An Interpretative Phenomenological Analysis of Premature Treatment Termination Experienced by Service Providers with Lived or Living Experience of Anorexia Nervosa who have been Service Users.

Word Count: 30,707

(Excluding: Title page, acknowledgements, contents pages, abstract, tables, figures, references and appendices).

Emma Curry

July 2025

Portfolio Volume 1: Major Research Project

Submitted to the University of Hertfordshire in partial fulfilment of the degree of Doctorate in Clinical Psychology

Acknowledgements

To our Participants, whose experiences sit at the very heart of this study:

My sincerest gratitude goes to you, Rachel, Serena, Samantha, Louise, Sarah, Rose, Kevin, and Amy. Thank you, with all my heart, for entrusting me with your experiences and for being so generous with your time and expertise. It is an absolute privilege to have met you. I hope that, despite your anonymity, you feel as seen and heard as can be in the pages that follow.

To Natalie and Jenny:

Thank you so very much for believing in me and this study. Thank you, too, for discussing languaging with me until the cows came home, left out of disinterest, returned to see whether conversation had brightened up a little, and eventually left once more with the intention of permanently relocating to a field closer in proximity to a decidedly different thesis.

Natalie, if I am permitted entry into our profession, please know that you are entirely to blame. I read the BPS' position statement on psychologists with lived and living experiences as my invitation into the profession; a warm embrace of a welcome into a space I had felt certain I was not permitted to enter.

Jenny, I am forever indebted to you for being the person who shared the BPS' position statement with me. Thank you, from the depths of my heart, for seeing and hearing me, and for being so generous with your time and wisdom. Thank you, too, for your patience with me while I continue to learn and grow.

To our Consultant:

Thank you for being there for me back then and thank you for being here with me now. I am so very proud of us.

To Chris and Jareth:

My family… I wouldn't be here without you. I owe you the world. Since the world is not mine to give, I hope you'll accept payment of my debt in the form of time. And carrots. I'll be home soon.

To KAC:

"Hey, what a day – our journey is underway and there's a line in the sand that my tears have washed away. This is the day I learn to disobey. For now I understand the beauty of this disarray."

And Finally, a Note for Myself:

You've done what you could. No matter the outcome, I'm proud of you.

You can breathe, now.

Table of Contents

Table of Appendices

List of Tables and Figures

List of Abbreviations

AAN	Atypical Anorexia Nervosa
AN	Anorexia Nervosa
APA	American Psychiatric Association
APPG	All-Party Parliamentary Group (Eating Disorders)
BMI	Body Mass Index
BPS	British Psychological Society
CAMHS	Child and Adolescent Mental Health Services
CMHT	Community Mental Health Team
DSM-V	Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition
EbE	Expert by Experience
ECDA	Ethics Committee with Delegated Authority
ED	Eating Disorder
FTP	Formally Trained Prosumer
GDS	Gender Dysphoria Service
GETs	Group Experiential Themes
HCPC	The Health and Care Professionals Society
ICD-11	International Classification of Diseases, 11th Revision
IPA	Interpretative Phenomenological Analysis
IwAN	Individual(s) with Anorexia Nervosa
IwDEAN	Individual(s) with Dual Experience of Anorexia Nervosa
LEs	Lived and/or Living Experiences (of Mental Health Difficulties)
MEED	Medical Emergencies in Eating Disorders

MeSH	Medical Subject Headings
PETs	Personal Experiential Themes
PICU	Psychiatric Intensive Care Unit
PIS	Participant Information Sheet
PR	Primary Researcher
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PTT	Premature Treatment Termination
RCP	Royal College of Psychiatrists
RJE	Reflexive Journal Entry
‘SPiDER’	‘Sample, Phenomenon of Interest, Design, Evaluation, Research Type’
UH	The University of Hertfordshire
UK	United Kingdom
WHO	World Health Organisation

Abstract

Background: Anorexia nervosa (AN) is a pervasive eating disorder that is associated with significant morbidity, mortality, and poor prognosis. Individuals with anorexia nervosa (IwAN) have high rates of treatment not being completed as planned – often referred to in literature as 'premature treatment termination' (PTT) – which has been found to significantly hinder AN prognosis. Studies have called for the elucidation of this phenomenon alongside the centring of voices of lived experience in AN research more broadly. The dual-experienced population of AN service providers with lived or living experience of AN who have been service users is under researched. This population's personal experiences of PTT and the meaning that they give to them has yet to be explored.

Aims: The present United Kingdom-based study aimed to explore experiences of PTT and the meaning given to them by individuals with dual experience of AN.

Method: Interpretative Phenomenological Analysis (IPA) was applied to eight participant interview transcripts collected via individual semi-structured interviews to inform the development of group level experiential themes.

Results: Four group experiential themes were identified: systemic barriers: becoming lost; the systemic feeding of anorexia; being hurt by the helpers; and the gifts of dual experience of anorexia. These findings suggest that PTT is a systemic phenomenon, contrasting with some existing literature suggesting that PTT is inherently self-initiated by IwAN. The present participants' experiences of PTT left them feeling abandoned to their AN, lost in between treatment settings and within diagnostic margins, powerless and neglected around PTT events, feeling as though they were screaming and shouting to be heard, and lucky when receiving a good standard of care.

Implications: The present study's participants called for urgent systemic and cultural change within United Kingdom-based AN-treating systems with a view to reducing instances of

PTT, better managing transition processes between- and out of- treatment settings, reducing professionals' misunderstandings of AN, and improving AN prognoses.

Keywords: Anorexia nervosa, AN, eating disorders, EDs, dual experience, prosumers, lived experience practitioners, mental health, Interpretative Phenomenological Analysis, IPA, lived experience, living experience, qualitative, experiential, premature treatment termination.

1.0 Introduction

1.1 Overview

This chapter will begin by outlining the languaging of this report and introducing anorexia nervosa (AN), exploring contemporary literature to provide an overview of the illness' current clinical landscape and associated challenges. It will then explore the phenomenon of premature treatment termination (PTT) in relation to AN, consider the need for novel lenses in AN research, and provide an overview of the existing literature relating to the experiences of individuals with dual experience of AN. This chapter will conclude by situating the Primary Researcher (PR), outlining their ontological and epistemological positions in relation to their research and considering their personal relationship to the project.

1.2 A Note on Language

The languaging of this project has been guided by the project's Consultant and participants, each of whom have lived or living experience (defined by Music et al. (2021) as historic or present experience respectively) of AN. In accordance with their unanimous preference, diagnosis-first language has not been used. Instead, and in accordance with the participants' preference, people experiencing AN will be referred to as 'individuals with AN' (IwAN) unless citing research which adopts alternative terminology to specify the nature of its population of study (eg. 'inpatient').

1.3 The Clinical Landscape

1.3.1 Anorexia Nervosa

AN is a pervasive eating disorder (ED) that is associated with significant morbidity, mortality, and poor prognosis (Arcelus et al., 2011). Current diagnostic criteria in the International Classification of Diseases, 11th Revision (ICD-11: World Health Organisation [WHO], 2022) distinguish AN by a significantly low body weight for an individual's height, age and developmental stage, that cannot be explained by the presence of another health condition or the unavailability of food. Commonly used diagnostic thresholds for AN in adults are either a body mass index (BMI) of less than 18.5kg/m^2 or a loss of more than twenty per cent of their total body weight within a six-month period (WHO, 2022). WHO (2022) note that AN's associated low body weight is accompanied by a persistent pattern of behaviours intended to promote weight loss or prevent weight restoration. AN is typically associated with a fear of weight gain, where body weight and shape become central to the individual's self-evaluation and can be inaccurately perceived to be average or excessive (WHO, 2022). While, in previous editions of diagnostic manuals, low weight was a requirement for an AN diagnosis, ICD-11 (WHO, 2022) included diagnostic recognition of individuals who are recovering from AN and have returned to a normal body weight (defined as above 18.5kg/m^2); it specifies that an AN diagnosis should be retained until a full and lasting recovery is achieved where, independent of treatment, a healthy weight is maintained and behaviours aimed at reducing body weight cease. While AN has historically been conceptualised as a visible illness identifiable by low body weights (Schmidt and Treasure, 2006), diagnostic criteria are beginning to shift towards a place of recognising that one 'can't weigh mental health' (Curry and Andriopoulou, 2023) and that AN cognitions can persevere once weight loss has been corrected.

While AN is considered a mental health diagnosis (American Psychiatric Association [APA], 2013; WHO, 2022), it is an illness that often has severe psychological and physical symptoms (Takakura et al., 2019). AN can pose a high risk of medical complications resulting from self-imposed dietary restriction and subsequent weight loss (Hambleton et al., 2022), compensatory behaviours intended to counteract perceived or real weight gain (such as excessive exercise, intentional exposure to cold temperatures, self-induced vomiting, the misuse of laxatives and/or diuretics, the omission of insulin in individuals with diabetes, and the use of weight loss products (Chapuis-de-Andrade, 2019)), and self-harm or suicidal tendencies due to psychological distress related to AN psychopathology (Smith et al., 2017; Smithuis et al., 2018). AN continues to have among the highest mortality rates of any psychiatric condition, where more than 5% of IwAN die within four years of initial diagnosis (Auger et al., 2021) and reported long-term recovery outcomes are just 62.8% at a 22-year follow-up (Eddy et al., 2017). One in five deaths associated with AN is due to suicide, with comorbid diabetes (where insulin has been misused to influence weight and body shape), pneumonia, and heart failure also being leading causes of death (Sardar et al., 2015). AN is associated with 2.47 times the risk of death compared to individuals without AN, increasing to IwAN having 9.01 times the risk of death compared to non-AN controls after five years (Auger et al., 2021), contributing to a recognised need and urgency for early treatment intervention (Mills et al., 2023).

1.3.2 Treatment

Treatment approaches for AN should be multi-disciplinary and conducted with the support of specialist ED services (National Institute for Health and Care Excellence [NICE], 2020). NICE (2020) guidelines suggest that AN treatment should prioritise weight restoration (the process by which an individual is re-fed to their ‘normal’ body weight - a weight or ‘band’ of weights - at which their body functions optimally (Norris et al., 2024)) with a view to swiftly reversing the psychological and biological effects of starvation. Weight restoration should be supported by medical monitoring and evidence-based talking therapies, both of which should include psychoeducation about the illness (NICE, 2020). No treatment approach to date, however, has been found to reliably treat the potentially life-threatening condition and slow its high mortality rate, and research suggests that all existing approaches leave a proportion of sufferers symptomatic or at high risk of relapse (Muratore & Attia, 2021). After ten years of medical support, approximately 40% of IwAN continue to present with prolonged symptoms and disabilities (Rigaud et al., 2011). Treatment for AN is well-evidenced in research as being marked by IwANs' frequent and recurring relapse (Gregertsen et al., 2019), further illustrating the current limitations of treatment. AN incidence rates have continued to rise (Martinez-Gonzalez et al., 2020) and the number of IwAN with an illness severity requiring inpatient admission has increased unprecedentedly (Haripersad et al., 2021) while prognosis remains poor (Jagielska and Kacperska, 2017), despite the recent development and implementation of novel specialist-AN therapeutic approaches (Monteleone et al., 2022). Research suggests a lack of predictive validity around recovery (Crow, 2023) and death rates continue to rise (Van Eeden et al., 2021), leading researchers to highlight an urgent need for further understanding of the factors associated with the poor prognosis of the illness (Crow, 2023). Despite AN's high risk and unparalleled mortality rates amongst all diagnostically recognised psychiatric disorders (Treasure et al., 2020), ED research remains underfunded compared to other psychiatric fields, with the available funds being divided amongst all currently known ED diagnoses and hindering AN research prospects (All-Party Parliamentary Group (APPG) on EDs, 2021 and 2025; Stone et al., 2021).

Studies suggest that AN treatment approaches may be limited in their efficacy because the aetiology of the illness remains unclear (Clemente-Suarez et al., 2023; Stockford et al., 2018), with research associating the development of AN with a broad range of sociocultural, biological and psychological factors (Bakarat et al., 2023). Bakarat et al.'s (2023) rapid review, for example, found evidence of associations between AN and experiences of abuse, trauma, bullying, personality traits such as perfectionism and compulsivity, gender identity, neurodivergence, genetic components, internet usage, family context, and a broad range of psychological co-morbidities. The physiological mechanisms of the illness and how they might successfully be addressed are, however, a little clearer. Weight loss caused by intentional malnutrition of the significance and/or speed required for the conferral of an AN diagnosis, in addition to the impact of nutritional restriction, has been found to result in biological changes (Skowron et al., 2020). Studies of IwAN have observed sizeable, widespread reductions in cortical thickness, subcortical volumes and cortical surface area of the brain (Walton et al., 2022), which can impact upon cognitive functioning and contribute to the maintenance of the illness (Nickel et al., 2018; Stedal et al., 2018). Research has also found that effects of malnutrition, such as bloating and water retention, contribute to the perpetuation of AN's psychopathology due to their role in exacerbating physical and psychological discomfort when refeeding (Puckett et al., 2021). Researchers suggest that AN-related medical complications cannot resolve without weight restoration and that weight restoration is key to restoring a sufferer's psychological flexibility and enabling them to challenge AN's psychopathology (Cass et al., 2020). Research has also found that the less severe an individual's weight loss and the earlier the illness is addressed through weight restoration, the better the individual's prognosis for the full reversal of medical and psychological complications (Cass et al., 2020).

Studies reflect, however, that while weight restoration is crucial, the psychological difficulties associated with the illness extend beyond this point of physical recovery from starvation (Curry and Andriopoulou, 2023; Matter et al., 2012). Both pre- and post- weight restoration, research has associated AN with: significantly low self-esteem (Kelly et al., 2014); negative environmental factors and life experiences (Branley-Bell et al., 2023); suicidal thoughts (Lian et al., 2017); body image difficulties (Calugi et al., 2018); internal conflict (Bergamin et al., 2022); stigma (Brelet et al., 2021); discrimination (Curry and Andriopoulou, 2023); and psychological co-morbidities (Cardi et al., 2018). Research warns that treatment processes that overly focus on weight restoration as the panacea for recovery from AN can lead to individuals appearing recovered on clinical measures but continuing to experience enduring difficulties - which are evidenced as predictors of post-treatment relapse - that go uncaptured (Bardone-Cone et al., 2010; Kinnaird and Cooper, 2023).

1.3.3 'Recovery'

Definitions of 'recovery' from AN are broad and varied (Khalsa et al., 2017) and clinical and lived experience definitions often differ (Elwyn, 2023). There is, however, a consensus between the two groups that AN, as a physiological and psychological illness, requires treatment of- and improvement in- both domains in order for recovery to be obtained (Khalsa et al., 2017). In clinical settings and research, psychological and physiological improvements are commonly measured through the administration of psychometrics and weight and BMI measurements (WHO, 2022). In the context of AN's poor prognosis and treatment limitations, some studies have utilised the term 'recovery' interchangeably with 'improvements in weight and AN behaviours' (Karlsson et al., 2021), which researchers suggest may be complicating the field's conceptualisation of recovery from AN, conflating improvements with illness remission, and reducing the field's expectations of treatment (Bardone-Cone et al., 2010).

For those with lived or living experience of AN, research has found that recovery feels more personal (Dawson et al., 2014) and may be less clinically measurable or generalisable; studies suggest that lived experiences of recovery centre around hope (Asaria, 2023), autonomy and empowerment (Burke et al., 2024), interpersonal connection and quality of life (Dawson et al., 2014), and recognition that it is an ongoing process as opposed to an end point (Elwyn, 2023). Despite differing definitions of recovery and what it looks and feels like, research suggests that AN is a condition that, conceptually, should be treatable to the point of remission, with most medical and neuropsychological complications arising from the starvation associated with the illness recognised as fully reversible through weight restoration and psychological support (Cass et al., 2020; Matter et al., 2012).

1.4 Treatment Difficulties

1.4.1 Conceptualisations of Treatment Difficulties

While, in theory, there is some sense of what is needed for IwAN to 'recover', AN is a complex illness that is well documented in literature as a challenging presentation to treat (Abbate-Daga et al., 2013; Vitousek et al., 1998). Some research suggests that this may be due to the illness' ego-syntonic nature, whereby IwAN tend to identify with- and subsequently protect- their illness (Gregertensen et al., 2017; Monteleone et al., 2022). IwAN commonly report gaining comfort from their AN (Arcelus et al., 2011) and can therefore struggle to engage in treatment by choice, often reporting feeling ambivalent or fearful of doing so (Melles and Jansen, 2023). Some IwAN can struggle to recognise that they are unwell, and resist support due to an illness-related misconception that they are either healthy or, paradoxically, overweight (Vitousek et al., 1998). Research exploring the experiences of IwAN additionally suggests that some may experience positive effects resulting from starvation that can motivate them to maintain their AN and/or further their weight loss; in these contexts, the offer of treatment may be perceived as a threat to something that serves a positive function for the IwAN (Coniglio et al., 2019). These positive effects have been found to include feelings of emotional numbness, self-control and/or of having control, strength, freedom, and autonomy (Fuchs, 2022; Selby and Coniglio, 2020), and IwAN report that these positives often outweigh the negative experiences and risks associated with the illness (Fuchs, 2022). Researchers suggest that these positive experiences may contribute to both the emergence and persistence of AN psychopathology by forming reinforcing feedback loops (Selby and Coniglio, 2020).

