I went from like, anorexic to more like, binging. So I had a short period where I was anorexic and then some bulimic, but it's been always unspecified for me, because I don't meet all of the criteria for like, the specific ones. Um, recovery started… I had gone to a psychiatrist that wasn't specialized in eating disorders so that like, didn't help that much. But then when I started going to a psychiatrist that was, it got better because then you've got information on like, diet, what you should eat, what a portion size looks like and so on, and how much exercise the body needs, what's too much, it was a lot of information and learned a lot. For me, I feel like the things that helped the most was—first, stop measuring your weight so you don't have the control over the weight. And then after that it was getting like, routines. Getting out of the house, doing things and meeting friends, and having like a support system. It was very important to have a supportive environment but also having things in your daily routine that wasn't a focus on food. Because when you're sick, your main focus is on food. And when you go see a psychiatrist it's very easy to—like they'll tell you have to eat at certain times, and so many times during a day, and it's all focused on food. For me, like, recovery happened when you start to get everything else in life rolling, when I had other things that I enjoyed doing that wasn't based on food, so you can just sort of like, forget about it. Uh, and like obviously it goes back and forth. But like, having goals, that was for me, maybe like going to the gym—like not necessarily going there and staying for an hour. Even like five minutes, ten minutes, even just getting there meant that I had to leave the house and that like, walk would be like enough to make you feel a bit better. So, routines, support, and having activities or things that you do throughout the day that are not food based.

I: I hear you, that is such an issue in treatment experiences of people. The obsession with food and it taking up your whole life and then in treatment adding more of a focus on it can be so difficult—

P: Yeah, establishing some routine, cus like, even people who don't have eating disorders, they eat because they are bored. And if you have an eating disorder and you have pushed all your close friends away, and you don't have interests in other activities cus you're consumed with thoughts about food, it erm—I lost my thought. What was I saying in the beginning?

I: That if you don’t have a group of friends around, you become even more occupied with food…

P: Okay yeah so, in treatment, in short, it’s more like about food, and it’s important that you like, sort of, do talk about food and it’s important that you do pressure yourself a bit you know, to test the limit, if you have food restrictions. But I think I was a pretty special case, because when I moved for university, at the dorm where I live in they actually cook the food for us, so I didn’t have that control anymore. So in the beginning it was really hard to adapt because I didn’t know what was in the food, but the end result was it really helped a lot, not having that control. Cus you couldn’t count calories, because you wouldn’t know what’s in it really.

I: So when you first went to see this psychiatrist, what happened? Did you make the decision yourself or did your parents push you to go or?

P: Well, my parents first put me in the waiting line to see a psychiatrist. And like the first one that I had that wasn’t a specialist in eating disorders, I was kind of fine going to. But when I went to see the eating disorders psychiatrist at first I was a bit hesitant because there was so much focus on weight and food. Erm, and like weight was like a big issue so actually I would have preferred if it was more focused on food and recovery rather than weight. Because like you know, every time you had to weigh in and stuff like that. So like, I was like, I started when I was fifteen going to the psychiatrist but I was eighteen when I started going to the like, eating disorders psychiatrist. So by then I could have like, quit if I’d wanted to but it depends where you’re at in the eating disorder. So like if you’re losing weight, erm, most people I don’t think will seek help by their own will because it’s like you’re succeeding or the eating disorder is succeeding. But if you’re struggling going up and down up and down or just up up up, I think it’s more common that you seek help by yourself. So anyways, I ended up liking her the woman that I got, she understood me and like I told her that I didn’t want to focus that much on weight so I wouldn’t look when I got weighed in and I didn’t want her to like, afterwards talk to me and say ‘oh it’s bad that you’ve lost weight’ or ‘oh it’s good that you’ve gained weight’—I was okay with her like, seeing it, even though I would have preferred not to be weighed in. but as long as she didn’t bring it up during our meeting it didn’t matter that much.

I: So when you were going through your recovery, since weight was something you didn’t want to focus on, what were the goals you kind of set yourself? What did you want to achieve or were hoping to get out of being in treatment?

P: Obviously you wanted to get rid of that like, all or nothing mentality—like, either you would like, starve and try to lose weight or you would binge and go all in, so you wanted to stabilize it so your emotions wasn’t like… all over the place. So like you know, you binge, you’re full, but you have anxiety. Where if you’re starved your brain is kind of like, at ease, but kind of not because you’re thinking about food so it’s like you’re not really happy, you’re focused on food, but you’re not feeling bad. And you want to just feel happy, sort of. And that's more focus on… like getting friends, you know, and having hobbies and being passionate about something. Cus you know you miss that, because your focus was so on food and it wasn't necessarily positively on food it was more like, control. You wanted your brain to be at peace, you wanted to be happy and have the life you had before like as a kid, just enjoying things.

I: I hear you! What was the hardest bit? What challenges came up in your early recovery that were really difficult?

P: I think it was to like, to let go of control, definitely was the hardest. And it was like, something—some parts that I could control, I could control if I went out or did things, like tried new things like hanging out with friends. But also some things I had to be more pushed into. Like for example here where I live now, I can't control what I eat because they serve us. I mean I could if I really wanted to because I could go out and buy it but then I would have to pay extra because my food is already part of my rent here. Maybe if I would have been like, deep in my eating disorder I would have paid for the food and not eaten it and just made my own but now that I'm so far along, it was the next step. First step was like, not weighing yourself and trying to get like passionate about new things or the things you were passionate about before.

I: So it's been now a couple years, what's coming up day to day now for you in recovery that's different from when you were 18?

P: What's different? Well I think I do like, a lot more things now, and so the eating disorder gets a lot less—if any—space because I have my routine. Leaving the house, going for a walk, talking to friends over the phone. And where I live I know that breakfast is served between this and that time, and lunch, and dinner, so I have routines so that's very very important. That's also why I enjoy the work—like my future job, I felt like being a teacher you have a routine. Like, when you're busy with kids you can't really focus on overthinking things because there's always things happening like, you're focused on them, so time flies by. And you usually eat with the kids so you eat at a certain time, you're outside, you're inside, yeah.

I: Have you experienced any relapses since starting recovery?

P: Of course there's like harder days, easier days, and thoughts like feelings that you had can come back. But it's like how you react to them. Like I had a few days ago, a day where I wasn't very active, like I was just at home, I didn't go out, I didn't do my regular routine. So then I was like okay, how can I make the best out of this situation? And so I just made like, a cup of coffee, took a blanket and watched a movie. Stuff like that—instead of overthinking things, being comfy.