Treatment limitations, in conjunction with the illness' ego-syntonicity and the positive reinforcement that AN can offer, have led to an association between IwAN and the narrative of being 'treatment resistant', despite there being no established clinical definition of the concept (Smith and Woodside, 2021) and the potential negative implications of this terminology for IwAN being recognised in literature (Weissman et al., 2016). The conceptualisation of AN as 'treatment resistant' appears to locate treatment difficulties within the IwAN as opposed to the treating system, and has become a commonly used term for explaining unsuccessful outcomes within AN research and clinical spaces (Weissman et al., 2016). In research, the illness' perceived 'treatment resistance' has most commonly been associated with the IwAN population's well documented high treatment attrition rates (eg. Vitousek et al., 1998), which studies consistently identify as a recognised threat to IwANs' already poor prognoses (Manon, 2000; Sly, 2009; Ulven et al., 2025; Vinchenzo et al., 2022). Attrition rates present a key challenge to the efficacy of ED treatments (Ulvan et al., 2025) and may contribute to AN's low remission rates (Fernandez-Aranda et al., 2021). Studies submit that ED treatment non-completion rates are amongst the highest of known psychiatric conditions (Linardon et al., 2017; Vinchenzo et al., 2022). Reviews have suggested that around 40% of individuals receiving treatment for an ED do not complete their full course of treatment, with further studies, spanning over thirty years, finding that attrition rates for IwAN receiving treatment rise beyond 50% (DeJong et al., 2012; Mewes et al., 2008; Vandereycken and Pierloot, 1983; Wallier et al., 2009); Sly et al.'s (2013) study of treatment 'drop-out' in IwAN across four specialist services found an overall attrition rate of 57.8%. In part due to the existing 'treatment resistant' or 'uncooperative' conceptualisation of IwAN (Stockford et al., 2018), research into the illness' treatment non-completion, attrition, and 'drop-out' rates has historically centred around IwANs' individual characteristics to identify possible traits for predicting their departure from treatment (Franzen et al., 2004; Sly et al., 2013; Pereira et al., 2006). To date, no studies have found significant individual predictors and there remains a lack of evidence relating to the causes of the phenomenon (Mahon, 2000).

1.4.2 Premature Treatment Termination

Wallier et al.’s (2009) review of literature identified key methodological barriers in research seeking to understand the phenomenon of IwAN ending treatment early. The first barrier was the field’s inconsistency in naming the phenomenon, thought to be prohibiting cohesion. Commonly adopted terms included treatment ‘drop-out’, treatment attrition, treatment non-completion, treatment refusal, administrative discharge, and non-routine discharge (eg. Dejong et al., 2012; Manon, 2000; Masson and Sheeshka, 2009; Wallier et al., 2009). Sly (2009) proposed that, as part of a conscious shift away from the privileging of language that centres blame within- or pathologises- IwAN, AN researchers adopt the single, over-arching term, ‘premature treatment termination’ (PTT) to refer to the phenomenon with a view to avoiding pejorative language. The present report will join contemporary research in adopting this terminology in accordance with Sly’s (2009) recommendation (eg. Björk et al., 2009; Seidinger-Leibovitz et al., 2020).

Wallier et al.’s (2009) second identified barrier was the absence of a shared definition of PTT amongst researchers. While researchers hold a broad consensus that the ‘premature’ component of PTT relates to treatment ending before originally expected (eg. Wallier et al., 2009), Manon (2000) defines it as ‘unforeseen’ while noting that other researchers leave it undefined (eg. Sly, 2009). Vinchenzo et al. (2022) noted that ‘premature’ in this context may mean different things to different stakeholders; some studies have defined it as a treatment ending prior to obtaining a desired outcome such as weight restoration (Smith et al., 2023), whereas others have conceptualised it as treatment terminated before a prescribed number of treatment sessions have been administered (eg. Jordan et al., 2017). Sly (2009) and Manon (2000) suggest that PTT is a unilateral event, actioned by either an IwAN or a clinician without the other’s agreement and with predicted negative consequences, whereas other studies recognise that PTT can lead to positive outcomes (eg. Bjork et al., 2009). Some recent publications conceptualise PTT as patient-initiated (eg. Vinchenzo et al., 2022), whereas others have considered the differences between clinician-initiated PTT and patient-initiated PTT, advocating that these are significant (eg. Sly et al., 2014). Some studies have centred around PTT in relation to evaluating a particular intervention (eg. Gregertsen, 2019) and many do not situate PTT events within the context of other interventions that may be ongoing for an IwAN after opting out of part of a wider treatment programme (eg. Elbaky et al., 2014). Further research suggests that, while PTT is a risk factor in AN prognosis, it has become an accepted and rationalised aspect of AN care due to persisting narratives around the illness' 'treatment resistance' and associated misconceptions (APPG on Eating Disorders, 2025; Forbes, 2020; Viljoen et al., 2023).

Lubieniecki et al. (2024) observed that the majority of literature relating to PTT in AN to date has centred around professionals' conceptualisations of the phenomenon and the collation of associated quantitative data, usually in relation to the evaluation of an intervention (Bjork et al., 2009). The findings of such studies are largely inconclusive and inconsistent (Bandini et al., 2006; Hoste et al., 2007; Mahon, 2000; Masson et al., 2007; Masson and Sheeshka, 2009; Ulven et al., 2025). At present, little research qualitatively captures IwANs' lived or living experiences of PTT. That which does suggests that such experiences are nuanced, and that PTT can be experienced as less of a standalone event, but instead as a series of experiences that culminate in the early ending of care (Vinchenzo et al., 2022). Vinchenzo et al. (2022) found that IwAN often associated self-initiated PTT with negative experiences of treatment. The authors reported that these experiences included feeling unheard and unsafe, and struggling with their treatment's 'hyper-focus' on weight, sharing that they felt this perpetuated their AN cognitions. Vinchenzo et al. (2022) identified PTT as a phenomenon comprising of not just individual-, but service- and wider system-level factors, and advocated for the need to improve AN service delivery to reduce IwANs' experienced need to self-initiate PTT events. Such findings are supported by wider research regarding lived and living experiences of AN treatment. Studies have noted that it is common in AN treatment for services to pursue partial weight restoration for IwAN and discharge them prior to reaching a period of either self-sustained stability, self-led recovery, or psychological recovery (Ayrolles et al., 2023; Federici and Kaplan, 2008). Kiely et al. (2023) and Kiely et al. (2024)'s metasyntheses of experiences of individuals with long-standing AN found consistent reference across retrieved papers to individuals feeling failed by treatments and treatment systems. Similarly, studies into the lived experience of AN have observed the withdrawal and withholding of AN treatment and care by clinicians (eg. Curry and Andriopoulou, 2023; Sly et al., 2014), and highlighted a weight stigma that can lead clinicians to assess IwAN as not being a low enough weight to require support, minimising their symptoms (Lubieniecki et al., 2024).

Evidenced clinician-initiated PTT rationales seem to reflect the difficulties named by IwAN who self-initiate PTT. Masson and Sheeshka's (2009) study found that clinicians perceived clinician-initiated PTT as a necessary action to protect a community milieu in their inpatient ED service. The authors found that IwANs' treatment was prematurely terminated when they were experienced by staff as breaking rules by engaging in AN-soothing behaviours (such as over-exercising), behaving in a way that was inconsistent with recovery, and struggling to eat; presentations which are consistent with an AN diagnosis (WHO, 2022). Masson et al. (2007) similarly found that PTT could be clinician-initiated due to IwANs' perceived non-compliance with a treatment programme.

While definitions of PTT continue to vary widely, the importance of addressing the phenomenon is well-recognised in research, as is the need for its further study from new perspectives (Mahon, 2000; Vinchenzo et al., 2022). Studies have associated PTT with significantly hindering IwANs' prognoses (Eddy et al., 2017; Elbaky et al., 2014) and being a barrier for effective treatment (Vinchenzo et al., 2022). Individuals who do not complete treatment are commonly discharged at lower weights, which are, in turn, associated with risk of rapid re-hospitalisation for treatment (Sly and Bamford, 2011); partial weight restoration – the incomplete treatment of AN’s associated weight loss and malnutrition – is associated with higher rates of relapse post-discharge (Rigaud et al., 2011). Mahon (2000) observed that IwAN who experience PTT, whether self- or clinician- initiated, are not a clinically or demographically homogenous population, and that the causes and experiences of PTT may be broader than is currently captured in research due to ongoing methodological limitations. Research also appears to suggest that multiple and varying instances of PTT can occur for someone during the course of their illness (Curry and Andriopoulou, 2023; Sly and Bamford, 2011). Such findings suggest that current understandings of PTT may be limited by the phenomenon’s fragmentation into subcategories, preventing its elucidation, and indicating a need for studies adopting a comprehensive, ‘multi-dimensional’ definition in order to facilitate an understanding of the phenomenon as a whole (Mahon, 2000). Mahon (2000) encouraged researchers and clinicians alike to hold curiosity about PTT rather than exclusionary preconceptions as to what it looks like and who decides what it is, and conduct qualitative, interview-based research with a view to learning about IwANs’ experiences of PTT and addressing the gap caused by the absence of this perspective.

1.6 Lived and Living Experience

1.6.1 Experts by Experience

The importance of capturing the voices of lived and living experience through Experts by Experience (EbEs) in mental health research is unequivocally evidenced (Music et al., 2022), with researchers highlighting its inherent value in informing service design and delivery, informing treatment approaches, providing peer support, improving clinical understandings of mental health difficulties, and addressing gaps in clinician and researcher-constructed knowledge (Duvall and Hanson, 2024; Kinnaird and Cooper, 2024; Mahon, 2000; Roe et al., 2022; Schleider, 2024). As such, lived experience research has become an increased priority in recent years and is becoming increasingly mandated by funding bodies (Evans and Papoulias, 2020; WHO, 2013). In the context of AN treatment, research has found lived experience perspectives to be crucial to the development of the field (Duvall and Hanson, 2024; Giel et al., 2024), leading to an increase in lived experience advocacy (Music et al., 2022). There remains, however, a scarcity of research undertaken in collaboration or consultation with IwAN (Music et al., 2022) and, compared to quantitative studies of outcome data, comparatively limited qualitative studies exploring lived and living experiences of AN (Eiring et al., 2021). Research has associated these limitations with researchers' tendency to privilege academic opinion over lived experience, thought to be born from their historical positioning as the 'expert' above 'the patient' (Schleider, 2024) and the stigmatisation of EDs by healthcare professionals (Graham et al., 2020; Music et al., 2022; Thompson-Brenner et al., 2012). While the term 'EbE' is now widely adopted, recognising and highlighting the location of expertise within those holding lived experience, there remain challenges to ensuring that their expertise is meaningfully sought, respected, and learned from in mental health fields (Schleider, 2024). AN literature frequently evidences a dearth of shared language and understanding between individuals with lived and living experiences and treating professionals (eg. Asaria, 2023; Branley-Bell et al., 2023; Elwyn, 2023; Kenny et al., 2022), often described as the 'us vs. them' dichotomy (Richards, 2010). In the context of the present study, IwANs' experiences of PTT and the meaning that they give to it appear to notably differ from those held by some professionals.

1.6.2 Experts by Dual Experience

Researchers have highlighted the need to approach ED research through new lenses due to an urgency for new insights and a need to become '[un]stuck' from 'old perspectives'

(Bulik, 2015). This need has been associated with the AN research field's 'difficulty unlearning misinformation' about the illness (Bulik, 2015) and the divide between the expertise held by individuals with lived and living experiences of AN and professionals (Curry and Andriopoulou, 2023). A lens that has yet to be widely explored in research is that of mental health workers with their own experiences of mental health difficulties – a population that includes both the peer workforce and formally trained clinicians with lived or living experiences of mental health difficulties (Boyd et al., 2016; Curry and Andriopoulou, 2023; Victor et al., 2022). As noted by Schleider (2024), 'EbE' and 'mental health professional' are not mutually exclusive roles, and the integration of EbE professional perspectives into their respective fields may further enrich our understanding of mental health difficulties. While it must be recognised that their perspectives do not and must not replace non-professional voices of lived experience, a growing evidence-base suggests their dual experience may provide them with a unique, adjunctive lens through which to contribute to our understandings of mental health presentations and experiences associated with treatment (Boyd et al., 2016; Curry and Andriopoulou, 2023; Victor et al., 2022). In the case of AN, where EbE and clinical/research voices often clash (eg. Graham et al., 2020; Sibeoni et al., 2017), individuals with dual experience of AN (IwDEAN) may be in a position to bridge this socially constructed divide and unite the two knowledge bases through their combined professional and personal experiences, offering a unique perspective to a 'stuck' field (Bulik, 2015; Curry and Andriopoulou, 2023).

To date, little literature has explored the experiences of IwDEAN (Curry and Andriopoulou, 2023), and experiences of PTT amongst this population have yet to be explored. The experiences of IwDEAN may contribute to the AN field's understanding of the phenomenon. While the dual-experienced population is understudied across all mental health fields (Victor et al., 2022), to date, more research has centred around the peer workforce subset of the population than the formally trained prosumer (FTP: qualified, accredited or registered mental health professionals with lived or living experiences of mental health difficulties whose roles do not necessitate the sharing of lived or living experiences) subset. While there is a precedent in existing IwDEAN studies to approach the dual-experienced population as a whole, grouping the peer workforce and FTP subsets together (eg. Curry and Andriopoulou, 2023), research has yet to synthesise the wider experiences of FTPs with lived or living experiences of mental health difficulties as has been done for the peer workforce. As such, it is currently unclear whether research approaching this dual-experienced population as a whole is sensitive and respectful to the population subsets' experiences, or whether the population as a whole is as homogenous as has been assumed. This therefore formed the basis of the present report's literature review, with a view to informing the development of the empirical research study.

1.7 Situating the Researcher

1.7.1 Personal Relationship to the Project

When researching any population, guidelines outline the importance of researchers acknowledging their relationship (or, indeed, lack thereof) to their participants, and considering the impact that their closeness (or distance) may have on their work (Corbin Dwyer and Buckle, 2009). In the case of qualitative research adopting an Interpretative Phenomenological Analysis (IPA) methodology where participants entrust their experiences and sense-making to the researcher (Smith, Flowers and Larkin, 2022), it is additionally important that I acknowledge my position as an insider researcher (Greene, 2014) – a researcher who studies one's own social group or society (Naples, 2003) - and speak to one of the lenses that I hold and have reflected upon throughout my involvement in this study: to invite in necessary discussions surrounding how this was both accounted for and embraced.

I am privileged to be able to share that I consider myself both personally and clinically recovered from AN in the sense that my recovery both meets my expectations of what it should be and meets clinical criteria – the long-term remission of symptoms and associated difficulties - that would have me considered as such (Kinnaird and Cooper, 2024). I am also in the privileged position of being a Trainee Clinical Psychologist; a professional position that I must acknowledge I pursued out of recognition that decision-making processes around AN are often managed- and supported by research conducted by- individuals without lived experience and the associated insight given by the experience of the illness itself. I felt that the voice of lived experience was absent from key discourses around AN and my own care and treatment, and, professionally, I have felt that my voice of lived experience can be unwelcome in clinical discussion. I now find myself in a dual relationship with AN, holding both personal and professional experiences - dual experience - of the illness, yet somewhat excommunicated from the two communities I sit between: to those with lived experience I am a clinician, and to clinicians I am forever a patient. In my own (dual) experience, ED research and clinical settings are marked by a strong yet often unaddressed 'them versus us' dichotomy between those in need of care and their care providers. I am both proud and humbled to be one of many people who span this divide. While both my professional and lived experience voices will be bracketed outside of my reflections and these two paragraphs, you, the reader, and I should hold this lens in mind and to account, and acknowledge its inevitable presence, value, and potential risk in my sense-making role as a researcher. I would like to take this opportunity to extend to you the invitation to consider the lenses and value that you, too, bring to this project through your engagement with this report.

1.7.2 Insider Research

Insider status can be valuable; knowledge that is born from lived experience can be insightful and harnessed to provide a project's sample population with a sense of safety and increased trust through an equalised relationship between the researcher and their participants (Chavez, 2008). This has the potential to facilitate speed and quality of rapport and improve the depth to which the research can go by facilitating the sharing of more deeply personal experiences (Chavez, 2008). It can contribute meaningful insight into the experiences of the participants and has been found to improve the detection of participants' unspoken, non-verbal, or hidden meaning-making indicators (Chavez, 2008). It can equally, however, present challenges, such as misplaced assumptions of sameness with participants or presumptive leanings during analysis (Chavez, 2008). It may obscure the role of the researcher through the unintentional privileging of their insider identity, leading to complications, and may bring the risk of selective reporting due to pre-existing sense-making narratives (Chavez, 2008). Regarding the collection of data, the insider researcher may experience conflict between their methodologically required interview format and the communication style of their community (Brayboy and Deyhle, 2000), attempt to compensate for their 'insiderness' by biasing interviews towards academic topics (Zavella, 1996), or find that interview responses are affected by participants' meaning-making of their researcher identity (Merriam et al., 2001).

As someone holding the dual identity of recovered IwAN and clinician, who has somewhat successfully navigated bracketing one voice or the other depending on whether I am in a personal or a clinical setting, I subscribe to Naples' (1996) sense that my insiderness is not a fixed position, but rather something fluid; something I can move towards or shift away from as I do other aspects of my identity in different contexts. In the pages that follow, I hope to demonstrate this through excerpts from my reflexive journal and analytical processes. Excerpts from my journal entries will be signposted throughout this thesis within relevant sections and can be found in the Appendix A (see Reflexive Journal Entries (RJEs) 1 and 2).

1.7.3 Ontological and Epistemological Position

This study's PR adopts a critical realist ontological stance, taking the position that human experience is a subjective process, that a 'real world' exists beyond these subjective observations and beliefs (Bhaskar, 2016), and that our experience of reality is mediated through the filter of human experience and interpretation (Fletcher, 2017). Critical realism recognises the existence of a transcendental reality that operates independently of humanity's awareness or knowledge of it (Bhaskar, 2016), governed by laws independent of the human mind (Bhaskar, 1993). It also recognises the importance of both objective reality and subjective experiences in making sense of the world around us, situating these within their cultural, social, political and historical contexts (Miller and Tsang, 2011). Critical realism therefore acknowledges that research is a human activity which is mediated through social structures and language (Gorski, 2013). The PR acknowledges that the study of human experience is inherently subjective and cannot be reduced to natural laws (Bhaskar, 2016).

Laverty (2003) describes epistemology as the nature of the relationship between the knower and what can be known. Epistemologically, the PR adopts a phenomenological position. Phenomenology is the study of lived experience from consciousness in the world that is subjective and constructed by the individual (Laverty, 2003). Phenomenology embraces recognition that, in qualitative research, researchers interpret and seek to make sense of their participants' experiences, which are, in turn, the participants' interpretations and sense-making of their experiences. Referred to as 'double hermeneutics' (Smith and Nizza, 2022), this phenomenon is central to IPA methodology. This will be spoken to further in a later chapter (see *'Methodology'*).

2.0 Systematic Literature Review

2.1 Overview

Systematic Literature Reviews (SLRs) strive to synthesise existing research findings with a view to understanding the existing evidence base and highlighting gaps in the literature around an identified question (Siddaway et al., 2019). This chapter introduces and describes the SLR that was conducted to inform the wider research project. (RJE 3).

2.2 Definitions

Table 1 presents key definitions utilised in the present review.

Table 1

Table of Definitions in the Context of the Present SLR

Term	Definition in the Context of the Present Study
'Formally Trained Prosumer' (FTP)	A 'prosumer' is defined as an individual who has provided and 'consumed' mental health services (Lopez-Aybar et al., 2024). In literature, there is not yet consensus on the terminology used to refer to the subset of the prosumer population whose professional roles are not inherently reliant on the sharing of their lived or living experiences and who are formally accredited, qualified or registered mental health practitioners. In the context of the present SLR, the term 'formally trained prosumer' has been adopted.
'Mental Health Services'	Any service where mental health support is provided to others, not limited by mental health diagnosis, presentation or symptom type or the nature of the mental health support received (APA, 2018).
'Mental Health Difficulty'	Any mental health presentation, diagnosis, or experience of a mental health symptom as recognised by the Medical Subject Headings (MeSH) library - a controlled and standardised vocabulary thesaurus that lists all recognised alternative lexis for biomedical terms (National Library of Medicine, 2024).

2.3 Rationale and Objective

Research has identified that voices of dual experience (individuals holding lived or living- and professional- experience of a mental health difficulty (Boyd et al., 2016; Curry and Andriopoulou, 2023; Victor et al., 2022)), may provide valuable insight into their respective fields through the awareness that comes from their unique lens and experiences (Victor et al., 2022). The peer workforce subset of this population – those whose professional role centres around the sharing of their lived or living experiences such as peer support workers and lived experienced practitioners - have been more widely considered in research (LaMarre et al., 2024) and currently form the majority of the evidence base relating to the population, inclusive of SLRs (eg. Bailie and Tickle, 2015; Du Plessis et al., 2020; Lewis and Foye, 2021; MacLellan et al., 2015; Vandewalle et al., 2016; Walker and Bryant, 2013). The FTP subset of this population is comparatively under researched (Victor, 2022).

Existing studies of formally trained or training IwDEAN are exceedingly small in number. While this is, in itself, valuable knowledge (Boland et al., 2017) and supports suggestions that the population is, as yet, understudied (Curry and Andriopoulou, 2023), the quality and validity of such an SLR could be limited by a paucity of available data (Shaheen et al., 2023). Papers studying the experiences of FTPs across wider mental health fields are greater in number and an SLR of the experiences of FTPs encompassing multiple mental health experiences and professional contexts has yet to be conducted. Such a review may provide insight into the experiences held- and contributed to research- by the wider FTP population to further research's understanding of the dual-experienced population as a whole. (RJE 4).

The primary objective of the present SLR was therefore to synthesise existing findings in literature to answer the question: What does the empirical literature tell us about the experiences of FTPs?

2.4 Methodology

2.4.1 Protocol and Registration

A search was conducted via the platform PROSPERO to ensure that this would be a novel review and could meaningfully contribute to literature in the field. The review and its protocol were subsequently registered with the platform (protocol: CRD420250649603) to support researchers in avoiding the unintentional duplication of research efforts while holding the present review to account in terms of methodological rigour and transparency (Covidence, 2024). The review was informed by the PRISMA (2020) protocol for conducting SLRs to ensure methodological rigour (British Medical Journal, 2021).

2.4.2 Eligibility Criteria

The present review focused on qualitative research and the experiences of FTPs given that the FTP field of research is currently in its infancy (Victor et al., 2022); qualitative research permits the collation of rich, contextual insights into individuals' lived and living experiences (LEs) (Moser and Korstjens, 2017) and qualitative approaches are recommended when studying new populations or phenomena (Willig, 2019). The Sample, Phenomenon of interest, Design, Evaluation and Research Type (SPiDER) framework (Cooke, Smith and Booth, 2012) was utilised to inform retrieved paper screening inclusion and exclusion criteria (Table 2). SPiDER was adopted due to evidence suggesting that it is a robust framework for capturing clinical evidence for an SLR and for its evidenced suitability for both qualitative and mixed methods studies due to building upon the Population, Intervention, Comparison, Outcome (PICO) framework's more quantitatively suited components and incorporating components suitable for qualitative searches (Cooke, Smith and Booth, 2012).

Papers that centred around the opinions or experiences of others with regards to FTPs (those who are not themselves FTPs as defined in relation to the present SLR) were excluded. Papers that amalgamated data relating to FTPs' experiences across mental health and non-

Table 2

Inclusion and Exclusion Criteria Utilising SPiDER

Inclusion Criteria	Exclusion Criteria
S: Sample	
- FTPs (individuals with lived or living experience of a mental health difficulty who have also been/were in training to become an accredited, qualified, or registered provider of care for others with mental health difficulties). Not limited by type of mental health presentation/diagnosis, setting in which they carried out their provider role, or the accredited, qualified, or registered role they held. - Studies that included FTPs in addition to individuals with other experiences where FTPs' data were considered or analysed in isolation.	- FTPs whose lived or living experiences captured in a study did not directly relate to mental health difficulties (for example, FTPs who held lived or living experiences of physical health conditions, neurodevelopmental presentations, and neurocognitive presentations). - Prosumers with lived or living experiences of mental health difficulties who were not also FTPs. - Researchers with lived or living experience of mental health difficulties who have not also held an accredited, qualified, or registered mental health care provider role

Inclusion Criteria	Exclusion Criteria
	- Studies where data pertaining to the experiences of FTPs were amalgamated with data pertaining to other prosumer groups and not considered or analysed in isolation.
Pi: Phenomenon of Interest	
- The experiences of FTPs.	- Studies that did not focus on the experiences of FTPs.
D: Design	
- Qualitative studies (not limited by design, methodology or philosophical epistemology). - Mixed methods studies where the qualitative components were analysed and discussed in their own right.	- Quantitative studies. - Mixed methods studies where relevant qualitative data are not analysed and discussed in their own right (eg. if the data pertaining to the population of interest (FTPs) was amalgamated with data belonging to a different population (eg. peer support workers)).

Inclusion Criteria	Exclusion Criteria
	- Studies that lacked qualitative methodology (eg. first-person narratives).
E: Evaluation	
- FTPs experiences, FTP population subset (professions), sample size, year published, methodologies, key findings, limitations, study location.	
R: Research Type	
- Peer-reviewed empirical qualitative studies. - Published in any year. - Published in English but not limited by country of origin. - Full-text available.	- Opinion papers, editorials, first-person narratives (due to lacking narrative methodology) and grey literature. - Studies published in a language other than English. - Full-text unavailable.

mental health presentations where analyses or conclusions pertaining to the population of interest could not be separately identified were not included. This is because the present review was centred around FTPs' experiences and information pertaining to other dual experiences might introduce themes that are not shared by the population of interest and therefore affect the review's findings.

Inclusion criteria required that papers be available in full-text to ensure that they could be sufficiently critically appraised and analysed, and that they were published in English as this is the PR's first language and attempts to use software to translate a paper may have resulted in inaccuracies at risk of confounding the present review's findings. No exclusion criteria were applied regarding date of publication out of recognition that published empirical research in this field is limited and that all experiences held by members of a community are inherently valid and meaningful when seeking to explore a phenomenon (Laverty, 2003) and do not become less valid or meaningful with the passing of time; they continue to reflect their cultural, social, political and historical contexts and remain valuably subjective (Miller and Tsang, 2011). Grey literature was not included because it would not address the review's research question which centred around understanding what is currently captured in empirical studies.

2.4.3 Information Sources

Three bibliographical databases were identified as information sources for this SLR, inclusive of Scopus, Medline, and CINAHL. These databases were selected for their inclusion of relevant qualitative and experientially-led literature in the FTP field of research (determined by the PR's preliminary searches) and their availability to the PR via their institutional library's subscriptions. Trial runs of the SLR's search phrase found that the addition of further databases that were available to the PR duplicated results rather than retrieving additional relevant papers. Hand searching of references from papers retrieved by the search phrase was conducted to ensure that all relevant papers were included in the review (Tricco et al., 2008).

2.4.4 Search Strategy

As advised by Siddaway et al. (2019), the key components of the research question were identified with a view to informing the development of a search phrase. Relevant terms for each component were then identified based on the terminology utilised in relevant literature (identified through the PR's familiarisation with research in the field) and the search terms utilised in previous SLR's conducted on the subject of FTPs. Both controlled terms (those that were identified from searching the MeSH library) and uncontrolled terms (synonyms or descriptors, as recommended by Hausner et al. (2012)) were included to ensure that all relevant literature was captured by the search. A Boolean search phrase was constructed utilising identified search terms. This was an iterative process, through which multiple variations of the search phrase were trialled on the identified databases to ensure the final search phrase functioned optimally and captured relevant papers.

The development of the search phrase proved challenging. Initially, terms relating to each of the SLR's inclusion criteria were included in the search phrase with a view to optimising relevant paper retrieval. However, it transpired that this failed to retrieve many relevant papers; existing literature in the field of study appeared to less frequently include direct descriptions of their methodologies and used inconsistent language to refer to the population of interest in their titles, abstracts, and keyword choices, causing relevant papers to be excluded. The same difficulty was encountered when some components of the SLR's question were included as separate modifiers in search phrase iterations (ie. FTP role (eg. "psychologist*") AND "liv* experience") rather than as complete phrases (eg. "psychologist* with liv*experience*"), and when alternative terms relating to 'mental health difficulties' did not include specific diagnoses. These difficulties also transpired to be the result of inconsistent terminology and keyword labels in relevant literature. The most successful search phrase (with optimal relevant paper retrieval) therefore minimised the use of the review's inclusion criteria, amalgamated FTP roles and terms relating to LEs, and included specific mental health diagnoses. As this meant that the final search phrase was broad and did not limit paper retrieval by methodology or experiential focus, irrelevant papers captured were manually excluded at the screening stage. While these difficulties resulted in an inelegant and complex search phrase, the final phrase was carefully constructed and successful in navigating the inconsistencies within the field of study and retrieving appropriate papers. (See Appendix B for search phrase trial trail and Table 3 for the final search phrase).

A pilot search was conducted in December 2024 to ensure that the search phrase operated as expected and retrieved appropriate papers. The review's final search was conducted in January 2025. Prior to submission, the search was run once more to determine whether any further studies had been published so that these could be considered in the SLR's discussion: none were retrieved. The same final search phrase was utilised across all three databases for paper retrieval; no adaptations were required to optimise relevant paper retrieval on the different databases. When employing the search phrase in the identified source databases, the 'advanced search' function was used to implement the modifiers utilised in the Boolean search phrase, enable the use of search filters to ensure that only peer-reviewed articles and articles available in English were sought in accordance with the review's inclusion criteria, and ensure that the databases applied the search phrase to the title, abstract, and keywords of each paper. The decision to employ these filters was taken to reduce the number of irrelevant papers retrieved and optimise relevant paper retrieval given the breadth of the search phrase.

Table 3

Final Search Phrase

Key Question Components Utilised for the Search Phrase	Adopted Search Terms
Formally Trained Prosumers	(“Dual experience*” OR “dual experience* clinician*” OR “clinician* with dual experience*” OR “liv* experience clinician*” OR “clinician* with liv* experience*” OR “dual experience* practitioner*” OR “practitioner* with dual experience*” OR “practitioner* with liv* experience*” OR “liv* experience practitioner*” OR “professional* with dual experience*” OR “dual experience* professional*”OR “professional* with liv* experience*” OR “liv* experience* professional*” OR “psychologist* with dual experience*” OR “dual experience* psychologist*” OR “psychologist* with liv* experience*” OR “liv* experience* psychologist*” OR “nurse* with dual experience*” OR “dual experience* nurse*” OR “nurse* with liv* experience*” OR “liv* experience* nurse*” OR “psychiatrist* with dual experience*” OR “dual experience* psychiatrist*” OR “psychiatrist* with liv* experience*” OR “liv* experience* psychiatrist*” OR “doctor* with dual experience*” OR “dual experience* doctor*” OR “doctor* with liv* experience*” OR “liv* experience* doctor*” OR “psychotherapist* with dual experience*” OR “dual experience* psychotherapist*” OR “psychotherapist* with liv* experience*” OR “liv* experience* psychotherapist*” OR “therapist* with dual experience” OR “dual experience* therapist*” OR “therapist* with liv* experience*” OR “liv* experience* therapist*” OR “dual experience* mental health professional*”OR “mental health professional* with dual experience*” OR “mental health professional* with liv* experience*” OR “liv* experience*

	mental health professional*” OR “mental health practitioner* with dual experience*” OR “dual experience* mental health practitioner*” OR “mental health practitioner* with liv* experience*” OR “liv* experience* mental health practitioner*” OR “mental health worker* with dual experience*” OR “dual experience* mental health worker*” OR “mental health worker* with liv* experience*”OR “liv* experience* mental health worker*” OR “mental health provider* with dual experience*” OR “dual experience* mental health provider*” OR “mental health provider* with liv* experience*” OR “liv* experience* mental health provider*” OR prosumer*)
Mental Health Difficulties	AND (“mental illness*” OR “mental health” OR “mental difficult*” OR “mental disorder*” OR “mental problem*” OR “psychological problem*” OR “psychological illness*” OR “psychological distress” OR “psychological difficult*” OR “psychiatric illness*” OR “psychiatric difficult*” OR “psychiatric disorder*” OR psychos* OR “hearing voices” OR schizo* OR “delusional disorder” OR “eating disorder*” OR “anorexia nervosa” OR “bulimia nervosa” OR “avoidant and restrictive food intake disorder” OR “ARFID” OR “binge eating disorder” OR diabulimi* OR pica OR “rumination*regurgitation” OR “body dysmorphi*” OR “obsessive compulsive” OR “OCD” OR “perinatal mental health” OR “personality disorder*” OR “bipolar disorder*” OR “dissociative” OR “depersonali*ation dereali*ation disorder” OR “trance disorder” OR “bodily distress disorder” OR “prolonged grief disorder*” OR “post-traumatic stress disorder*” OR “panic disorder*” OR *phobia* OR addict* OR depression OR depressive OR “mood disorder” OR “dysthymic disorder” OR anxiety* OR “fear*related disorder” OR “self*harm” OR “self*injury” OR suicid* OR “selective mutism”)

Search outcomes from each database were imported into the SLR management software ‘Covidence’ (Covidence Systematic Review Software, 2025). Initial database searches produced a combined total of 153 papers for review after 107 duplicates were identified and removed by Covidence’s duplicate paper detection processes.

2.4.5 Study Selection

In Covidence, all non-duplicate studies retrieved through the initial search underwent title and abstract screening followed by full-text review by both the PR and a Trainee Clinical Psychologist colleague utilising the SLR’s eligibility criteria. No points of conflict regarding the inclusion or exclusion of an article arose.