I: So you are quite attuned to knowing that this routine is very important to you, staying occupied seems to be like a kind of cornerstone keeping you in recovery. How do you think you've changed as a person, if you have, in recovery?

P: I think I've become like, more… definitely more interested in like psychology, I think a lot of people are. But also like, you know, your view of the world changed because you see one side as very happy and then one side as like pressure and stuff like that, like societal pressure. I have a brother, I don't know how he feels mentally but he seems very happy, he has always been very popular and things like that and always the sporty kid. I feel like I'm more aware of less happy things in life…yeah.

I: So yeah, maybe not becoming pessimistic but definitely a lot more realistic about the world having experienced that struggle. What about your relationships with other people, have those changed as you've gone through recovery?

P: Uh, I think better because I was always very open—well, not always, but when I started recovery I became more open about it. Cus that was also like…it's hard to have friends when you're trying to hide something like, consuming you a bit. Like often you go out to eat with friends like, often it's around food, going to cafes and things like that. And if you always say no, people will wonder or you think people will think things, and you will be like, the the party pooper if you will, always saying no, no, no. And so that's why like, eventually you don't go to those meetings. But when you're open they're more understanding…and so it became, the more open you were the more understanding they were. Or at least close friends were. Some people might get intimidated and back off cus they don't like know how to treat you. But I was lucky. Most people where I went to school had some kind of psychological hardship like depression or eating disorders and everyone was quite open about it so it wasn't really a problem.

I: Yeah so there's that level of understanding. Um, what about managing triggers, is there anything that you kind of have like in place, for yourself to take care—um, that you do?

P: Not anymore, but like, in the beginning I had to try to rethink things. So instead of thinking like, I can't have chips, I would compare maybe like chips and fruit and think like okay, this is what the fruit will give my body and this is what the chips will give my body. And that would like make it so that I would choose the fruit and not forbid the chips. So it's seeing food as something positive. Erm, so I would always try to, in the beginning when it was still hard, I would try to think like, 'what will this food give my body' instead of just good/bad calories. And then I would usually pick more healthy foods because I would think of all the nutrients it would give. And the longer you came into recovery, the more you could experiment with the more tough foods. Like now recently, the last year, I've been able to have like a bowl of chips instead of the bag. So it's become more like, nothing is forbidden, and I can have it whenever I want in moderation, like in a moderate size.

I: Nice! So I think a lot of people have different definitions of recovery, so how do you define recovery, and how does that differ from how other people might define it?

P: I define recovery as when you like, learn to live happy—like when the eating disorder doesn't control your life and you can do things. Nothing is forbidden, you can do whatever you want, and you're happy. Cus I remember like also early in the recovery, it's maybe a normal misconception, maybe not, that you should do the opposite to your eating disorder. So if your eating disorder says you can't have like, coke, so you say okay I have to have sugary coke because that's how I overcome the eating disorder. But then, later I learned like, I don't have to do the exact opposite. Cus like before I had my eating disorder my family would drink diet coke all the time, and I didn't have to do the exact opposite of the eating disorder, I could still like—it's about like not, not restricting. So I could have a sugary soda, but it's not like I have to have a sugary soda instead of a diet soda. Because it shouldn't be like, I have to do this or I have to do that, it should be like, I can do whatever and I'll just choose whatever suits me at the moment or what I want. So it's like, basically recovery is no 'musts'. Or 'musts' or 'can'ts'—I can't have this or I must have this. I take whatever I want when I want it, sort of thing. And I don't feel horrible afterwards.

I: It sounds like you've really developed a lot of trust in yourself in knowing and knowing that what you decide to have will be okay, will be good for you whether that's nutritionally or just for your happiness, for your mood. It's hard to get to that place—how do you kind of know that you're in an okay place to trust yourself about making those decisions?

P: I think it's a lot about routine, like having like a life that you enjoy. Like for me, I go out a lot, seeing friends whether that's in person or over the phone or like I have classmates or I'll go training…just doing things that like—I think physical activity is very important. Cus in the beginning I wouldn't do physical activity because it was seen as bad, as compensating. Because again you do the opposite—if the eating disorder says you've got to move then you say okay, I shouldn't move. But physical activity is like, good for humans. And so like getting the routine was kind of, erm, important—almost more important, because then my focus was on something else and then the food sort of followed because partly I changed the mindset towards food—I tried to change the mindset towards food. And then it was like, you know I eat so I can do these activities instead of like, I have to do these activities to allow myself to eat. And then like, losing control. Losing control about what I eat and about how much I weigh. More like looking at the, 'okay I have my vegetables here, this is a normal portion size, I feel full, and I have enough energy to do my activities that give me like, joy.'

I: Yeah. Um, what advice would you give to people starting to think about their recovery?

P: It's to take it at your own pace. Cus I don't think recovery is like—real recovery—is possible until you want to recover. So take it at your own pace, it's not like, a rush to recovery. Take small steps.

Um, start trying to have, establish a routine that makes you feel happy, or like good mentally. Like getting fresh air and things like that. Um, yeah. And just figuring out what works for you and establishing yeah a routine.

I: And what about people trying to maintain recovery long-term or prevent relapse?

P: I think then it's like important to focus on like, your hobbies. And if you don't have any hobbies then try new things and don't push like, the bar too high. It's not like you're gonna be the best the first time you try something. Put the bar low. Like for me it was just leaving the house, getting to the gym, it wasn't how long I was gonna stay at the gym, it was just getting there that was like the goal. And don't have like, a picture of what recovery is, sort of. It's not that you have to do the complete opposite of your eating disorder, it's that you have to find a way that works for you. So like don't stop exercising completely, don't go to the extreme difference and just eat junk food, it's just about finding that balance.

I: It's about finding that moderation, yeah. Cus like you say, doing the opposite of your eating disorder doesn't like, set you up to get back to reality does it? So, if you think back to 18-year old you, if you had a recovery app then, what would have been helpful for you then or what would you have wanted to see?