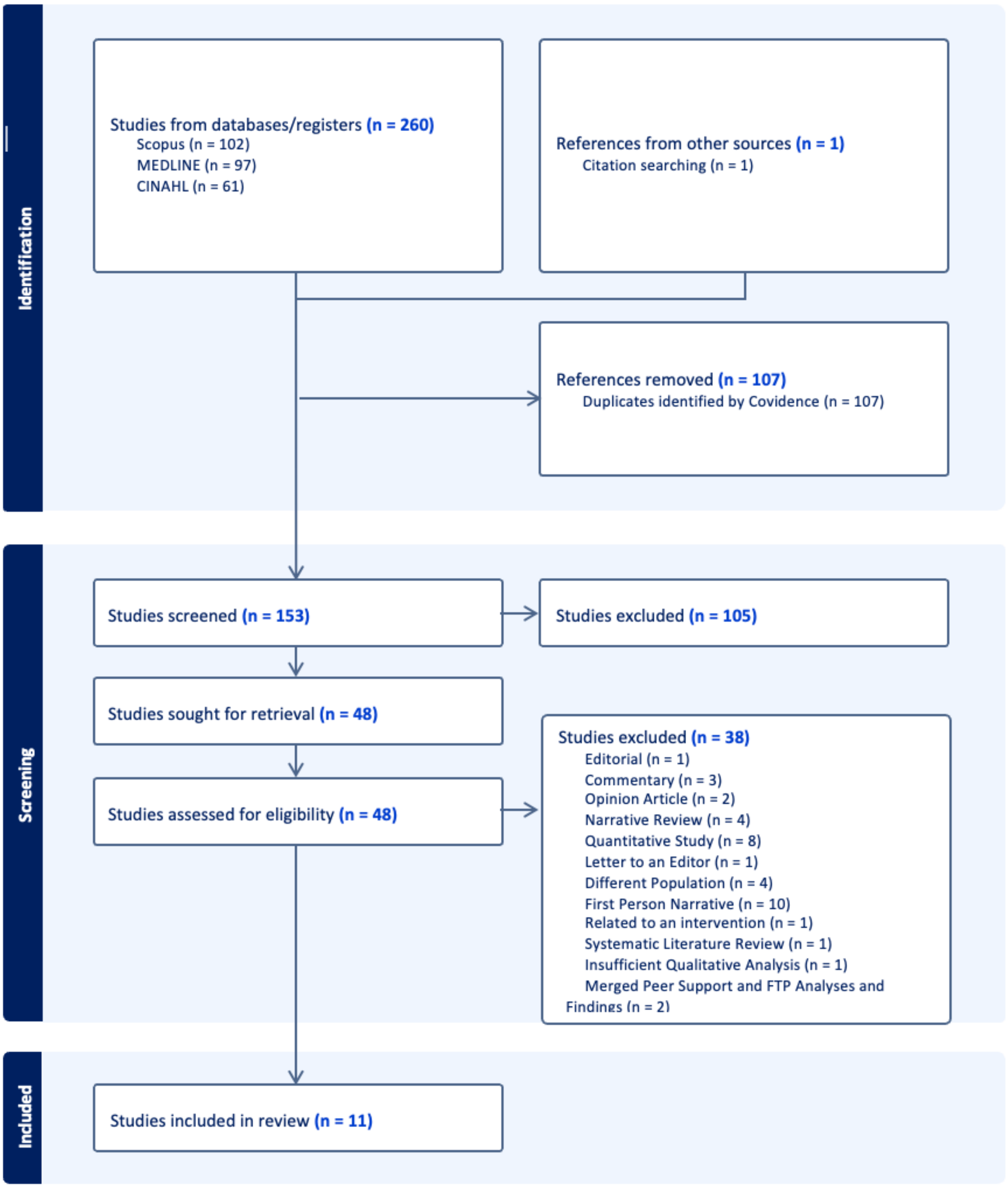
One-hundred-and-five studies were excluded at the point of title and abstract screening due to irrelevance, and 48 studies proceed to full-text review. A further 38 studies were excluded at this stage, leaving 10 papers for inclusion in the review. A review of retrieved references yielded an additional study that met eligibility criteria and was deemed viable for inclusion by both the PR and the second reviewer. Therefore, a total of 11 studies proceeded to the data extraction phase. (See Figure 1: PRISMA Flow Diagram).

2.4.6 Critical Evaluation of Papers

The quality of the included papers was assessed utilising the Critical Appraisal Skills Programme (CASP) qualitative checklist (CASP, 2018) (Appendix C). CASP (2018) is recommended by the Cochrane Qualitative and Implementation Methods Group and is commonly used in qualitative evidence syntheses by the World Health Organisation (Majid and Vanstone, 2018; Noyes et al., 2018). Additional appraisal criteria were considered as advised by Long et al. (2020) with a view to optimising the quality appraisal process utilising Yardley’s (2000) adjunctive criteria (Appendix D). No papers were excluded following quality appraisal.

Figure 1

PRISMA Flow Diagram of Systematic Literature Search



CASP (2018) assessment outcomes indicated that the studies were of good quality and valuably contributed to research. Clear aims were detailed in all papers and qualitative methodologies and research designs were universally appropriate to these. Data collection was consistent with the papers' purposes and clear statements of findings were present in all reports. The Yardley (2000) adjunctive appraisal outcomes suggested that compassion towards the participant population and their experiences was universally apparent and that all studies were coherent, impactful and important.

The quality assessments did, however, highlight some limitations amongst the papers. While ethical approval from recognised institutions was clearly stated, ethical issues were not addressed in five reports[1], nor were the relationships between the researchers and their participants in five of the studies[2]. While research evidences the importance of reflexivity across all qualitative methodologies adopted by included papers (Braun and Clarke, 2018; Josselson and Hammack, 2021; Smith et al., 2022), only three studies spoke to this process in their reports[3] despite reflexivity being subjectively apparent to the present reviewers throughout the papers. One paper did not have a formal recruitment strategy (Woods and Springham, 2011), although this was addressed and considered within the study's report and, given its design and aims, was deemed by reviewers as not negatively affecting the value of the research.

2.4.7 Data Items and Data Collection Process

The type of study, methodology, sample size, participant demographics, research aims, findings, limitations, and relationship of the researcher(s) to the participants were manually extracted from each included paper and tabulated.

2.4.8 Study Characteristics

---

[1] Adame (2011); Boyd et al. (2016); Huet and Holttum (2016); Lopez-Aybar et al. (2024); Woods and Springham (2011).

[2] Boosma-van Holten et al. (2023); Boyd et al. (2016); Huet and Holttum (2016); Karbouniaris et al. (2022); Lopez-Aybar et al. (2024).

[3] Cleary and Armour (2022); Curry and Andriopoulou (2023); Turner et al. (2021).

Of the included papers, four were from the United Kingdom (UK), three from the United States, three from the Netherlands, and one from Northern Ireland. Included papers explored the experiences of FTPs from a range of professional contexts inclusive of clinical psychologists, trainee clinical psychologists, psychiatrists, art therapists, social workers, nurses, counsellors and psychotherapists. Seven papers studied a specific FTP professional group[4] and four papers studied the experiences of individuals across multiple FTP professional groups[5]. One paper studied FTPs' experiences associated with a specific mental health difficulty: AN[6]. Qualitative methodologies varied and included IPA[7], narrative inquiry[8], thematic analysis[9], heuristic methodology[10] and grounded theory[11]. One paper utilised mixed methods[12] and two papers adopted a participatory action research approach in their studies' design[13]. All studies were published in peer-reviewed journals.

2.4.9 Data Extraction Process and Synthesis Method

The data extraction process involved the collation and organisation of data from the review's included studies into a summary table (see Appendix E) informed by the Cochrane checklist of items to consider for data extraction (Lasserson et al., 2021) and adapted to be relevant to the present SLR's subject matter. Findings from the review's included papers were synthesised thematically in accordance with Thomas and Harden's (2008) methodology (Table 4), permitting the researcher to integrate findings and develop a narrative. Thomas and Harden (2008) acknowledge that their method for qualitative thematic synthesis is dependent

---

[4] Boomsma-van Holten et al. (2023); Cleary and Armour (2022); Huet and Holttum (2016); Karbouniaris et al. (2023); Lopez-Aybar et al. (2024); Turner et al. (2021); Wood and Springham (2011).

[5] Adame (2011); Boyd et al. (2016); Curry and Andriopoulou (2023); Karbouniaris et al. (2022).

[6] Curry and Andriopoulou (2023).

[7] Cleary and Armour (2022); Curry and Andriopoulou (2023); Karbouniaris et al. (2023).

[8] Adame (2011).

[9] Boomsma-van Holten et al. (2023); Boyd et al. (2016); Huet and Holttum (2016); Karbouniaris et al. (2022).

[10] Wood and Springham (2011).

[11] Turner et al. (2021).

[12] Lopez-Aybar et al. (2024).

[13] Karbouniaris et al. (2022); Karbouniaris et al. (2023).

Table 4

Synthesis Method (Thomas and Harden's (2008) Method for Thematic Synthesis)

Stage of Synthesis	Analytical Process
Stage One	The PR immersed themselves in the retrieved papers by reading and re-reading each study. Free line-by-line coding of each line of text within each study's findings was conducted by the PR by hand. Coding was inductive with the intention of capturing the meaning and content of each sentence.
Stage Two	Through an inductive process, the PR organised the free codes into related groups to begin constructing 'descriptive themes' of the studies' findings. This was actioned by looking for similarities and differences between the codes in addition to considering the frequency of their occurrence. As anticipated by Thomas and Harden (2008), this resulted in the development of a tree-like hierarchical structure of overarching descriptive concepts and nestled descriptive subthemes. These were reviewed by the wider research team and agreed upon.
Stage Three	The PR developed analytical themes from the descriptive themes with a view to more directly addressing the present review's research question. This is described by Thomas and Harden (2008) as 'going beyond' the content of the original studies and considering their findings more broadly with a view to developing higher order themes. This was an iterative process that continued until analytical themes encompassed the descriptive themes of the studies' findings and considered the overarching experiences of the population of interest according to the retrieved evidence.

upon the judgement of the reviewers and is, therefore, a subjective process. For example, the authors' methodology does not require a theme to be present within a particular proportion of a review's included papers in order for it to be endorsed. Instead, Thomas and Harden (2008) require that a review's final analytical themes should encompass all initial codes and descriptive themes that are relevant to its research question, irrespective of the number of included papers that they are found within. While this methodological requirement is, in a sense, objective, the initial coding and subsequent descriptive themes themselves are reliant upon the reviewer's own interpretation of the included papers, introducing subjectivity.

Thomas and Harden (2008) advise that, in the context of this inevitable subjectivity, reviewers prioritise grounding their thematic synthesis in the contexts and contents of their review's included papers. This is with the intention of supporting the development of analytical themes that remain 'faithful to the cases from which they were developed' (Thomas and Harden, 2008). The authors recommend that this is pursued through the use of multiple reviewer perspectives at all stages of synthesis. As such, all analytical stages of the present SLR were reviewed, discussed with- and approved by- the PR's wider supervisory team.

In accordance with Thomas and Harden's (2008) methodology for thematic synthesis, the development of the review's analytic themes sought to build upon the identified descriptive themes (themes that had stayed close to the contents of the included studies, reflecting their similarities and differences) and 'move beyond' them with a view to addressing the research question. Thomas and Harden's (2008) methodology does not have formal requirements for analytic theme construction beyond the need to pursue higher order themes, nor does it include a formal process. Instead, this process embraces the decision-making of the reviewer, encouraging them to make inferences that are rooted in the contents and context of the original studies (Thomas and Harden, 2008). In the context of the present review's experience-focused research question, inferences were made based upon the frequency with which experiences occurred, the emotional weight given to those experiences (based upon the language used to describe the experiences, the contexts surrounding the experiences, and the nature of the experiences themselves), similarities between experiences, potential connections between experiences, points of divergence between experiences, and the meaning given to the captured experiences in the included studies.

2.5 Synthesis of Results

Thematic synthesis resulted in the generation of two overarching themes (Table 5). For ease of distinction, participant quotes are indicated in italics and quotations from the researchers' reports are indicated in single quotation marks in the present review.

Table 5

Summary of Results: Analytical Themes

Analytical Themes	Subthemes
The Difficulties of Navigating the Dichotomy, 'Us vs. Them' (Professionals vs. Clients).	Othered: Being Positioned as 'Them'. Professional Culture: The Expectations of Being with 'Us'. Not Belonging: The Paradox of Being both 'Us' and 'Them'. The Disclosing of LEs: Feeling Fearful and Unsafe.
Harnessing Experiential Knowledge.	A New, Complimentary Knowledge. The Drive for Stigma Resistance. Continuously Learning how to Harness Experiential Knowledge.

The Difficulties of Navigating the Dichotomy, ‘Us vs. Them’ (Professionals vs. Clients)

All of the present review’s retrieved studies captured participant experiences of navigating the socially constructed divide between mental health professionals and clients as individuals whose experiences encompassed both groups’ identities.

Othered: Being Positioned as ‘Them’

Ten studies captured participant experiences of anticipating- or enduring- being othered by their professional colleagues and the systems surrounding them due to their FTP status. Many participants shared experiences of their colleagues perceiving them as holding client-like qualities despite their professional positions, and subsequently treating them as though they were *“other”* and *“inferior”* (Huet and Holttum, 2016). Karbouniaris et al. (2022) captured FTP experiences of being looked down upon by their colleagues due to their LEs, and Huet and Holttum (2016) captured experiences of colleagues doubting FTPs’ ability to professionally ‘cope’ because of their LEs. Cleary and Armour (2022) similarly captured FTP experiences of their LEs being perceived by their colleagues as a ‘liability’, and Curry and Andriopoulou (2023) found experiences of FTPs’ experiential knowledge being perceived by their colleagues as *“alarm bells”* relating to their competence and ability to work professionally.

Lopez-Aybar et al. (2024) found that their participants had witnessed psychologists othering individuals with LEs, inclusive of FTPs. For some participants, this dissuaded them from disclosing their own LE to their colleagues and supervisors or seeking support. One participant shared: *“I feel that they would see me as unstable and not worthy of getting my doctorate”*, suggestive of having experienced their profession conceiving LEs as making one innately unreliable, unpredictable, and undeserving of access into the profession. Participants in the same study shared experiences of being *“disregarded”*, mocked and *“gossiped”* about by colleagues due to their LEs in similar ways to which the same study's participants experienced their colleagues discriminating against their clients.

Three studies captured contrasting participant experiences of sharing their FTP status with professional colleagues as feeling supportive and inclusive, although these experiences were notably sat alongside other, less positive experiences of being othered by some other colleagues. Karbouniaris et al. (2023) found that some participants valued sharing their 'patient identity' and found that this eased feelings of shame and associated emotional burdens. Other participants within the same study, however, found that sharing their LEs with colleagues resulted in the perceived devaluation of their professionality and subsequent stigmatisation. Three participants from Curry and Andiopoulou (2023) recalled their FTP status being respected and their LEs being consulted by some of their colleagues, although those same participants also held experiences of being stigmatised by other colleagues. Lopez-Aybar et al. (2024) captured some participant experiences of feeling unconditionally accepted, celebrated and supported by their colleagues after sharing their LEs, but with the notable caveat that those participants felt this was because their LEs were not considered *"severe enough"* for them to be subjected to stigmatising attitudes.

Professional Culture: The Expectations of Being with 'Us'

Ten studies reported participant experiences of navigating mental healthcare professional culture and its expectations as individuals with LEs. Boosma-van Holten et al. (2023) discussed the professional cultural values held by their participants' profession, noting that psychiatrists' professional identity is carved from the high expectations the clinicians were required to have met from a young age in order to access their professional training. The researchers noted the professional culture's condemnation of colleagues who cannot work to the expected norm and its subsequent othering of individuals who are perceived as lacking *"psychological strength"*. They found that FTPs were required to *"accommodate the* *profession[al culture]"* in order to gain entry into it, often necessitating the masking of their LE-selves. Lopez-Aybar et al.'s (2024) FTP participants spoke to experiencing their clinical psychology colleagues as positioning themselves as *"all-knowing, infallible experts"* and conceptualising the LEs of FTPs as a "*weakness"* innate to the individual that was indicative of *"incompetence"*. One participant shared, *"psychologists act like it's impossible that a mentally ill person could be sitting in the room with them, not as a client, but as a colleague",* suggestive of experiencing exclusivity and mental health perfectionism within the profession. Participants across these ten studies experienced their LEs being framed by colleagues as *"morally undesirable"* and therefore something in need of *"masking"*, *"concealing"*, or *"hiding"*.

Turner et al.'s (2021) participants shared feelings of embarrassment and shame around acknowledging ongoing experiences of mental health difficulties as FTPs due to contemporary professional cultural expectations, with one participant alluding to the emotional weight of professional expectations when sharing, *"you feel like you should not have these sorts of problems if you are a trainee clinical psychologist."* Karbouniaris et al. (2023) similarly described a 'cultural norm' in psychiatry of 'not be[ing] open about LEs'. Boyd et al. (2016) captured experiences across a range of mental health professional contexts, finding that the wider *"culture is still to hide"* experiential knowledge. For some participants, being a part of the mental health professional culture required the acceptance of an absence of understanding or, in some cases, tolerance from colleagues. One participant shared, *"I have to deal with the lack of knowledge and support from my direct manager"*, echoing Boosma-van Holten et al.'s (2023) finding that FTPs are required to accept and adapt to the existing mental health culture in order to work within their respective professional fields. A participant from Curry and Andriopoulou (2023) reflected upon their experiences of their profession's expectation that their LEs go unspoken, and shared, *"it makes me sad if I think* *that people wouldn't want me as a whole";* further alluding to the exclusivity of mental health professions and the cultural expectation that FTPs conceal or withhold their LE-selves in order to be seen as professionally desirable or acceptable.

Participants across multiple studies held experiences of being described by colleagues as *"exhibitionistic"* (Karbouniaris et al., 2022) or *"acting out"* (Karbouniaris et al., 2023) for speaking to their LEs in professional settings. Karbouniaris et al. (2023) found that participants experienced openness about their experiences being viewed by colleagues as 'violating professional codes of conduct', contrasting with the experiences of participants from Turner et al. (2021) who saw their openness as a professional responsibility to ensure that they were appropriately supported, supervised, and practicing safely: *"It was very clear. It was my professional duty to disclose".* Cleary and Armour's (2022) participants spoke to the 'moral dilemma' – the moral injury – inherent to being an FTP due to the silencing of their LE knowledge and the knowledge that they represent a professional culture that can cause harm. This moral injury was also recognised in Adame (2011).

Not Belonging: The Paradox of Being both 'Us' and 'Them'

Three studies captured participant experiences of holding both professional and client identities and yet feeling that they did not belong with either group. Some participants held experiences of finding that they were rejected by both their clients and their colleagues due to their FTP status, and all three studies captured experiences of not belonging and struggling with one's identity.