P: Educational like, um, presentations like with a dietitian and physician and psychologist. And then like, um, you know, having that, taking it at your own pace. Not rushing it, there's no clear end goal, it's about finding what works for you, it's not black and white. Like make it very clear that there is no one recovery and it's all about you taking it at your own pace and finding out what works for you. You could also encourage like, new ways of thinking. For example I found it very helpful to think about food through education, like you know an apple could like help your fingernails or your hair or this food could be good for your heart or brain. Have the good parts of food. Like, I don't know how to like phrase it but nutrition without the calories. Why we need it, focusing on the good.

I: Was there anything, um, on the more psychological side of things that you found to be helpful either in therapy or in your own time that has helped you?

P: On my own time it's like friends, and getting out. Moving could be like go for a walk or something more intensive but like just not staying at home basically. As for the psychologist I thought it was fun to like talk, I would be happy for the hour that I was there. I had one hour sessions like every other week. And so for the time between my sessions it was very important to have routine and a support system. I found like that my parents, when they found out or when I tried to talk to them and tell them how I wanted them to treat me and what I needed help with, they would more act out of fear. So they were afraid of me losing weight so they would give me a lot of cookies and just applaud like, yay, she's eating. Where the psychiatrist was more understanding and obviously had more experience about the matter. Yeah.

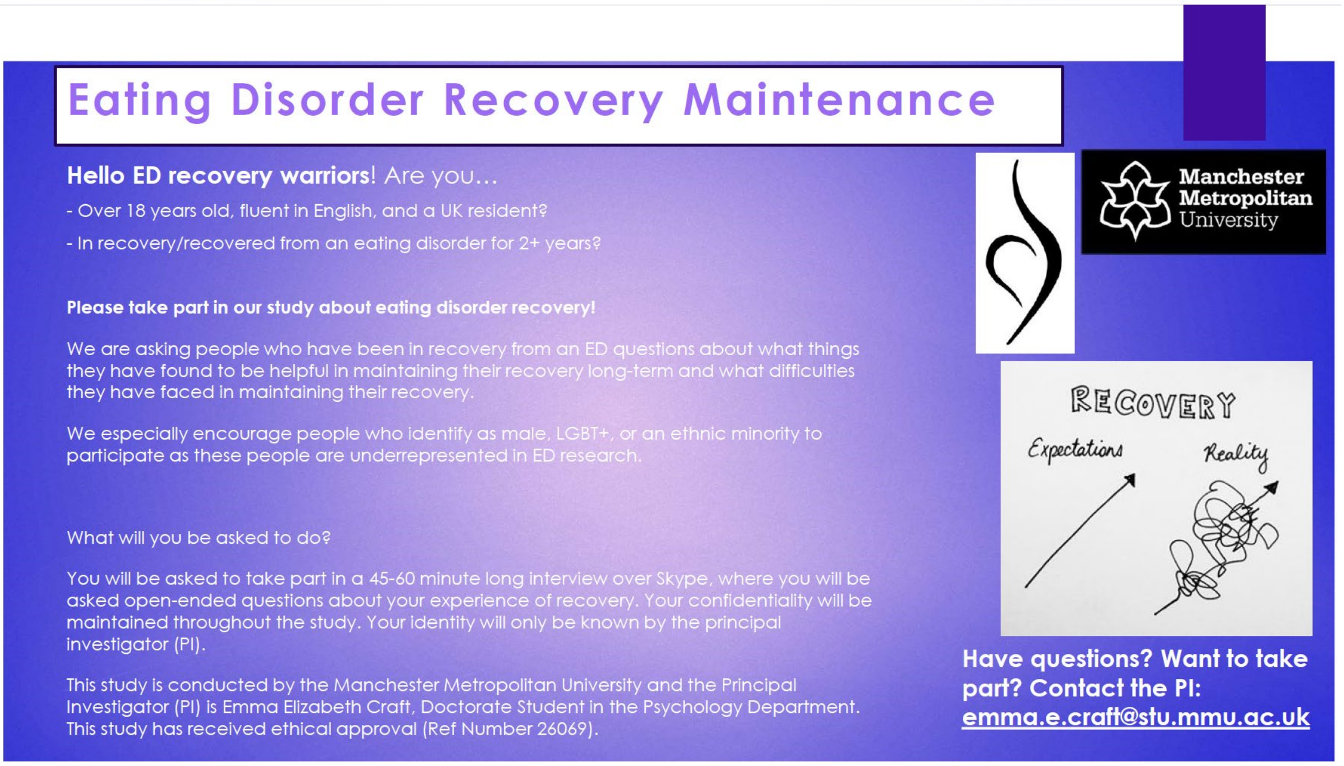
I: That is the end of my questions, is there anything else that you want to add or that you think might be relevant?

P: Mm, not that I can think of. I hope that I answered all of your questions.

I: Thank you so much for your time, it has been such a joy talking to people. It’s nice to hear people’s experiences and what has worked for people in recovery. Um, yeah, thank you.

# Chapter Two: Appendix 5. Recruitment Flyers

## Stage Two Digital Recruitment Flyer



Eating Disorder Recovery Maintenance

**Hello ED recovery warriors**! Are you…

- Over 18 years old, fluent in English, and a UK resident?
- In recovery/recovered from an eating disorder for 2+ years?

**Please take part in our study about eating disorder recovery!**

We are asking people who have been in recovery from an ED questions about what things they have found to be helpful in maintaining their recovery long-term and what difficulties they have faced in maintaining their recovery.

We especially encourage people who identify as male, LGBT+, or an ethnic minority to participate as these people are underrepresented in ED research.

What will you be asked to do?

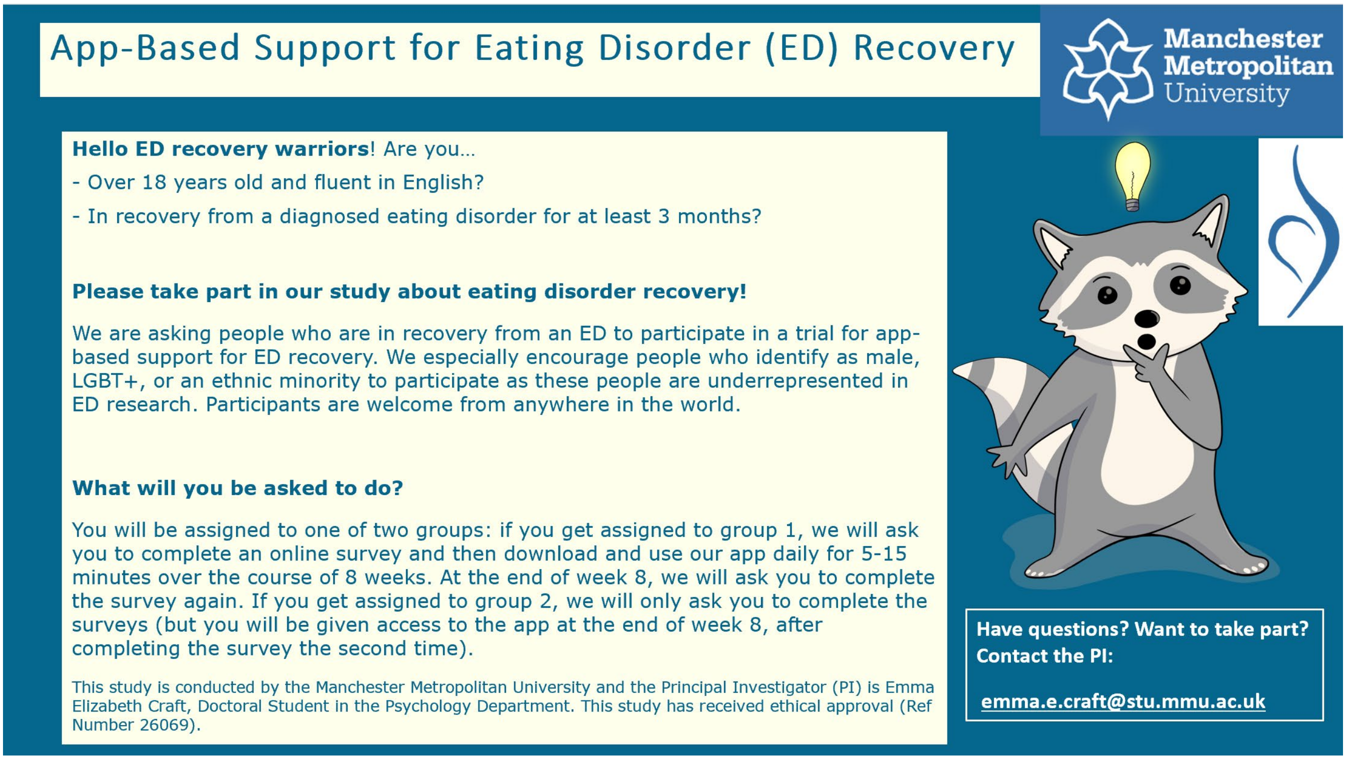
You will be asked to take part in a 45-60 minute long interview over Skype, where you will be asked open-ended questions about your experience of recovery. Your confidentiality will be maintained throughout the study. Your identity will only be known by the principal investigator (PI).

This study is conducted by the Manchester Metropolitan University and the Principal Investigator (PI) is Emma Elizabeth Craft, Doctorate Student in the Psychology Department. This study has received ethical approval (Ref Number 26069).

Manchester Metropolitan University

**Have questions? Want to take part? Contact the PI: emma.e.craft@stu.mmu.ac.uk**

## Stage Three Digital Recruitment Flyer



App-Based Support for Eating Disorder (ED) Recovery

Manchester Metropolitan University

**Hello ED recovery warriors**! Are you…

- Over 18 years old and fluent in English?
- In recovery from a diagnosed eating disorder for at least 3 months?

**Please take part in our study about eating disorder recovery!**

We are asking people who are in recovery from an ED to participate in a trial for app-based support for ED recovery. We especially encourage people who identify as male, LGBT+, or an ethnic minority to participate as these people are underrepresented in ED research. Participants are welcome from anywhere in the world.

**What will you be asked to do?**

You will be assigned to one of two groups: if you get assigned to group 1, we will ask you to complete an online survey and then download and use our app daily for 5-15 minutes over the course of 8 weeks. At the end of week 8, we will ask you to complete the survey again. If you get assigned to group 2, we will only ask you to complete the surveys (but you will be given access to the app at the end of week 8, after completing the survey the second time).

This study is conducted by the Manchester Metropolitan University and the Principal Investigator (PI) is Emma Elizabeth Craft, Doctoral Student in the Psychology Department. This study has received ethical approval (Ref Number 26069).

**Have questions? Want to take part? Contact the PI:**

**emma.e.craft@stu.mmu.ac.uk**

# Chapter Two: Appendix 6. Stage Three Participant Information Sheet

## Eating Disorder Recovery Maintenance:

## A Mixed-Methods Exploration of Protective Factors and Relapse Buffers

### 1. Invitation to research

I would like to ask you to take part in a research study about eating disorder recovery. My name is Emma Craft and I am the primary researcher for this project; I am also a doctoral student at Manchester Metropolitan University. This information sheet is about part two (of two) of the research study. This stage will involve asking people who are currently in recovery from an eating disorder to participate in the trial of a recovery-focused smartphone app, which myself and my research team at the University have developed. Half of the participants of the study will be asked to use this eating disorder recovery app for 8 weeks. All participants will be asked to fill in a few brief questionnaires before and after 8 weeks. Participants who were not randomly selected to use the app for 8 weeks will gain access to use the app following the trail period.

### 2. Why have I been invited?

You have been invited to take part in this study because you expressed interest in the app in a Facebook ED recovery group, have received a diagnosis of an ED, and have been in recovery for at least three months. **It is important that you have received a professional diagnosis of an ED and that you consider yourself to have been in recovery for a minimum of 3 months.** Adults of all ages, genders, and ethnicities are welcome to participate, and we especially encourage participants who identify as male, LGBT+, or an ethnic minority to participate as these people are underrepresented in eating disorder research. Approximately 42 people in total will be included in this stage of the research.

### 3. Do I have to take part?

It is up to you to decide after reading through this information sheet. I will be available to contact via email for any questions you have about the information presented here. I will then ask you to digitally sign a consent form to show you agreed to take part; this will be done by you reading through the consent form on the digital software Qualtrics (via which you will also fill in the questionnaires) and clicking on ‘I agree’ at the end. Again, you are free to email me with any questions you may have about the consent form. You are free to withdraw from the research study at any time, without giving a reason.