'Róisín', a participant from Cleary and Armour's (2022) study shared:

> *"You're always balancing this idea of being both a survivor and a practitioner… but in that moment, I don't know, it was like I was somehow both a survivor and practitioner and yet neither at the same time."*

Róisín describes her dual identity – her FTP status – as something different to the sum of its survivor and practitioner parts, and conceptualises it as something different. This 'both yet neither' paradox is echoed by participants in Karbouniaris et al. (2022), one of whom shared experiences of personal pride yet professional shame in being an FTP, suggestive of an internal conflict and stigma resulting from their FTP status. In contrast, a participant from Adame (2011) expressed a level of both personal and professional comfort in their FTP and survivor statuses, but noted that navigating the coming-together of their dual identity was *"not easy"*. This participant spoke to their experience of their professional status leaving their clients unable to see past their title and trust in their experiential knowledge:

> *"By identifying as a therapist, you're already suspect with a lot of the survivor people. Because they've been so wounded by mental health professionals. That they just automatically distrust."*

For several of Adame's (2011) participants, their dual identity as professionals with lived experience of mental health difficulties and iatrogenic harm (described as 'psychiatric survivor' status in the context of the study) left both their colleagues and their clients feeling suspicious and mistrusting of them. The study's participants shared experiences of their clients feeling unable to accept their shared survivor status due to their position as a mental health professional. The study's participants empathised with this, noting that, *"a lot of us came to this profession because of our own woundings"*, yet that, *"we are still mental health professionals who buy into the system that employs us."* Adame (2011) noted that FTPs with experience of iatrogenic harm can therefore find it difficult to find their place within the mental health system due to their dual identity, leaving them feeling isolated and with a sense of not belonging. This finding was shared by Cleary and Armour (2022), where participants voiced the difficulties they experienced when attempting to balance their dual identity as both a service user and a practitioner. This study's participants described a 'fluctuating sense of self', whereby their 'patient' and 'professional' identities would step back and forth in salience in turn. One study, Karbouniaris et al. (2022), captured FTP experiences of tension from the peer workforce due to being perceived as encroaching on 'their field of expertise' and navigating worries about being associated with the peer workforce and the difficulties they perceive their profession as being associated with, suggestive of a divide within the dual-experienced community.

The Disclosing of LEs: Feeling Fearful and Unsafe

Participants across all retrieved studies shared experiences of fear and unsafeness around the sharing of their LEs with their colleagues. Turner et al. (2021) described this as fear of the 'consequences' of disclosure. Multiple studies captured the silencing nature of the fear experienced by their participants, with one participant sharing, *"fear [of professional repercussions] kept my mouth shut"* (Huet and Holttum, 2016). Participants often shared experiences of fearing *"punishment"* due to their FTP status (Boyd et al., 2016; Karbouniaris et al., 2023; Lopez-Aybar et al., 2024). Turner et al.'s (2021) participants shared fears of being perceived by their colleagues as *"weak"* if they were to share their LEs, associating this with their experiences of their profession and its antithetical conceptualisation of mental health difficulties. Lopez-Aybar et al.'s (2024) participants similarly spoke to witnessing their colleagues holding stigmatising beliefs about individuals experiencing mental health difficulties, leaving them feeling fearful of sharing their own LEs. The study's participants recalled witnessing their colleagues discriminating against their clients, dehumanising them in treatment, addressing them with condescension, diminishing their autonomy and punishing them by denying them access to services (Lopez-Aybar et al., 2024). Lopez-Aybar et al.'s (2024) participants found this witnessed discrimination both distressing and silencing, leaving them fearful of being treated in the same way should they speak to their own experiences.

For those participants who held experience of sharing their FTP status with colleagues, some shared experiences of subsequently being cautioned to conceal their LE and dual identity so as to avoid professional rejection and loss of professional status (Huet and Holttum, 2016; Lopez-Aybar et al., 2024; Turner et al., 2021). Turner et al.'s (2021) participants spoke to their desire to be seen as 'a good trainee' by their peers and how, in some cases, this dissuaded them from speaking to their experiences. Such experiences were alluded to by Boyd et al.'s (2016) participants, one of whom advised, *"use good judgement about sharing your personal history with others [colleagues]. Not everyone is your ally."* On the subject of disclosure, another of the study's participants noted, *"I am still very cautious. I have not seen many positive outcomes and there are many potentially negative outcomes."* One participant shared this experience of feeling unsafe yet challenged their need to accept this, alluding to strength in numbers, sharing, *"there are a lot of us"*, and advocating, *"we need to share our experience and use our success coupled with a loud voice. Stigma will never end unless or until we all do."* A participant from Boomsma-van Holten et al.'s (2023) study spoke to their fear of the permanence of sharing their LE and possible consequences despite their belief in the value of their disclosure: *"the misery is that, once I have said it, I cannot turn back."*

Harnessing Experiential Knowledge

Participants across ten studies shared their experiences of utilising their LEs in their professional work. The eleventh study reflected upon how the participant's LEs has changed their understanding of their professional role. Described in Boosma-van Holten's (2023) study as the *"harnessing"* of experiential knowledge, this theme encompasses both participants experiences of the value of their LEs and what they have learned through their experiences of utilising them to inform their practice.

A New, Complimentary Knowledge

Participants across all included studies acknowledged holding two types of learned knowledge; knowledge acquired through their training and professional practice, and experiential knowledge learned through their LEs. Participants across a number of the studies considered their experiences of the differences between their knowledge sets, and described their experiential knowledge as something novel, valuable, and both different and complimentary to their professionally acquired knowledge.

A participant in Karbouniaris et al.'s (2022) study described their LEs as an *"intuitive and embodied knowledge [...] a very powerful tool!"*, suggesting both that their experiential knowledge felt different to their professionally acquired knowledge – that it was not just held differently in their body but that it was instinctive and visceral – and that they experienced it as a valuable, practical therapeutic tool. Similar experiences of experiential knowledge as a powerful, visceral compliment to their professional knowledge were shared by participants across the included studies. Adame (2011) described their participants' experiences of their experiential knowledge as 'organic' and forming the foundations for their professional work. This experience was shared by participants in Curry and Andriopoulou (2023), who described their LEs as enabling a *"true understanding"* of AN that could not be achieved through professional learning alone. Participants from Boosma-van Holten et al. (2023) similarly found that their experiential knowledge provided them with a greater ability to 'understand the [client's] problem'. Boosma-van Holten et al.'s (2023) and Turner et al.'s (2021) participants experienced their clients' stories as more central for them than for their colleagues, who seemed to focus on 'fixing' their clients' difficulties rather than sitting with- and respecting- difficult emotions. Cleary and Armour (2022)'s participants similarly shared experiences of their LEs fostering connectivity between them and their clients within a *"disconnected system"*, referencing their dual experiences of the systemic difficulties inherent in mental healthcare systems today.

Participants across the majority of studies shared experiences of their experiential knowledge providing them with new, different levels of compassion for- and connection with- their clients. A participant from Boomsma-van Holten et al. (2023) described their experience of, *“sitting opposite someone [a client] who is just like me, knee-deep in mud and has to get through the viscousness of existence”,* suggestive of a deeper level of experiential connection and a more balanced distribution of power in the therapeutic relationship. This echoes experiences captured in Karbouniaris et al. (2022), which were described as a ‘felt understanding’ between FTPs and their clients. Participants from two studies shared experiences of their experiential knowledge going unspoken yet being innately recognised by their clients (Boosma-van Holten et al., 2023; Karbouniaris et al., 2022). Boomsma-van Holten et al. (2023) associated such shared experiences between FTPs and their clients with higher degrees of collaboration during treatment and more quickly established therapeutic relationships. This was also captured in Woods and Springham (2011), which reflected upon AW’s experiences of the assumptions made by the professionals involved in her own care and how her own professional assumptions had shifted based on her recent LEs. Participants described the role of their experiential knowledge as *“powerful”* (Boosma-van Holten et al., 2023; Cleary and Armour, 2022; Curry and Andriopoulou, 2023; Karbouniaris et al., 2022). Boosma-van Holten et al.’s (2023) participants additionally shared experiences of being able to detect the early signs of symptoms in their clients due to their LEs. For some participants, their experiential knowledge served to strengthen their competence: *“I am more competent to treat certain populations because I have a deeper understanding of the experience of having the diagnosis”* (Lopez-Aybar et al., 2024).

Other participants considered the coming-together of their learned (through training) and experiential (learned through LEs) knowledges. A participant from Adame (2011) adopted the metaphor of a tree for their professional practice; their LEs of mental health difficulties and iatrogenic harm were the roots and the trunk of the tree. In contrast, their professional learning was the leaves that continuously changed colour and were shed with the passing of time. This metaphor suggests that their LEs provided a groundedness, consistency and stability from which their professional growth was enabled; a growth that was marked by the cyclical shedding and learning of new clinical concepts.

Several studies also captured FTP experiences of their combined knowledges being meaningful on a personal level. A participant from Cleary and Armour's (2022) study shared that their, *"theoretical knowledge gave structure to my inner world and a language with which to express it, and I found this to be really powerful."* Boyd et al. (2016) and Curry and Andriopoulou (2023) similarly reported participant experiences of finding personal pride and strength through their combined knowledges.

The Drive for Stigma Resistance

Across ten studies, participants shared experiences of sharing their LEs as acts of activism and stigma resistance. This stigma resistance was sometimes described by participants as both a personal and professional responsibility (Boomsma-van Holten et al., 2023; Cleary and Armour, 2022; Curry and Andriopoulou, 2023; Lopez-Aybar et al., 2024), although participants also shared experiences of stigma resistance bearing both personal and professional risk (Adame, 2011; Boomsma-van Holten et al., 2023; Cleary and Armour, 2022; Curry and Andriopoulou, 2023; Lopez-Aybar et al., 2024; Turner et al., 2021). Some participants reported experiencing a *"drive to advocate"* for others experiencing mental health difficulties (Huet and Holttum, 2016), and a *"drive to enhance therapy accessibility"* for future clients (Cleary and Armour, 2022). Adame (2011) captured experiences of feeling driven to challenge *"vile, mainstream stigma"* and utilising experiential knowledge to challenge systemic oppression: *"I know what that's like… dealing with the system."*

Karbouniaris et al. (2023) and Boomsma-van Holten et al. (2023) described participants' experiences of their LEs as catalysts for openness within psychiatry's professional culture capable of stimulating destigmatisation. Similarly, participants in Karbouniaris et al. (2022) experienced their FTP status as facilitative of professional cultural change. Karbouniaris et al.'s (2022) participant alluded to their sharing of their LEs with colleagues as a form of cultural activism:

> *"After I started talking openly, a few colleagues individually shared details from their personal lives, which I appreciate because if we want to realise a broader climate change, more openness and safety are vital."*

Boomsma-van Holten et al. (2023) found their participants were 'driven' to destigmatise and stand-up against injustice within their professional teams while advocating for the importance of experiential expertise and the centring of patient experiences in psychiatric practice. Multiple studies captured FTPs' experiences of being 'evidence of recovery' (Boyd et al., 2016) and challenging misconceptions held by colleagues that recovery was futile (Lopez-Aybar et al., 2024). Turner et al.'s (2021) participants spoke to using their LEs to influence narratives around mental health. Participants from Lopez-Albar et al. (2024) and Boyd et al. (2016) described finding strength and pride in their acts of stigma resistance through the sharing of their LEs.

Continuously Learning to Harness Experiential Knowledge

Six studies captured participant experiences of learning to harness experiential knowledge in their professional practice. While the majority of participants found their LEs to be valuable in their professional practice, participants also spoke to the difficulties they encounter due to a lack of training and support as to how best to integrate their complimentary knowledge base into their clinical work. All six studies described this learning as a continuous, ongoing process as a result.

A participant from Lopez-Aybar et al.'s (2024) study shared: *"I think my experiences will make me more credible, authentic, and empathetic as a clinician, but without proper training and supervision that acknowledges and supports this, it's a lot harder to integrate into my work."* This was an experience echoed across multiple studies. Turner et al. (2021) found their participants were left questioning whether their LEs were professionally acceptable due to the absence of any model for speaking to those experiences in supervision or reflexive spaces, let alone within their clinical work. Participants from Karbouniaris et al. (2023) shared experiences of finding professional spaces such as peer supervision and reflexive practice groups *"superficial"*, despite ostensibly being facilitated to support reflection and professional development. Karbouniaris et al. (2022) associated the lack of spaces in which to explore dual experiences of mental health difficulties with systemic challenges arising from the risk aversity of the western medical model of mental healthcare. Boosma-van Holten et al. (2023) associated the same lack of safe, meaningful spaces within which to reflect on LEs with systemic challenges of organisational culture, inclusive of rapid staff force changes that prevent the growth of open, safe and stable professional teams. This experience was echoed by participants in Karbouniaris et al. (2023), some of whom experienced their LEs as 'burdensome' because they had not been taught how to navigate them during training.

Participants from Adame's (2011) study shared experiences of encountering difficulties harnessing their experiential knowledge in their client work. Ron shared his experience of a client questioning his clinical competence after reading about his LEs online. Participants also spoke to experiences of *"mistakes"* (Adame, 2011) they made and learned from when finding ways of harnessing their experiential knowledge in practice. Participants from Adame (2011) and Boosma-van Holten et al. (2023) spoke to experiences of overidentifying with a client, in addition to experiences of boundaries becoming difficult due to therapeutic relationships feeling ‘too powerful’ (Boosma-van Holten et al., 2023), feeling as though they are working outside their professional role, ‘missing the mark’ (Adame, 2011), and unintentionally invalidating clinical constructs that their clients found useful.

2.6 Summary of Evidence and Implications for Clinical Practice and Research

2.6.1 Summary of Evidence

The present SLR identified two overarching themes surrounding the experiences shared by the participants of the retrieved studies: navigating the dichotomy between ‘us vs. them’ and harnessing experiential knowledge. These wider themes encompassed a range of emotional and practical experiences. FTPs’ emotional experiences included feelings of being othered, stigmatised, fearful, unsafe, deconstructed, left with a sense of not belonging, bearing weight of professional cultural expectations and, in some cases, included and unburdened. Practical experiences included encountering difficulties utilising experiential knowledge in the absence of practical support within the mental healthcare system, the drive for stigma resistance, and navigating the decision as to whether to disclose their LEs as professionals.

While the findings of the present review suggest that FTPs’ combined experiential and academic knowledges are valuable to their fields and individual practices (as found by all included papers), they also suggest that the population routinely encounters and subsequently braces themselves for discrimination, stigmatisation, and *“punishment”* for their dual identity (as found by ten of the eleven included papers). There was a high level of experiential consistency across all papers, despite the studies being conducted across different western countries, recruiting FTPs from a broad range of professional backgrounds, recruiting FTPs with a broad range of experiences of mental health difficulties, representing FTP experiences as captured in research over the span of a decade, and focusing on different aspects of FTPs’ experiences. This review’s findings suggest that FTPs experience their dual identity and LE-informed work as something they are proud of, value, and want to nurture, but that these can also feel like personal and professional burdens when their training needs go unmet and they feel silenced by their professional cultural contexts and fearful of discrimination. The universality of experiences captured by the included papers may be suggestive of a systemic misunderstanding, devaluing, and stigmatisation of LEs within mental health professional contexts; FTPs' experiences of both being harmed by- or fearing harm from- their colleagues and witnessing the harm their colleagues cause to their clients may be indicative of an antithetical culture of mental health discrimination amongst mental health professionals, as identified in wider literature (eg. Hamilton et al., 2016; Vistorte et al., 2018). FTPs experiences of being neither the 'us' nor 'them' of the reported professional-client paradigm were experienced by some participants as situating them between the two groups, holding insight into both yet belonging to neither, embodying different skills and, in some cases, differing values.

While unrelated to the analytical themes that arose from the review itself, the process of searching for and retrieving relevant papers might also be considered as having revealed some valuable findings. Seventeen papers, written by FTPs as either first-person narratives, letters to editors, or opinion pieces were excluded from the present review due to falling outside its inclusion criteria; inclusion criteria sought empirical research studies adopting clear qualitative methodological procedures with a view to ensuring its findings were of a good quality (CASP, 2018; Yardley, 2000). It should be noted that, while those 17 papers did not meet the present SLR's inclusion criteria, the experiences they speak to are empirical in the sense that they are based on LEs (APA, 2025), and those experiences must not be considered less valuable due to how their authors elected to share them. This does raise the question, however, of why the FTP subset of the dual-experienced community seems to favour the sharing of their experiences in more narrative formats as opposed to more traditionally methodologically informed empirical studies. While it is outside the remit of the present review to answer this question, it is a question that the dual-experienced research community might consider reflecting upon as it continues to build an evidence base relating to the population. The present findings align with experiences shared within FTP first-person narrative publications. Friesen (2022), a psychiatrist, found that their LEs of bipolar disorder provided them with a *"deeper insight"* into the experience of psychological crises and now enables them to reduce the stigma and shame experienced by their clients and their families through their experientially-informed empathy and patience. Also analogous with the present findings, Bhattacharya (2022), a psychologist, shared how their LEs of clinical depression led them to fear professional and societal stigmatisation, and to advocate for interdisciplinary reflexive learning relating to the empowerment of clients as opposed to *"mere symptom amelioration"*. Vierthaler (Vierthaler and Elliott, 2022) was warned against disclosing their mental health difficulties to colleagues by professional peers and their treatment providers due to the risk of loss of professional status, and found support in their *"battle buddy"* – a professional ally who supported them to navigate their FTP status amidst their professional culture. However, like Friesen (2022) and Bhattacharya (2022), Vierthaler and Elliott (2022) reported Vierthaler's drive to fight the mental health stigma and discrimination experienced by both FTPs and clients.

The present findings similarly align with quantitative and non-experientially based FTP studies suggestive of the systemic stigmatisation of FTPs. For example, Boyd et al.'s (2016) American study regarding state psychology licensure questions about mental illness found that several states assumed diagnosis was synonymous with impairment or imposed indefinite timeframes that did not recognise the possibility of recovery or remaining competent whilst living with a mental health difficulty, inherently stigmatising and discriminating against FTPs. Similarly, Harris et al.'s (2022) survey of 40 FTPs, 35 reported experiencing workplace bullying either presently, historically, or both; significantly higher than rates for the wider mental health professional workforce suggestive of the othering experienced by FTPs as found in the present review.