**4. What will I be asked to do?**

After you have consented to participate in the project, you will be asked to download a free application (either our eating disorder recovery app or CBT thought diary) from the Apple or Android app store and set up an account. You will be asked to fill in a series of brief questionnaires before you start using the app. You will be asked to use the app every day, to the best of your ability. The app will contain activities for you to do, which are based on evidence-based therapies as well as input from people in long-term eating disorder recovery whom we interviewed for stage one of the study. You will be asked to fill in the same set of questionnaires again after 8 weeks.

**5. Are there any risks if I participate?**

There is a potential risk that the questions you are asked about your eating disorder recovery in the questionnaires or the content you are presented with in the app may be triggering. If you feel triggered or distressed in any way, you will have support available to you. If you do choose to participate in the study, you will be given a distress protocol which will outline this support and what to do if you are feeling negatively affected by the study. Additionally, you can always withdraw from the study at any time.

**6. Are there any advantages if I participate?**

There is no direct advantage of participating, though you may find the app you are using to be helpful in your recovery. Your participation will help to contribute to research about eating disorder recovery which may ultimately help yourself and other people in recovery from an eating disorder. If the eating disorder recovery app is successful and participants find it helpful, it will be made freely available in the app stores to the public so that other people in recovery can use it too.

**7. What will happen with the data I provide?**

When you agree to participate in this research, we will collect from you personally-identifiable information.

The Manchester Metropolitan University (‘the University’) is the Data Controller in respect of this research and any personal data that you provide as a research participant.

The University is registered with the Information Commissioner’s Office (ICO), and manages personal data in accordance with the General Data Protection Regulation (GDPR) and the University’s Data Protection Policy.

We collect personal data as part of this research (such as name, telephone numbers or age). As a public authority acting in the public interest we rely upon the ‘public task’ lawful basis. When we collect special category data (such as medical information or ethnicity) we rely upon the research and archiving purposes in the public interest lawful basis.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained.

We will not share your personal data collected in this form with any third parties.

If your data is shared this will be under the terms of a Research Collaboration Agreement which defines use, and agrees confidentiality and information security provisions. It is the University’s policy to only publish anonymised data unless you have given your explicit written consent to be identified in the research. **The University never sells personal data to third parties.**

We will only retain your personal data for as long as is necessary to achieve the research purpose.

I, the principal researcher, will be solely responsible for the data entry and analysis. The data will be collected online (via the above-mentioned questionnaires on the Qualtrics software) and the set of all the participants’ data will be securely stored on my MMU OneDrive.

Your anonymity and confidentiality will be protected by asking you to create a unique identification code. You will be prompted to create the code after having consented to participation and before seeing the first measure of the Qualtrics survey. Your data will only be identified by using this code, and your personal information will be stored separately from your data. My director of studies and project supervisors will have access to the data, as well as authorised representatives from MMU to permit study-related monitoring, audits and inspections. The anonymised data and the research records will be stored for ten years on my OneDrive folder.

For further information about use of your personal data and your data protection rights please see the University's Data Protection Pages (https://www2.mmu.ac.uk/data-protection/).

**What will happen to the results of the research study?**

The research study is being conducted for my doctoral dissertation, will be submitted for marking, and will be made available on the MMU theses repository. I also aim to submit the research for publication in an academic journal such as The International Journal of Eating Disorders or The European Eating Disorders Review. The findings of the study may also be discussed in national and international conferences on the themes of mental health, eating disorders, and mental health-related mobile apps. Any publications or discussions about the research will maintain your anonymity. You are welcome to contact me after the study is complete in January 2022 if you would like to receive a summary of the findings via email.

**Who has reviewed this research project?**

This research project has been reviewed by my director of studies (Daniela Di Basilio), research supervisors (Maria Livanou and Amuda Agneswaran), field supervisor (Hannah Wilson), the director of Oakwood Psychology Services (Caroline Vermes), the MMU Ethics Committee, and the participants of stage one of the study as part of a patient/public involvement activity.

**Who do I contact if I have concerns about this study or I wish to complain?**

Primary researcher: Emma Elizabeth Craft, Doctorate Student, Psychology Department
emma.e.craft@stu.mmu.ac.uk
Dr. Daniela di Basilio, Director of Studies (DoS): Psychology Lecturer, Psychology Department
d.di-basilio@mmu.ac.uk / 0161 247 2593
Dr. Maria Livanou, 1st Supervisor: Senior Lecturer, Psychology Department
m.livanou@mmu.ac.uk / 0161 247 5463
Dr. Amuda Agneswaran, 2nd Supervisor: Lecturer, Psychology Department
a.agneswaran@mmu.ac.uk / 0161 247 2547
Prof Juliet Goldbart: Faculty Head of Ethics Department of Psychology
j.goldbart@mmu.ac.uk / 0161 247 2578

If you have any concerns regarding the personal data collected from you, our Data Protection Officer can be contacted using the legal@mmu.ac.uk e-mail address, by calling 0161 247 3331 or in writing to: Data Protection Officer, Legal Services, All Saints Building, Manchester Metropolitan University, Manchester, M15 6BH.

You also have a right to lodge a complaint in respect of the processing of your personal data with the Information Commissioner's Office as the supervisory authority. Please see: https://ico.org.uk/global/contact-us/

**THANK YOU FOR CONSIDERING PARTICIPATING IN THIS PROJECT.**

# Chapter Two: Appendix 7. Stage Three Participant Debrief Sheet

## Eating Disorder Recovery Maintenance:

## A Mixed-Methods Exploration of Protective Factors and Relapse Buffers

Thank you for participating in our study about eating disorder recovery, and for the contributions of the data gathered from your app usage. We hope that you have found it interesting and have not been upset by any of the topics presented in the app or questionnaires. However, if you have found any part of this experience to be distressing and you wish to speak to one of the researchers, please contact:

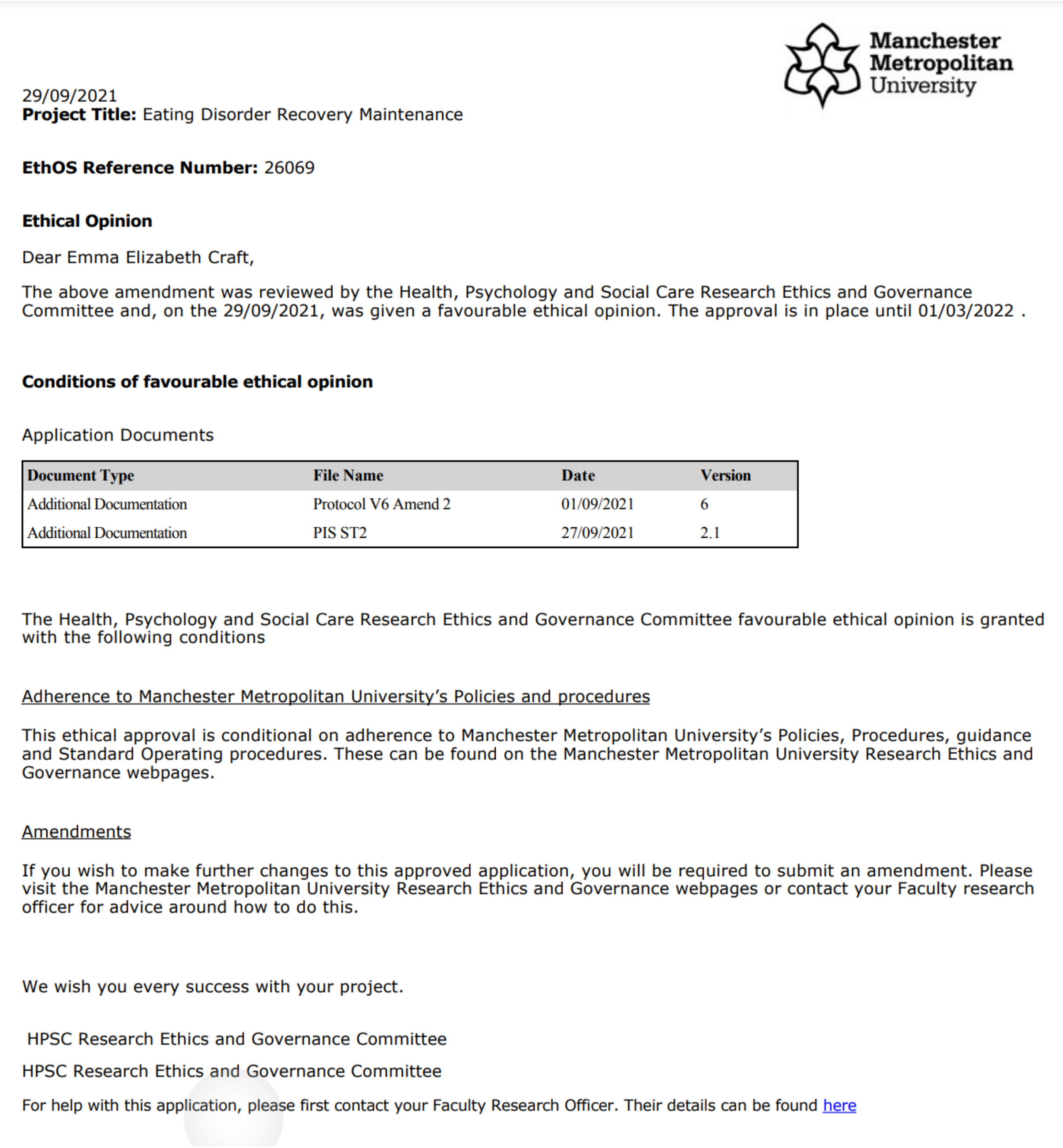
Emma Elizabeth Craft, Primary Investigator, Doctorate Student, Psychology Department, emma.e.craft@stu.mmu.ac.uk
or
Dr Daniela di Basilio, Director of Studies (DoS): Psychology Lecturer, Psychology Department
d.di-basilio@mmu.ac.uk / 0161 247 2593

You can also contact the service from which you have previously accessed support for your eating disorder, or the following organisations:

**B-eat Eating Disorders**
https://www.beateatingdisorders.org.uk/support-services
0808 801 0677 (9am–8pm during the week, and 4pm–8pm on weekends and bank holidays)
One-on-one Help Chat also available on website

**Samaritans**
https://www.samaritans.org/
116 123 (Available 24/7)
Jo@samaritans.org (response within 24 hours)

# Chapter Two: Appendix 9. MMU Ethical Approval Letter



Manchester Metropolitan University

29/09/2021
**Project Title:** Eating Disorder Recovery Maintenance

**EthOS Reference Number:** 26069

**Ethical Opinion**

Dear Emma Elizabeth Craft,

The above amendment was reviewed by the Health, Psychology and Social Care Research Ethics and Governance Committee and, on the 29/09/2021, was given a favourable ethical opinion. The approval is in place until 01/03/2022 .

**Conditions of favourable ethical opinion**

Application Documents

| Document Type | File Name | Date | Version |
|---|---|---|---|
| Additional Documentation | Protocol V6 Amend 2 | 01/09/2021 | 6 |
| Additional Documentation | PIS ST2 | 27/09/2021 | 2.1 |

The Health, Psychology and Social Care Research Ethics and Governance Committee favourable ethical opinion is granted with the following conditions

Adherence to Manchester Metropolitan University's Policies and procedures

This ethical approval is conditional on adherence to Manchester Metropolitan University's Policies, Procedures, guidance and Standard Operating procedures. These can be found on the Manchester Metropolitan University Research Ethics and Governance webpages.

Amendments

If you wish to make further changes to this approved application, you will be required to submit an amendment. Please visit the Manchester Metropolitan University Research Ethics and Governance webpages or contact your Faculty research officer for advice around how to do this.

We wish you every success with your project.

HPSC Research Ethics and Governance Committee

HPSC Research Ethics and Governance Committee

For help with this application, please first contact your Faculty Research Officer. Their details can be found here

## Chapter Three: Appendix 1. Stage Two Interview Schedule

1. Can you tell me about how you started your ED recovery journey?
2. What prompted you to seek help?
3. Can you tell me about the goals you set for yourself when you started your recovery journey?
4. What were the main challenges you faced, or are facing, if any, during your recovery journey?
5. What are the main resources (personal and/or external—for example, people or services), that you feel are/were most useful to you during your recovery process?
6. What do you attribute your long-term recovery to the most?
7. If you have received therapeutic support, which aspects were the most helpful to you?
8. What are the strategies that you currently use to prevent relapse?
9. If you have experienced relapse, recently or in the past, can you tell me how you coped with it?
10. How do you feel you have changed, if you have changed, throughout your recovery journey?
11. Can you tell me a bit more about the areas in your life (e.g., relationships with your loved ones, work, hobbies, etc.) that you feel have changed the most since you have started your recovery?
12. What does recovery mean to you/how do you define it?
13. Is this different from how others (your GP, your friends and family, other people in recovery) define it?
14. What advice would you give to people starting recovery? What about people maintaining it?
15. Is there anything you would like to add?