The present findings also align with studies exploring the experiences of the peer workforce – another subset of the dual-experienced workforce. Such studies similarly captured experiences of occupying the liminal space between service provider and service user, neither feeling wholly service user nor wholly staff, and of peer support workers struggling to navigate the balance between sharing their LEs and self-preservation (eg. Gillard et al., 2013). Research also captures peer support worker experiences of assuming their role through a perceived 'moral obligation' to help others with their experiential knowledge, and the difficulties and learning curves that they encounter in their work (eg. Gillard et al., 2022). Research further suggests that the peer support workforce commonly encounters tension and difficulties with clinical professionals (eg. Otte et al., 2020). To the best of the present reviewer's knowledge, research has not yet directly explored the similarities and differences between the experiences of FTP and peer support subgroups of the dual-experienced population, although existing literature appears to suggest that they hold some overarching, shared experiences of feeling driven to stigma resistance, finding personal and professional value in their LE-informed work, and encountering stigma due to their dual relationship with mental health difficulties.

Of note, the process of searching for the present SLR's included studies highlighted notable inconsistencies in the use of language and the signposting of adopted methodologies in papers' titles, abstracts and keyword codes within the FTP field of research. While it may be that FTP researchers are carefully considering the languaging of their publications and perhaps utilising their participants preferred terminologies (for example, Adame (2011) adopted the term 'survivor-practitioner' whereas Lopez-Aybar et al. (2024) adopted the term ‘prosumer’, both of which have been utilised to refer to the wider dual-experienced population, inclusive of the peer workforce, in wider literature (eg. Aikawa and Yasui, 2017)), the FTP field of study might consider working towards a shared language with a view to enabling a clearer, shared understanding of the dual-experienced population and its subgroups in research. This is not with the intention of fissuring the dual-experienced community, but rather advancing the ability of research to capture the richness of experiences, needs and value that the population encompasses.

This review highlights a paucity of empirical qualitative research exploring the experiences of FTPs, and, to date, those that have been conducted are spread across multiple mental health fields and professional contexts. The data captured by this review’s included studies suggest FTPs’ dual knowledge and experiences are valuable and illuminate underexplored difficulties within mental health treating systems, yet that they remain understudied along with, albeit to a marginally lesser degree, the wider dual-experienced population.

2.6.2 Critical Evaluation

The present review is limited in that it only included papers utilising qualitative methodologies. While this felt important given that the evidence base relating to FTPs is currently predominantly qualitative in nature and the field of research is still in its infancy, this meant that quantitative papers that might have contributed to the review’s understanding of the experiences of FTPs were excluded. Such papers may provide valuable contextual data that contribute to a broader understanding of this population’s experiences. Additionally, the present SLR does not capture the experiences of FTPs which are shared within first-person narrative articles, editorial and opinion pieces, and which may provide further thematic considerations. The present SLR did, however, retrieve 11 studies of a good quality (CASP,

2018) that had researched the FTP population, inclusive of a wide range of FTP professional and mental health difficulty experiential contexts.

2.6.3 Implications for the Present Study

The experiences of the included studies' participants suggest that FTPs' combined professionally learned and experientially acquired knowledges provide them with a unique, organic, felt, and shared understanding of their clients. The present review has contributed FTPs' shared experiential themes, as captured within existing empirical qualitative research, to research's understanding of the FTP subset of the wider dual-experienced population. The findings from the present review echo those arising from studies of the experiences of the peer workforce subset of the dual-experienced population – the subset upon which the majority of existing research relating to dual-experienced individuals is based. This suggests that the wider dual-experienced population may share common experiences of encountering stigma and discrimination, finding strength and pride in their experientially-informed work, and utilising their professional and LE knowledges to inform their work, their understanding of mental health treating systems, and acts of stigma resistance intended to improve mental health systems' understanding of LEs of mental health difficulties (as found by the present review and as suggested in peer workforce research: eg. Gillard et al., 2013; Gillard et al., 2022). FTPs, like the peer workforce, report experiencing themselves as sitting outside the 'them' and 'us' socially constructed divide observed between mental health professionals and their clients. While this evokes a sense of unbelonging and otherness (eg. Gillard et al., 2013; Cleary and Armour, 2022), studies suggest that this enables them to view mental health systems from a different position, witnessing them from a different perspective (eg. Adame, 2011) and with a lived awareness of systemic mental health stigma (eg. Karbouniaris et al., 2022). While the FTP and peer workforce subsets of the dual-experienced population also hold experiences unique to their subgroups (eg. Karbouniaris et al., 2022), research appears to suggest that approaching both groups to learn of their experiences with a view to elucidating a phenomenon (in the case of the present project, PTT in AN) as studies have done to date (eg. Curry and Andriopoulou, 2023) would be meaningful at this stage given the homogeneity of their overarching experiential themes and the unknown IwDEAN population size.

3.0 Empirical Study

3.1 Overview

This chapter will outline the rationale, aim and research questions for the present study.

3.2 Rationale for the Present Study

High rates of PTT are well documented in AN research and present a significant barrier to effective treatment and prognosis (Vincenzo et al., 2022). Recent studies have begun to explore PTT through the lived and living experiences of IwAN and have called for further qualitative investigation of the phenomenon as a crucial means of addressing knowledge gaps on the subject (Mahon, 2000; Vinchenzo et al., 2022). There remains, however, a broader, notable disconnect and paucity of shared understanding between those with lived or living experience of AN and some professionals and researchers (Music et al., 2021), and AN researchers have called for a new, adjunctive approach and lens through which to elucidate PTT (Bulik et al., 2015; Forbes, 2020).

An ever-expanding body of evidence is showing that lived experience perspectives of mental health difficulties are not only valuable for, but necessary when thinking about service development, improving care, embodying hope, normalising experiences, and constructing treatment approaches (Beames et al., 2021; Conchar & Repper, 2014; Curry & Andriopulou, 2023; Repper & Carter, 2011; Zerubavel & O'Dougherty-Wright, 2012). Voices of dual experience – those holding both personal and professional expertise of AN - remain underrepresented in AN research to date (Curry & Andriopoulou, 2023; Victor et al., 2022) and have yet to be included on the subject of PTT. This dual-experienced lens has the potential to bridge the divide between those with and without lived or living experience of AN and contribute a novel perspective to a field where the need for a greater understanding of barriers to successful treatment is ever increasing (Bulik et al., 2021; Curry and

Andriopoulou, 2023; Victor et al., 2022). IwDEAN are in the unique position of being able to draw upon both personal and professional expertise of the illness when providing care, improving services and reflecting upon their experiences (Curry and Andriopoulou, 2023); qualities that researchers have recognised as an adjunctive asset to the understanding of the lived experiences of illnesses (Victor et al., 2022).

The present study therefore explores IwDEANs' experiences of PTT. It was anticipated that the present study's findings could help to inform narratives around PTT in the context of AN and address the gap caused by the paucity of dual experiences in current AN literature and discourses. Key definitions adopted in the context of the present study are provided in Table 6.

3.3 Research Aim

The present study aimed to explore in depth how IwDEAN experience(d) PTT.

3.4 Research Questions

- How do IwDEAN make sense of their experiences of PTT?
- What meaning do IwDEAN give to their experiences of PTT?

Table 6

Key Definitions Adopted in the Context of the Present Study

Term	Definition in the Context of the Present Study
'Individual(s) with Dual Experience of Anorexia Nervosa' (IwDEAN)	A person or group of people who have both personal experience of living with AN and who have held a role providing treatment for others with AN, inclusive of the peer workforce and FTPs (Curry and Andriopoulou, 2023).
'Premature Treatment Termination' (PTT)	The present study adopted an inclusive approach towards identifying experiences of PTT, uniting existing conceptualisations of the phenomenon: an event or events whereby an individual's treatment ended earlier than planned (Wallier et al., 2009); an event or events that may be patient-initiated and/or provider-initiated (Sly et al., 2014; Wallier et al., 2009); an event or events that may mark the end of treatment programme (eg. discharge from inpatient admission: Wallier et al., 2009) and/or a particular aspect of a treatment programme (eg. discharge from individual therapy in an outpatient setting where contact with other professionals (such as for psychiatric review or medical monitoring) may remain ongoing: Jordan et al., 2017); and/or a series of multiple events that occur during a person's illness (Curry and Andriopoulou, 2023). Allowing participants to conceptualise what 'PTT' entailed was a key aspect of the present study. This study was therefore also open to definitions offered either directly by participants or through the analysis of their experiences with a view to developing the conceptualisation of PTT and informing future research into the phenomenon.

4.0 Methodology

4.1 Overview

This chapter will outline the methodology utilised for the present study, detailing the study's design inclusive of ethical considerations, participant recruitment strategy and participant demographics, the data collection process and information pertaining to the interview schedule and interview approach, the nominated method of analysis and how this was applied, and associated decision-making processes.

4.2 Design

4.2.1 IPA

This is a qualitative semi-structured interview-based study, where IPA was applied to participants' interview transcripts. It is a meaning-focused project (Smith, 1996), committed to understanding the experiences and perspectives of the project's participants. IPA centres around the detailed examination of personal lived experience with a view to clarifying and elucidating a phenomenon (Eatough and Smith, 2017). IPA utilises purposeful, largely homogenous sampling (in the case of the present study, individuals with dual experience of AN who have experience(s) of PTT) (Smith, 2009). Instead of seeking transferability, IPA seeks to learn about the qualities of a particular experience as they are lived by an experiencing subject (Eatough and Smith, 2017) rather than as prescribed by pre-existing theoretical preconceptions (Smith and Osborn, 2015).

IPA adopts a phenomenological epistemological position, and its primary interest is in a participant's experience of the nominated phenomenon (in this case, PTT) and the sense they make of it (Eatough and Smith, 2017). Richardson et al. (1999) illustrated this, explaining that our nature or being as humans is not just something we find, nor is it something we make; instead, it is what we make of what we find. As such, IPA understands that people and the worlds they inhabit are socially and historically contextually bound and considers this throughout the analytic process (Eatough and Smith, 2017). The methodology is committed to elucidating a phenomenon through the experiences of its participants, in addition to being curious as to what can be learned from those experiences as they are lived by an embodied socio-historically situated individual (Eatough and Smith, 2017). Eatough and Smith (2017) describe IPA as resolutely idiographic, in that it seeks to understand a phenomenon while maintaining the integrity of the individual; tentatively approaching generalisability while remaining grounded in the participant's individual, unique experiences and the meaning they give to them. This can be seen through IPA's use of small participant sample sizes with a view to ensuring that each individual can be attended to individually – idiographically – before comparative analysis of participant data is attempted (Eatough and Smith, 2017).

IPA adopts an interrogative position to both its own findings and existing literature, and IPA researchers acknowledge the inevitability of biases and assumptions when conducting their research (Eatough and Smith, 2017). The methodology embraces the understanding that experience is subjective, as experience is phenomenal as opposed to a direct reality (Eatough and Smith, 2017). While IPA researchers are interested in entering and understanding the lifeworld of their participants - the realm of immediate human experience (Halling and Carroll, 1999) - from the perspective of the inherently reflective and meaning-making individual, they are, themselves, inherently reflective and meaning-making individuals (Smith et al., 2021). This double hermeneutic, which is central to the methodology, illustrates how IPA's analysis is inherently a synthesis of both the participants' and the researcher's sense-making (Giddens, 1986). IPA methodology acknowledges that, as experiencing subjects themselves, researchers are inherently biased, and it harnesses these assumptive stances through reflexivity, encouraging engagement with them to further their understanding of their participants' experiences (Smith and Osborn, 2015).

4.2.2 Limitations of IPA and Consideration of Alternative Methods

While IPA centres its participants' experiences to elucidate a phenomenon (Eatough and Smith, 2017), aligning with the PR's epistemological stance, it should be noted that IPA has received criticism for lacking robust standardisation, generalisability, and validity, and for embracing the voice (and subsequently, the experiences) of the researcher (Tuffour, 2017). This had led some researchers to challenge the methodology's claims to capture, centre, and deeply explore participants' experiences, and consider the researcher's subjectivity to be an inherent flaw (Brocki and Wearden, 2006; Tuffour, 2017). Smith et al. (2009) acknowledged that two IPA analysts may make different interpretations of the same source material, but advocated for the embrace of the researcher's role through the methodology's underpinning reflexive and bracketing practices. Oxley (2016) concluded that IPA embraces the importance of individuals' perceived experiences as they were lived and contributes meaningfully to research through its thorough exploration of the accounts of small samples of expert groups. In an article relating to the value of IPA, the British Psychological Society (BPS) described lived experiences as the 'very bread and butter of psychology' (Reid et al., 2005) and advocated for the value of the methodology.

Prior to deciding to proceed with IPA, the PR considered alternative methodologies that aligned with their ontological and epistemological positioning with a view to ensuring that their choice of analytical approach was appropriate for their research aims, questions, insider researcher positionality and target population. Reflexive Thematic Analysis was considered for this study due to its focus on meaning-making, which it views as inherently context-bound (Braun and Clarke, 2022). Similar to IPA, it is a process requiring the researchers' reflexivity and immersion in their participants' experiences and can be well-suited to insider research (Braun and Clarke, 2022). Narrative Analysis was also considered for its focus on its participants' meaning-making – storying - of their experiences and depth of analysis (Josselson and Hammack, 2021).

Both alternative methodologies are often chosen for the richness of data that they evoke and their use coding and interpretation, and they each carry similar limitations to IPA regarding their generalisability and the risks associated with researcher subjectivity (Findlay, 2021; Josselson and Hammack, 2021). Research suggests that IPA's idiographic approach, however, combined with its smaller sample sizes permits the researcher to more deeply immerse themselves in their participants' experiences (Smith and Woodside, 2021); this felt important, given the present participant population is currently underrepresented in research and the field is in the early stages of studying this sometimes stigmatised population (Curry and Andriopoulou, 2023). While Narrative Analysis closely examines the structure and meanings of personal stories, IPA explores the subjective meaning-making processes behind such experiences (Josselson and Hammack, 2021; Smith et al., 2009) – processes that the present study hoped to explore. An additional consideration in the design of the present study was that of potential recruitment challenges; while studies evidence that there is a population of dual-experienced individuals in the context of AN, the stigma that dual-experienced individuals can encounter is well-evidenced (Curry and Andriopoulou, 2023; Tay et al., 2018). Therefore, concerns around confidentiality, while carefully considered and protected against in the design of the present study, may have prevented prospective participants from self-identifying. As the size of the IwDEAN population is also currently unknown, this study's design had to consider the potential for a very small number of participants coming forwards. As such, the thematic saturation sought in Reflexive Thematic Analysis (Naeem et al., 2024) may not have been achievable. It was therefore decided that IPA would be the most appropriate methodology for the present study.

4.2.3 Ethical Considerations

Ethical Approval. In accordance with the University of Hertfordshire (UH) policy (UH, 2025) and the British Psychological Society's (BPS) Code of Human Research Ethics (BPS, 2021), ethical approval was sought from- and granted by- the UH Health, Science, Engineering and Technology Ethics Committee with Delegated Authority (ECDA) following the PR's completion and submission of the UH Ethical Approval form. The present study's protocol number is LMS/PGR/UH/05844 (Appendix F). Deviations from- and non-compliance with- the approved research proposal were not permitted without ECDA approved amendments to the protocol. No changes to the research protocol were required following approval and no further ethical approval was therefore sought.

Informed Consent. The project's consent form (Appendix G) and participant information sheet (PIS: Appendix H) were shared with prospective participants during the initial correspondence phase, to ensure that their decision to proceed with their involvement was as informed as possible. Participation in the project was entirely voluntary. Interviews would not have proceeded if the participant had any concerns, and only proceeded when the participant signed the consent form, confirming their understanding of their involvement in the project. The consent form also invited participants to indicate whether they wished to be informed of the outcomes and dissemination of the study and consent to their nominated email address being retained for one-year post-research completion for this purpose.

A debrief form (Appendix I) was shared digitally via email with each participant following completion of their interview and prior to terminating the Teams meeting, signposting support services and outlining next steps. Participants were asked to verbally confirm receipt of the debrief form prior to the meeting ending with a view to ensuring they had access to the information it contained. Participants were informed both verbally and through the consent form, PIS and debrief form that they could withdraw at any time prior to, during, or up to two weeks following their interview, without needing to provide an explanation. There were no benefits to participation in this project.

Confidentiality and Data Management. Table 7 outlines confidentiality and data management procedures followed during the present study. All data was handled in accordance with GDPR (2018) and no data breaches occurred.

Potential Distress. Should participants have become distressed at any stage of their involvement with this project, the PR would have adhered to the project's distress protocol (Appendix J), which was designed in accordance with Whitney and Evered's (2022) guidance for qualitative research. This protocol outlines the steps that the PR would take should a participant have experienced distress. Contact details for support services were provided on the PIS, which was shared with prospective participants prior to obtaining their consent for their participation in the study. Contact details for complaints and concerns were shared via the PIS and debrief form, including those for the project's PS, the Doctoral College, and the UH ECDA. All participant interviews were conducted between Mondays and Thursdays between 9am and 4pm to align with the typical working hours that support services are most widely available should a participant need to access them post-interview. This also aligned with the working hours of the PR's supervisory team so that they could seek their support and guidance should the need arise during or immediately following an interview. No participants expressed or reported experiencing distress at any stage of their involvement in the study.

The Research Team's EbE Consultant. An EbE Consultant was recruited to the project's research team via existing professional connections and invited to inform the development and progress of this study. The Consultant wishes to remain anonymous.

4.2.4 Recruitment

This study aimed to recruit between five and ten participants in accordance with Smith et al.'s (2021) guidance for doctoral level research and the UH Doctoral College requirements for projects utilising IPA methodology for research in partial fulfilment of the

Table 7

Confidentiality and Data Management Procedures

	Procedure Followed
Consent Forms	Each participant’s signed consent form (a digital Microsoft Word document) was saved on the PR’s university OneDrive in its own password protected folder named under the participant’s chosen three-digit unique identification code. The consent form itself contained a note of the first three letters of the participant’s chosen pseudonym. No participant’s chosen pseudonym shared its first three letters with another’s. This process was to enable the PR to accurately identify a participant’s data and destroy it should they have chosen to withdraw within the two-week post-interview period while protecting their confidentiality and taking preventative action against the potential for any data breaches.
Interview Recordings	Each participant’s interview was digitally audio-visual-recorded using the recording function of Microsoft Teams due to the secure encryption of the platform (Microsoft, 2024). A backup digital audio recording (in case of any difficulties arising with the Teams recording) was made using a password encrypted digital voice recording device that was not WiFi enabled (model: Homder Digital Voice Recorder). Immediately post-interview, all recordings and transcriptions were uploaded to the PR’s university OneDrive where they were stored in password-protected folders named with their chosen pseudonym (separate to the folders storing each participant’s consent form) and deleted from Microsoft Teams and the backup recording device. This was to ensure that their data was safely and securely stored as swiftly as possible and further reduce the risk of a data breach.