## Chapter Three: Appendix 2. Stage Two Feedback Questions

1. Please tell me what type of app activity you found most helpful (e.g., journals, CBT worksheets, CFT worksheets, guided meditations...?)
2. Please tell me what aspect of the app you liked the most, and why?
3. Please tell me what aspects of the app you disliked, and why?
4. Please tell me if the app influenced any aspect of your mental/physical/emotional health? Why or why not and how?
5. Do you have any suggestions for how to improve the app in terms of content? Was there something you felt was missing? Something you would have liked to see?

## Chapter Three: Appendix 3. Stage Three PPI Survey

1. Imagine a mobile app that helps people who are in recovery from EDs. What would be the three types of contents (for example, body image/mood tracking, thought diaries, worksheets, guided meditations, etc.) that you think could be most useful to include? If you can think about more than 3, please feel free to add more!
2. What are the types of contents that you think should not be included in a recovery support app, as they may be 'triggering' and/or create discomfort?
3. We are planning to create an app that will engage people in activities and tasks based on psychological principles every day, for 8 weeks (2 months). We think that this will give people the opportunity to get the support they need, and experience the long-term benefits of the app programme. Do you think this length of time (8 weeks) is appropriate?
4. Have you ever tried using any mobile apps to support your mental health or eating disorder recovery?
5. What is a 'helpful habit' that supports you to stay in recovery, that you think we could include in our app? This could be anything that works for you. If you have more than one and you want to share, please do!
6. Are there any particular risks* that you see in people using a mobile app to support their recovery from ED(s)? * "Risk" here refers to 'negative effects' linked to using the app, such as experiencing distress.
    a. You answered 'yes' to the previous question. What risk(s) do you think could be linked to using an app to support recovery? How do you think we could best protect people from these risk(s)?
7. Think about three words, phrases, or activities that you would not want to see in the app as they may cause distress/make people feel uncomfortable. What would they be?
8. Now think about the layout of the app (colours, fonts, graphics etc.). Do you have any comment on these aspects? For example, are there particular colours we should be using, or other graphic aspects (widgets on the screen etc.) that you think we should include?
9. This is Reddy, the 'buddy' that will be part of our app and act as a companion for app users engaging with the app. What do you think of Reddy? Any suggestion is welcome (for example, would you prefer if Reddy was a human, instead of an animal?)
10. Now think about creating the 'most useful app for people in ED recovery'. What is the one thing this app should be able to do?
11. Thanks for your answers so far. The final part of our survey includes some questions about your current and past eating habits. We would appreciate it if you could answer all of them, as this would improve the quality of our data, but if you feel uncomfortable with any question, please remember you are free not to answer. We collect this information to understand if there are links between people's eating habits and what they might need/look for in an app to support recovery from EDs.
12. Can you tell us which type(s) of eating disorders you have been diagnosed with? Please select all that apply.
13. For how many years have you suffered from one or more eating disorders (EDs)?
14. How long have you been in recovery for?

Hi, welcome back! Let's start a relapse prevention plan today. I'll keep this handy for you to look at any time you need. Thinking about relapse can be a little scary, so take it slowly and gently and remember all that you have accomplished and overcome already in your recovery journey!

So… what are your early warning signs for relapse? Thoughts? Feelings? Behaviours? Circumstances? If you've already worked on making a plan like this in therapy before, feel free to input what you already have and add anything else that might be relevant!

**Lapse Warning Signs**

| My Early Warning Signs | Thought/Behaviour? | How Can I Challenge This? | What is My Plan? |
|---|---|---|---|
| *Example: Skipping a meal* | *Example: Behaviour: skipping a meal. Thought: it's 'no big deal'.* | *Example: Reminding myself that meal skipping is a slippery slope that can lead to other ED behaviours. Eating regularly is a central part of my recovery.* | *Example: Stick to a regular eating schedule and set reminders or schedule meals with family/friends if needed.* |

Hey there! I'd like to start out by asking how you're feeling about your recovery today?

*(Sliding scale 0-10 with sad at 0, neutral at 5, and happy at 10). They pick one, then are brought up to the respective correlating screen.*

*Prompts:*

**Feeling Good! (7-10):**

That's good to hear! Can you tell me a little more information about how you're feeling?

(Free Text Input)

Which of these activities would you like to work on today?

*(Menu selection to choose from their activities for the week)*

(After the activity) Thanks for trying one of these out! Can you tell me how you're feeling, now? (Present the sliding scale again)

**Neutral (4-6):**

Feeling a bit on the fence, huh? Can you tell me a little more information about how you're feeling?

(Free Text Input)

Which of these activities would you like to work on today?

*(Menu selection to choose from their activities for the week)*

Thanks for trying one of these out! Can you tell me how you're feeling, now? (Present the sliding scale again)

**Not Great. (0-3):**

Sorry to hear you're struggling right now. Can you tell me a little more information about how you're feeling?

(Free Text Input)

Which of these activities would you like to work on today?

*(Menu selection to choose from their activities for the week)*

Thanks for trying one of these out! Can you tell me how you're feeling, now? (Present the sliding scale again)

This worksheet is from CBT-E. CBT-E is the abbreviation for "enhanced cognitive behaviour therapy" and is one of the most effective treatments for eating disorders.

This worksheet looks at the practical aspects of long-term recovery maintenance. Key points to remember are:

- Beware of labelling a setback as a 'relapse' (being back at square one).
- Nip setbacks in the bud by following treatment guidelines (e.g. restart food and mood monitoring; adopt a pattern of regular eating; plan eating ahead; avoid following rigid and extreme dietary rules; question "feeling fat"; use distraction activities and problem-solving; reduce problematic body checking or avoidance).
- As a general guideline, do the opposite of what the eating disorder mindset makes you want to do and get involved in other aspects of your life.

| **Minimizing the risk of setbacks** | |
|---|---|
| Maintain a regular eating pattern | My regular eating pattern is:<br>*(Ex: I aim for 3 meals and 3 snacks a day)* |
| Avoid dieting or avoiding food groups | What this means for me:<br>*(Ex: I shouldn't cut out a food group, like carbs)* |
| Maintain weight in healthy weight range | My healthy weight range is: |
| Beware of engaging in unhelpful body checking or body avoidance | What this means for me:<br>*(Ex: I'm aiming to only look in the mirror to check my outfit looks tidy for work)* |

Journaling can be a way to practice self-compassion through showing up for yourself, opening up to vulnerability, and embracing imperfections. Your inner critic might rear its ugly head when you're journaling, but you can use this to help your words flow through creating a dialogue with yourself. Acknowledging your inner critic is a key part of developing self-compassion.

When you're journaling, set aside around 5 minutes to write—you don't want to become too overwhelmed. If your journaling brings up difficult feelings, give yourself space to talk about what's come up with a supportive person like a friend, trusted family member, or counsellor. Don't forget you have access to helplines on the 'Help' page here in the app, too.

If you can, try to write for the full 5 minutes. If you run out of words, you can write about your current feelings, thoughts, or physical sensations in the moment. Don't worry about writing full sentences or grammatically correct phrases; a messy stream of consciousness is good! It's about the process, not the product.

**CBT Journaling: What Causes Eating Disorders? (5 Mins)**

*Prompt: What do I think causes eating disorders? What personal, cultural, or societal influences are involved? How have these impacted me? What factors do I think contributed to me developing my eating disorder?*

(Free Text Input)

## CFT Worksheet: What do I Tend to Avoid? (10-15 Mins)

Though avoiding difficulties and anxiety-inducing situations is completely human and understandable, it can also contribute to maintaining problems. Avoidant behaviour's goal is to protect us and keep us safe—our brains doing their best to keep us away from danger. But this doesn't help us overcome our fears or reduce our anxiety—in fact, avoiding our fears can make us even more fearful of them, leading to a vicious cycle. A good example for this in people with eating disorders is avoiding eating socially/around others, or avoiding fear foods and food groups.

So, can you have a think about what you avoid that might be a fear you need to face?

| |
|---|
| To start with, spend some time thinking about the things or situations you feel nervous about and tend to avoid (certain emotions, memories, people, places, or situations)? Write them down here: |
| How do you try to protect yourself from the things you fear? What are your safety or avoidance strategies? |
| What are you afraid might happen if you don't engage in safety/avoidance behaviours? |
| Can you validate and have empathy for your fears, and crucially, the avoidant strategies you've been using to try to manage these? Is there a way of seeing that it makes sense that you may feel like this, given your fears? Could you make some notes on this, starting with, 'It is understandable that I respond like this because…' |

## End of Week Recovery Reflection (5-10 mins)

Well done completing your third week with me, and thanks so much for trying the exercises out and checking in!

It might be helpful for you to keep a diary of the work you do here in the app as well as your recovery overall. You can track your progress, monitor changes, remind yourself of your achievements, and notice and respond to any difficulties along your journey. Logging what you have done and its impact can help guide your recovery journey, highlighting what has been particularly helpful and what you want to work on more.

At the end of each week, I'll ask you to fill in this log to reflect on what you have learned about yourself and your recovery.

| |
|---|
| What have I found useful so far and would like to practice in the coming days, weeks, and months? |
| What will help me keep these practices up when I am struggling in my recovery? |
| How can I use compassionate self-help to prevent and cope with possible setbacks? |

Go ahead and update your 'Goals' tab and your Lapse Plan on the 'Help' page if there is anything you would like to add, too!

### Guided Meditation: Soles of the Feet (5 Mins)

This exercise is a good way to ground yourself and anchor your awareness in the present moment, paying specific attention to just the soles of your feet. It can be a helpful practice when you're feeling distressed and struggling to manage difficult emotions, like anxiety. It can be done pretty much anywhere, anytime. We'll be doing this exercise with the feet, but if that isn't possible for you, this can also be done with your hands and palms, too.

Get yourself into either a sitting or standing position, where your feet are flat on the floor. Now, take three slow, deep breaths. If it feels okay, you can gently close your eyes.

Now, focus on the feeling of the soles of your feet on the floor. Slowly wiggle your toes and see what you can feel beneath you and above you. Are you wearing shoes or socks? Are your feet on carpet or tile? Are your toes warm or cold? What are the physical sensations that you can feel very specifically in your toes while you wiggle them?

Keep breathing slowly and evenly while you now shift your attention to the arches of your feet and see what you can feel there. Really pay attention again to the physical sensation of your skin and any contact it has with the air or the floor. If you're barefoot, maybe see if you can feel the air flowing around your feet.

If your mind wanders, don't worry, it's normal. When you notice your mind has wandered, just gently bring your attention back to the physical sensations of the soles of your feet, or your hands if you are using those instead for this exercise.

Lastly, move your attention to the heels of your feet. You can dig them into whatever surface they're on and really pay attention to the feelings in your heels. Put all of your focus and attention into the heels of your feet.

If it feels okay, see if you can offer up some gratitude, appreciation, and respect to your feet and all that they do for you. Take one more moment to focus all of your attention on the soles of your feet and just notice whatever they're feeling right now.

## Planned Activity: (10 Mins)

Today's task is to just engage in your hobby or self-care for a few minutes! You can choose something you listed in Week One, or a suggested activity for this week is to build a self-soothe box.

Instructions for building a self soothe box:

A self-soothe box is a great toolkit to have on hand for managing anxiety, low mood, eating disorder or self-harm urges, or emotional distress. You'll be filling a container with items for all five of your senses that can help comfort you, ground you, or distract you when you're feeling overwhelmed.

It can be helpful to have your soothe box ready in preparation for times in which you might be triggered or distressed. It's best to build your box when you're feeling calm and positive.

Some suggestions/ideas for things you can include for each of your five senses:

Vision: a colouring book and pencils, pictures of loved ones or places you find soothing, or keepsakes/knickknacks that hold importance to you.

Touch: a favourite stuffed toy/pillow/soft clothing item, play-dough, a stress ball, or lotion.

Smell: a candle, incense, perfume/aftershave, or essential oil. Smell is our sense that best activates our memory, so if there's a certain smell you associate with feeling safe, try to find something to put in to jog your memory!

Sound: a pair of headphones as a reminder to listen to a meditation, white noise, or a playlist you can make yourself of songs that give you hope.

Taste: single-wrapped tea bags (mint is good for anxiety nausea), gummy vitamins, or a bottle of water as a gentle reminder to hydrate.