	Procedure Followed
Transcriptions	Transcription of participant interviews was made using the Microsoft Teams inbuilt transcription software in line with the UH ethics committee's recommendations due to both the secure encryption of the platform (Microsoft, 2024) and the reduced time for which participant recordings needed to be stored, subsequently reducing the risk of the potential for any breaches of their confidentiality (Information Commissioner's Office, 2024). These transcriptions were downloaded from Teams onto the PR's university OneDrive immediately post-interview, saved within a password protected file attributed to the participant's chosen pseudonym, and deleted from Microsoft Teams. These were then reviewed by the PR post-interview and amended to ensure they accurately represented each participant's interview based on their audio-visual recording and redacted to ensure that each participant's confidentiality was protected. Once a participant's transcription was deemed accurate, their audio and audio-visual recordings were permanently deleted from the OneDrive by the PR.
Personal Data	Participants were asked if they consented to sharing their personal data including their name, age, gender identity, preferred pronouns, ethnicity, and role(s) in the field of caring for or treating individuals with AN or AN-like presentations. The rationale for collecting this personal information was to provide context to the participants' experiences during data analysis (Smith and Woodside, 2021). Participants were at liberty to decline to share their personal information and it did not affect their ability to participate in the study. The participants' names were documented electronically on their consent form (a digital Microsoft Word document), were assigned a unique three-digit identification code (chosen by the respective participant), and stored on the PR's

	Procedure Followed
	university OneDrive, encrypted within a password protected folder, separately from the interview data. All other personal data was initially collected during the interview process and therefore initially stored within a digital audio-visual file on Microsoft Teams and a backup digital audio recording on the backup password-protected digital recording device used, prior to being deleted as outlined above upon successful review of the participant's transcript.
Management of Data During IPA Analysis Processes	While the majority of data collected during this study was in a digital format, participants' pseudoanonymised experiential statements, personal experiential themes, and group experiential themes were printed or handwritten onto small slips of paper (hardcopy data) as part of the analytical process (see *'Analysis'* for more information). When not in use, these slips of paper were stored in a locked cabinet at the PR's residence. The PR took photographs of all stages of analyses which utilised this hardcopy data as advised by Larkin et al. (2022) using a tablet device. These photographs were immediately uploaded to the PR's university OneDrive within a password protected folder and permanently deleted from the tablet device. Immediately following completion of analyses, all hardcopy data was destroyed via multi-directional shredding.
Access to the Study's Data	Access to this study's data was granted to its PR, principal supervisor and their research mentor, secondary supervisor, the UH Doctoral College, and UH's Ethics Committee for the purposes of monitoring, auditing, and approving. Any data that was shared was shared via internal password-encrypted emails with the password issued in a separate email. The analytical processes underpinning this project were discussed with the PR's IPA training group, comprising of other Trainee Clinical Psychologists at

	Procedure Followed
	UH and their IPA trainer (a qualified Clinical Psychologist at UH). In these instances, only anonymised excerpts were discussed and no data was shared either electronically or in a hard copy format. Participants consented to this data sharing via their consent form and received an explanation of these sharing processes and rationales via the PIS.
Email Communications	Email communication between the PR and prospective participants took place via the PR's secure, private university email address. All email communications to and from prospective participants were permanently deleted from the PR's inbox, 'sent items' and 'deleted emails' folders on their email account within a week of correspondence being sent or received with a view to protecting prospective participants' confidentiality.
The Ongoing Management of Data	All data and records (with the exception of participant audio and audio-visual recordings and hardcopy analyses resources which were deleted as outlined above) resulting from this project will be stored securely until completion of the PR's doctoral programme (expected completion date of the 1st October 2025), whereupon they will be destroyed by the PR. Participants' raw data will not be used beyond the present study; consent was not sought for this out of recognition that participants would not have had a say over who their experiences were entrusted to and that some of the key features of the present study (inclusive of the PR's insider researcher status and the epistemological approach of the study) may have been deciding factors for participants' involvement, and that their raw data may have been approached differently by other researchers.

Doctorate of Clinical Psychology. Participants were recruited via: (1) Gatekeeper-approved poster advertisements in appropriate settings/academic institutions/online platforms that were identified and approached by the supervisory team, (2) The public ‘sharing’ of the recruitment poster on social media/online platforms (3) Word of mouth resulting from the recruitment poster. The recruitment poster (Appendix K) invited prospective participants to self-identify and contact the PR via their secure student university email address. Participation in the study was discussed- and details for the study shared- via email correspondence with the prospective participant.

4.2.5 Participants

The present study recruited eight individuals with dual experience of AN: individuals with lived or living experience of AN or an AN-like presentation and experience of providing care or treatment for others with AN or AN-like presentations. Participant recruitment was purposive and its sample largely homogenous in accordance with IPA methodology (Smith et al., 2021), fulfilling the criteria in Table 8.

Table 8:

Eligibility Criteria

Eligibility Criteria	Rationale
Age 18 years or older.	This study did not seek ethical permissions to recruit children and young people because of the potential for its subject matter to be distressing and limitations to the support that could be provided at interview should a participant be in need (see *'Potential Distress'*).
Fluent in English.	IPA methodology includes a focus on language, and this was to ensure that participants' interviews captured their experiences through their own words and without the risk of misinterpretation or misrepresentation due to translation errors or difficulties relating to direct translation (for example, idioms).
Based in the UK.	This study did not seek ethical permissions to recruit participants from other countries due to being a UK-based research team and concerns around being able to accurately signpost individuals from other parts of the world to relevant local support services should they experience distress.
Had lived or living experience of AN or an AN-like presentation.	This was one half of the dual experience held by the study's target population and was therefore an eligibility requirement. No formal diagnosis of AN was required out of recognition that AN diagnosis is commonly missed (Waller et al., 2009), that some services utilise a transdiagnostic approach (Cooper and Dalle Grave, 2017), and that there are obstacles that prevent individuals with different social GRRRAAACCEEESSS (Burnham, 2012) – inclusive of being from the global

Eligibility Criteria	Rationale
	majority and ethnic and racial minorities (Gordon et al., 2006; Sinha and Warfa, 2013; Waller et al., 2009), being male (Richardson and Paslakis, 2021), transgender or gender diverse (Hartman-Munick et al., 2021), and being from a poorer socio-economic background (Bailey-Straebler et al., 2024) - from seeking- or being granted access to- support for their illness and which may mean they did not have access to a diagnostic assessment (eg. Kurdak et al., 2023). Participants were not required to formally evidence their experience nor did they undergo a formal (eg. psychometric) screening process for AN/AN history ahead of participation. While this is a common practice in AN research, adopted to enhance the validity and reliability of studies (Hatoum et al., 2023), the research team felt this may, understandably, be experienced as disrespectful or harmful by participants; it may be experienced as upholding the ‘us vs. them’ divide that remains present between those with lived or living experience of AN and non-lived experience clinicians and researchers (Curry and Andriopoulou, 2023; Music et al., 2021) by suggesting a degree of mistrust in prospective participants’ own evaluation of their experiences. This would be out of keeping with the epistemological stance of the PR. Recruitment criteria were reviewed with each participant after they self-identified for potential participation in the study, and participants’ own confirmation that they met all inclusion criteria was deemed sufficient. Participants were not required to consider themselves ‘recovered’; lived experience research suggests that recovery is a subjective and nuanced experience for IwAN as opposed to a distinct end point (Dawson

Eligibility Criteria	Rationale
	et al., 2014), and both lived and living experiences of mental health difficulties are held by mental health professionals (eg. Hogg and Kemp, 2020).
Had personal experience of PTT.	This was the phenomenon of interest for the present study and was therefore an eligibility requirement. This study's definition of PTT was detailed on its recruitment poster.
Held a role in providing care and/or treatment for individuals with AN or AN-like presentations for any length of time at any point during their career.	This is one half of the dual experience held by the study's target population and was therefore an eligibility requirement.
Felt that speaking to their personal experiences and the meaning they give to them would not negatively impact upon their personal wellbeing.	This was to support participants' own wellbeing and physical and psychological safety. The interview process required participants to speak to potentially uncomfortable, challenging and traumatic experiences, and this may have been distressing for the participant. Should a participant have become distressed during their interview, the PR was unable to provide direct support outside of directing them to support services. Contact details for support services were provided to all participants via the PIS and debrief sheet.

People were therefore excluded from participating if they were age 17 years or younger, not fluent in English, not based in the UK, did not have personal experience of AN or an AN-like presentation, did not have experience of PTT, had not provided care and/or treatment for individuals with AN or AN-like presentations, and/or felt that speaking to their personal experiences and the meaning they give to them may negatively impact upon their wellbeing.

Nine prospective participants self-identified for this study, and all prospective participants met inclusion criteria and were invited to- and consented to- their participation. One participant withdrew prior to their interview for reasons unrelated to the study. Eight participants (age range 24 to 47 years) were therefore included in the present study. All participants consented to sharing their personal demographic information in this report, which has been attributed to their chosen pseudonym (Table 9).

4.2.6 Data Collection

Data was collected via PR-conducted semi-structured participant interviews utilising a semi-structured interview schedule (Appendix L) that was informed by the project's EbE Consultant. The PR adopted a curious and empathetic stance during interviews in accordance with Smith et al.'s (2021) IPA methodology.

Interview Schedule. The study's interview schedule was informed by the project's EbE Consultant with a view to ensuring the questions were both sensitive to the participant population and optimally enabled participants to speak to their experiences of PTT (Music et al., 2021). In alignment with IPA methodological recommendations, the interview schedule was semi-structured and contained a series of pre-determined, open-ended questions, designed to encourage participants to speak about their experiences in relation to the research subject (Smith et al., 2021). This is because IPA researchers seek to learn and understand 'the experiences in which something comes to be grasped as known' (Moran, 2000) and typically

Table 9

Participants' Demographic Information

Chosen Pseudonym	Gender Identity	Preferred Pronouns	Ethnicity	Age (Years)	AN Presentation	Role(s) Held*	Clinician-/Self- Initiated
'Rachel'	Female	She/her	White British	42	Anorexia Nervosa (diagnosis)	Psychiatric Liaison and General Practitioner	Clinician-Initiated
'Serena'	Female	She/her	White British	31	Anorexia Nervosa (diagnosis)	Trainee Therapist	Clinician-Initiated
'Samantha'	Female	She/her	White British	38	Anorexia Nervosa (diagnosis)	Therapist	Self-Initiated and Clinician-Initiated
'Louise'	Female	She/her	White British	30	Anorexia Nervosa (diagnosis)	Support Worker, Assistant Psychologist, Therapeutic Practitioner	Clinician-Initiated
'Sarah'	Female	She/her	White	35	Anorexia Nervosa /Atypical Anorexia (diagnoses)	Psychological Therapist and Trainee Clinical Psychologist	Self-initiated and Clinician-Initiated
'Kevin'	Male	He/him	White British	47	Anorexia Nervosa (diagnosis)	Peer Support Worker	Clinician-initiated
'Rose'	Female	She/her	White British	24	Anorexia Nervosa (diagnosis)	Peer Support Worker	Self-initiated and clinician-initiated
'Amy'	Female	She/her	Mixed White and Black African	27	Anorexia Nervosa (diagnosis)	Support Worker and Assistant Psychologist	Clinician-initiated

**In the context of providing treatment or care for IwAN.*

Note: Bar Amy and Louise, all participants spoke to multiple experiences of PTT at interview.

explore existential matters of considerable importance for the participant by endeavouring to enter the participant's lifeworld as opposed to investigating it (Eatough and Smith, 2017). This requires the researcher to adopt a consciously naïve and receptive position, allowing themselves to be guided by the participant; the expert of their experiences (Eatough and Smith, 2017). As such, while the interview schedule informed every participant's interview, its semi-structured nature permitted the interviewer to ask additional, non-scripted questions in order to stay with participant narratives and further explore participants' experiences (Smith et al., 2021). This also enabled the PR to explore experiences that they may not have anticipated participants bringing when devising the interview schedule (Smith et al., 2009). Due to concerns around recruitment and accessing the prospective participant pool, the interview schedule was not piloted on a member of the participant population out of an awareness that, by nature of being a pilot interview, the experiences spoken to could not be included in the study. It was also not piloted on the research team's EbE Consultant due to their involvement in its design. Instead, the interview schedule was piloted on a fellow dual-experienced Trainee Clinical Psychologist who had experience of PTT in relation to treatment for a non-AN diagnosis. While their experiences did not directly relate to the study or the target population, it enabled the PR to practise their interview approach, better acquaint themselves with the interview schedule, assess the 'flow' of the schedule, and receive feedback regarding the schedule's ability to facilitate participants to speak to their experiences of PTT. No further amendments were made to the interview schedule following the pilot.

The Interviews. Interviews were conducted remotely via Microsoft Teams due to ongoing concerns around COVID-19. Remote interviews also enabled participants to choose a safe, familiar space in which to be interviewed, with a view to ensuring that participants' experiences of the interview process were as manageable as could be. As interviews were conducted between the PR and each participant individually, the PR adhered to their employing trust's Lone Worker Policy (Cambridgeshire and Peterborough Foundation Trust, 2023) to ensure their safety. Interviews lasted up to 90-minutes in duration. Prior to interviews commencing, all participants were made aware that they could 'pause' their interview at any point for any reason. This was to provide participants with the opportunity to take a break given the length of the interview and the personal and potentially challenging subject matter. No participants requested a 'pause'. (RJE 5).

Post-Interview Consultation with Research Participants. The research team was keen to invite multiple EbE perspectives into the language used throughout the study's written report. This was out of recognition that, while the study's participant population shared a dual identity, each member of the population would hold different points of intersectionality and may have experiences, thoughts and feelings that differed to those of the project's EbE Consultant. At the end of each participant's interview, they were invited to consult on the study's proposed language for key terms and propose preferred alternatives.

Transcription. Participant interviews were transcribed using the Microsoft Teams inbuilt transcription software in line with the UH ethics committee's recommendations (Microsoft, 2024). These were reviewed by the PR post-interview in conjunction with participants' audio-visual recordings and amended to ensure they accurately represented each participant's interview. These were also redacted to ensure that each participant's confidentiality was protected. As advised by Smith and Nizza (2022), all pauses, emotional responses, and non-verbal cues that occurred during each interview were noted within participants' transcriptions for consideration during analysis.

4.2.7 Data Analysis

IPA was applied to digital transcripts of participant interviews utilising Smith et al.'s (2021) IPA analysis guidelines. Analysis was conducted in accordance with Smith et al.'s (2021) seven step process. Table 10 outlines the PR's stages of IPA analysis.

4.2.8 Reflexivity

Due to the role of the PR when implementing IPA and the interpretative nature of the analysis, reflexivity was central to this study. The PR utilised regular supervision sessions with their principal supervisor as reflexive spaces in which to consider the PR's lens, emotional responses and personal narratives to ensure that the participants' narratives remained at the heart of the analyses, and that the PR's voice was noticed, acknowledged, and appropriately bracketed. The PR also kept a reflexive journal throughout all stages of the study, in which they sought to acknowledge their own thoughts, feelings and narratives relating to their work. The PR reflected upon their journal entries and brought those they felt would benefit from further reflection to their supervision spaces. Excerpts from the PR's journal entries have been signposted throughout this report within relevant sections to permit the reader insight into the PR's reflections.

4.2.9 Quality Assurance

As recommended by Smith (2010) for the appraisal of IPA studies, Yardley's (2000) principles for considering the quality of qualitative research were utilised to appraise the quality of the present study (see Table 11). This was used in conjunction with the CASP (2018) qualitative checklist for the appraisal of quality, to enable the present study to be considered in the context of the quality of those reviewed in the SLR (see Table 12). These evaluation processes suggested that the study was of a high quality.

Table 10

The Stages of IPA Analysis (Smith et al., 2021)

Step of Analysis:	Description of PR's Actions:
One	For the first step, the PR immersed themselves in one participant's narrative by reading and re-reading their transcript. The researcher attempted to bracket any presuppositions they may have held through the use of supervision, their reflexive diary, and their IPA methodological workshops, with a view to ensuring that the participant's experiences remained at the heart of the analytical process. IPA is a methodology which embraces the understanding that researchers will hold their own experiences when analysing data, and provides a robust methodology for the researcher to bracket their own experiences while valuing the dynamic whereby researchers make interpretations of how participants have interpreted their own experiences; the double hermeneutic cycle expected within the IPA methodology (Smith et al., 2021).
Two	Once immersed, the PR transitioned to step two, and annotated the participant's transcript with initial exploratory notes (defined by Smith et al. (2021) as notes with 'no rules' and 'no expectations') inclusive of descriptive comments (notes that centre around the content of what the participant is speaking to), linguistic comments (notes that explore the lexis and language use of the participant), and conceptual comments (notes that are centred around the participant's understanding and sense-making of what they are speaking to), in addition to any questions, thoughts, and reflections that arose (see Appendix M). The PR progressed to the next step once the technique of decontextualising sections of text (considering them as words in isolation of their context) yielded no further notations.

Step of Analysis:	Description of PR’s Actions:
Three	Step three saw the construction of experiential statements; succinct yet rich summary phrases that attempted to capture and assimilate both that which the participant had shared about their experiences and the researcher’s conceptualisation of what the participant had shared. These statements are drawn from the exploratory notes (see Appendix N).
Four	The PR subsequently transitioned to step four and began searching for connections across the participant’s experiential statements. Smith et al. (2021) advise that this stage of analysis is not prescriptive but, rather, iterative, and encourage the researcher to ‘explore and innovate’ as they begin to physically map out connections and consider similarities and differences between statements. Each previously identified experiential statement was written onto its own small slip of paper, which was then shuffled together with all other experiential statements and scattered across a flat surface so as to no longer have a considered order and facilitate the drawing of novel connections and the formation of experiential ‘clusters’; potential Personal Experiential Themes (PETs). Photographs were taken of each clustering arrangement prior to reshuffling and arranging into alternative potential clusters for later reference and the retracing of analytical thinking (see Appendix O).
Five	Step five included the naming of the PETs once clustering felt complete; when the PR felt they were a synergy of the participant’s experiences and the researcher’s analytical interpretations. The PETs and the subthemes that they comprised of were tabulated and annotated with page references (see Appendix P).
Six	Step six required that this analytical process was repeated for each participant’s transcript.

Step of Analysis:	Description of PR’s Actions:
Seven	Once individually analysed, step seven required that participants’ individual PETs tables were reflected upon alongside co-participants’ PETs, and connections and differences were considered. Emergent Group Experiential Themes (GETs) that arose were tentatively mapped as part of a dynamic process; different thematic groupings were trialed and adapted. This process led to the formation GETs and group level subthemes, which were discussed with the PR’s supervisory team and tabulated. (RJEs 6 and 7).

Table 11

Evidence of Yardley's (2000) Qualitative Research Principles for Quality in the Present Study

Yardley's (2000) Principles	Evidence of Each Principle in the Present Study
Sensitivity to Context	The present study's development and progress was informed by an EbE Consultant – someone who belonged to the participant population. Languaging used throughout the study was carefully considered in conjunction with the study's research team in addition to each participant to ensure that it was considerate of the participant population and reflected their experiences and preferences. The study's languaging also considered the terminology adopted within existing empirical literature relating to the participant population. Languaging used throughout the study is therefore fluid and dependent on context; it is appropriately signposted. The study's methodology was epistemologically phenomenological, permitting the in-depth analyses of participants' experiences which had previously been underrepresented in research. Participants selected their own pseudonyms with a view to enabling them to retain a form of ownership over their experiences. The PR was an insider researcher and a member of the participant population, providing them with some insight into the participants' experiences.
Commitment and Rigour	Commitment and rigour were demonstrated through the careful, thoughtful consideration of each participant's transcript and experiences following Smith et al.'s (2021) IPA guidelines. Each participant's voice was given its own protected time and space during analysis to ensure that they were heard and attended to. Exploratory notes, coding, PETs and GETs were meticulously considered and frequently

Yardley's (2000) Principles	Evidence of Each Principle in the Present Study
	revisited as part of IPA's iterative methodological process to allow for a synergy of the participants' experiences and the PR's analyses. The supervisory team consulted on all themes to ensure that multiple analytical perspectives were considered.
Transparency and Coherence	The PR took ownership of their personal context and connections with the research subject. They declared their ontological and epistemological positions and designed and conducted the study in alignment with these stances. They have included examples of all stages of their analytic processes within the study's appendices to ensure that their actions and decision-making processes are transparent. Excerpts from the PR's reflexive journal have been signposted at appropriate points throughout the report to provide the reader with further insight into these processes.
Impact and Importance	The present study addressed an important yet divided field of research in AN literature – that of PTT – through a novel, adjunctive lens with a view to elucidating the phenomenon and contributing the voices of an underrepresented population to discourses on the subject. The impact of the study will be clearer following the dissemination of its findings, but it is anticipated that the study will illuminate the population's experiences of PTT and the meaning that they give to them to contribute to the furthering of research in the field.

Table 12

The Present Study's CASP (2018) Qualitative Checklist Outcomes

Item Number	CASP Appraisal Question	Appraisal
1	Was there a clear statement of the aims of the research?	Yes.
2	Is qualitative methodology appropriate?	Yes.
3	Was the research design appropriate to address the aims of the research?	Yes.
4	Was the recruitment strategy appropriate to the aims of the research?	Yes.
5	Was the data collected in a way that addressed the research issue?	Yes.
6	Has the relationship between researcher and participants been adequately considered?	Yes.
7	Have ethical issues been taken into consideration?	Yes.
8	Was the data analysis sufficiently rigorous?	Yes.
9	Is there a clear statement of findings?	Yes.
10	How valuable is the research?	Valuable.

5.0 Findings

5.1 Overview

This chapter presents the findings of the present study. It will begin by providing additional supporting information pertaining to the chapter (Table 13) and presenting a table of the GETs and subthemes that arose from the analysis of participants' experiences. Each GET and subtheme will then be explored in further depth, supported by excerpts from participants' interviews and analyses.

Table 13

Supporting Information

Context	Supporting Information
Excerpt Formatting	In excerpts from participants' transcripts, their emphasis of a particular word or phrase has been indicated by the **emboldening** of text. Participants' non-verbal communications including pauses, laughter, sighs and gestures are indicated *(in brackets)*. Both text that has been amended to protect participants' confidentiality and instances where text has been removed from within an excerpt where it did not contribute to its meaning are indicated by *[ellipses in square brackets]*. Square brackets are also utilised to provide additional contextual information within a participant's excerpt.
A Note on Language	The language adopted throughout this chapter varies depending on the context it is used within. When sharing the analysis of an excerpt from a participant's transcript, their preferred terminology has been adopted where a personal preference was expressed. For example, some participants resonated with the concept of 'recovery' whereas others felt the term was misaligned with their experiences. The term

	‘recovery’ has therefore only been used in relation to participant excerpts where they had explicitly named this as a part of their experience during their interview.
A Note on the Externalisation of AN	Throughout this chapter, the reader might notice- and feel curious about- the participants’ tendency to externalise their AN. The externalisation of AN – sometimes referred to as the externalisation of the AN ‘voice’ – is a therapeutic technique commonly adopted in NICE (2022) guideline recommended treatments for AN (Cripps et al., 2024). Research suggests that IwAN often have both ‘friend’ and ‘foe’ relationship dynamics with this voice (Schmidt et al., 2023), and that IwAN often report finding this externalisation helpful (Medway and Rhodes, 2016). All participants externalised their AN and, as this externalisation was part of their experiences, the PR has reflected this within their analyses.
A Further Note on Double Hermeneutics	As is intrinsic to IPA methodology, the GETs and subthemes that follow reflect the PR’s interpretations of the participants’ interpretations of their experiences: a double hermeneutic (Smith et al., 2021). In the context of the present study, where the PR’s wider research team has supported the analytical process, Montague et al. (2020) suggest that this might even be more accurately described as a ‘multiple hermeneutic’, where the voices of multiple may be present within analytical interpretations. By engaging with this report, the reader, too, becomes a part of this meaning-making process (Smith et al., 2021).

5.2 Group Experiential Themes and Subthemes

Table 14 presents an overview of the GETs and subthemes that arose from the analysis of participants’ experiences.

Table 14

Group Experiential Themes and Subthemes

Group Experiential Themes	Subthemes
Systemic Barriers: Becoming Lost in the Gaps and Margins	*“Too sick, not sick enough”*: Falling into diagnostic margins.
	“You’re no longer with us”: Being lost in the gaps between services.
The Systemic Feeding of Anorexia	*“It was very much about weight. Which of course, anorexia* wants *it to be”*: Being reduced to a number.
	“Just left… to fend for ourselves”: Being abandoned to anorexia.
“Have you any idea…? The damage that you’ve caused?”: Being Hurt by the Helpers	*“Screaming, shouting”* to be heard: The silencing of experiential knowledge.
	“I don’t have a single choice in the world”: Powerlessness.
	“The Neglect*”*: Being met with a lack of compassion and understanding.
	“Had the wind just been blown in the other direction…”: Feeling lucky for receiving good care.
“Dual identity… A privilege and an honour”: The Gifts of Dual Experience of Anorexia	*“Professionally, the sense that I make of that is…”*: Consulting a professional lens.
	“I can see…”: Seeing the system.
	“On the other side”: A new knowledge.

See Appendix Q for Recurrence of Themes Table.

GET One: Systemic Barriers: Becoming Lost in the Gaps and Margins

This GET encompasses participants' experiences of falling into diagnostic margins and gaps between services around PTT events, becoming both practically and emotionally lost.

"Too Sick, Not Sick Enough": Falling into Diagnostic Margins

This subtheme describes participants' universally held experiences of PTT events being initiated due to being too unwell with AN and/or not unwell enough. The name for this subtheme is lent by Samantha's description of her experience of both being too unwell for one part of the mental healthcare system to continue providing care for her (her treatment by university counselling services was prematurely terminated due to the severity of her weight loss) and not being unwell enough to be given access to care via the next *"level"* of the system up (she was denied access to therapy via her community ED service because her weight loss was not deemed severe enough to warrant the intervention): a service-initiated PTT event. She shared, *"I was… on the diagnostic margins",* as she recalled the systemic double-bind of having been both *"too sick, not sick enough"*; falling between the two systems' criteria for treatment and into the care-less space between them. She recalled how she had felt at the time:

> *"If I wasn't this sick then I'd still be able to access this thing that I was finding helpful… […] You know, if I'd… if I'd been recovering faster… maybe I would have continued to have had this support…[…] and I definitely got the message of… like, you basically need to be sicker to access higher levels of care."*
> *(Samantha)*

Samantha's words evoked a sense of stuckness and alluded to an internalised blame for having become simultaneously too unwell and not unwell enough for ongoing care. There seemed to be a sense of futility in her position between the two services; she could not recover without support, yet, fundamentally, she could not access support without her health deteriorating further. Samantha reflected that she believed the counselling service had not *"actively intended to give"* her *"responsibility and blame for the… for the termination of the therapy"* while also recognising, *"but that is where it [the blame] existed, right? […] Your level of not okay, we can't deal with."*

Following an instance of self-initiated PTT having *"fought [her] way out"* of a *"neglect[ful]"* inpatient setting, Serena *"deteriorated more and more and more with no help"*. Despite her, her family and her local Member of Parliament *"fighting"* for increased support, she recalled: *"nobody would take me. Nobody would, because I wasn't meeting that [weight] criteria"*; *"I wasn't… (gestures to indicate air quotes) [in the]* ***'appropriate'*** *weight category"*. For Serena, her position below this diagnostic margin appeared to be marked by a constant, ongoing battle against AN-treating systems and their weight-based treatment criteria; one which needed to be fought on multiple fronts. Her words evoked a sense of abandonment and rejection while alluding to a scepticism of services' weight criteria.

Similarly to Samantha, Serena felt left with internalised feelings of blame, sharing how her *"failure"* to meet admission criteria *"told me I wasn't a good enough anorexic"*. She described this as *"feeding"* her feelings of worthlessness, as though these feelings were being nourished by services' weight criteria: *"**I** wasn't enough to be looked after properly"*; *"I'm not worthy. I'm a failure. I'm a disappointment"*. Serena reflected upon the consequences of being required to be a dangerously low weight before services would meaningfully intervene:

> *"It almost felt like I was being given* ***permission*** *to put my life even more at risk. […] I think the most shocking thing I heard was that I shouldn't have even been walking (becomes tearful). Because my heart could have given in at any point. […] And I just, I just felt like, how on earth could you say that to somebody?" (Serena)*

Serena’s lexis and emphasis seemed to convey fury and disbelief towards the ED service for enabling her AN by requiring her to become more unwell in order to access support; in Serena’s experience, a chance at wellness through treatment had come at the risk of death. She appeared to emphasise her experience of further weight loss feeling like a systemic imperative, adding: *“[It’s] really **warped** to feel that that's… you **have** to lose more weight, you **have** to be a certain category on the BMI scale to be **valued** as worthy… of treatment”.* Serena recalled how her AN responded to the position she was in: *“I can get to that weight. If that's where you'll see that I'm worth caring for”*. Service treatment criteria appeared to motivate and fuel her AN, which seemed to have entwined itself amongst- and thrived upon- her feelings of unworthiness.

> *“I just don't think I was ever valued until it came to the point where I could have literally **died**. (Laughs without smiling). And that's **awful**. And I imagine so many other people have been in that circumstance and unfortunately lost their lives before… you know, well before they [services] decided they could have intervened.” (Serena)*

Serena’s empty laughter conveyed a sense of disbelief and dismay towards ED services’ access requirements as she highlighted the great personal cost that her eventual return to treatment came at. She seemed to hold ED services accountable for what she experienced as their choice to withhold care from her and others with AN while they remained lost within the diagnostic margins.

“You’re No Longer With Us”: Being Lost in the Gaps Between Services

This subtheme encompasses participants’ experiences of finding themselves lost in care-less spaces between service provisions following PTT. Both Rose and Louise found themselves falling into- and feeling lost within- the gap between Child and Adolescent Mental Health Services (CAMHS) and adult services. Louise had been receiving treatment via a CAMHS ED team when she and her family moved house *"twenty minutes down the road"*, locating them outside of the catchment area for the service. Her CAMHS treatment immediately stopped: *"no, we can't see her anymore"*. Due to her new local ED service's policies, she *"fell into the adult pathway*". For Louise, the twenty-minute distance between her new and old homes translated into a vast experiential distance marked by a lack of control. Her experience of CAMHS - *"there was loads of people involved… the amount of appointments that I was having, it all felt very well structured… lots and lots of support"* – contrasted significantly with her two encounters with the adult service prior to the termination of her treatment – *"dismissed"*. Having been partway through treatment with CAMHS and undergone partial weight restoration prior to her family's move, the adult team deemed her too well to access treatment through their service despite her treatment being unfinished. She recalled how the adult team conveyed the termination of her treatment journey:

> *"You're either going to recover or you're going to relapse. If you relapse, we'll be here. And that was that. I was just kind of left to… go about my life and carry on." (Louise)*

The adult team seemed uncertain and ambivalent about the outcome of her discharge yet proceeded with it. Louise's words appeared to convey both a sense of lostness and finality; she seemed to have been left to navigate a liminal space between AN and recovery without ongoing support. She shared: "*I didn't matter to anyone anymore, like… people didn't care where I ended up. […] [It] felt like I didn't matter at that point."* Louise seemed to have lost her sense of self-worth as she fell into the gap between CAMHS and adult services, and appeared to be left feeling uncared for and hopeless.

Kevin described finding himself lost in the gap between his ED service and Gender Dysphoria Service (GDS) following a PTT event.

> *"The discharge from anorexia… that was it. So it was no longer… (assuming the voice of the professionals) 'You're no longer anorexic. You know, you're no longer with us. You're now with the GDS.'" (Kevin)*

Kevin's words emphasised the conclusiveness and finality of his discharge from the ED service, and were suggestive of a dismissive, exclusionary experience of PTT. He shared that the GDS had been unable to support him due to his enduring AN.

> *"They weren't…* ***together****? It was either you had anorexia or you had gender dysphoria. It's like… it was like they weren't* ***allowed*** *to come together?" (Kevin)*

Kevin's experience of falling between the GDS and ED services seemed to have shown him a disconnect and absence of cooperation between the treatment settings. For Kevin, his AN and gender dysphoria were inextricable, yet neither service seemed able- or open- to treating him holistically. His use of the word *"allowed"* seemed to carry connotations of permission; the ED and GDS treatment systems seemed to leave him feeling as though he was not permitted to exist as he was or suffer in the way he did.

GET Two: The Systemic Feeding of Anorexia

While participants experienced treatment for AN as focusing on the *"refeeding, refeeding, refeeding" (Kevin)* of their bodies, this GET speaks to participants' experiences of their AN, antithetically, being nourished by treating services through PTT-related events.

"It was very much about weight. Which of course, anorexia **wants** *it to be": Being reduced to a Number*

Treatment services' focus on weight as both a measure of wellness and a criterion for discharge featured in all participants' experiences surrounding PTT events and was universally experienced as detrimental. Serena seemed to speak directly to her treating professionals during her interview (*"in your eyes, that's fine"*) and accuse them of reducing her to nothing more than her weight, alluding to the systemic power that the measure was given: *"And I was a number. On a scale. That dictated where I was and what I was given next or when I was discharged."* Kevin reflected that this focus on weight served AN rather than the individuals with it, playing into AN's hands and feeding it: *"it was very much about weight. Which of course, anorexia* ***wants*** *it to be."*

Serena, Kevin, Sarah, Louise, and Rachel experienced improvements in their weight during treatment as triggering the premature termination of their care. Each of these participants experienced their treating services as prioritising their weight, treating them as merely a physical body, and neglecting their psychological wellbeing. The participants associated this with the perpetuation and, in many cases, the strengthening of their AN cognitions. Kevin described feeling that he and his inpatient peers were systemically failed through their treating service's prioritisation of weight:

> *"It [the service] failed many of us then. For how anorexia I think was… was* ***seen****. It was about weight and about refeeding and refeeding and refeeding and then… close the door." (Kevin)*

Kevin experienced his treatment as centring entirely around his weight, which he conceptualised as being the result of professionals' perception and understanding of the illness. Kevin's repetition of *"refeeding"* – the process by which IwAN weight restore in treatment – appears to emphasise the systematic nature of this failure; a failure that seems to have left them, unlike their weight, feeling unseen. Kevin's words also allude to a coldness and abruptness around the service's termination of his care.

Serena shared Kevin's experience of weight-centred treatment, and experienced multiple episodes of clinician-initiated PTT due to having reached what they considered to be a safer weight:

> *"It's just always been about the weight side of things. Back then it was* ***just*** *the numbers, hence why I believe my treatment ended, what I feel, prematurely… as soon as I got to a healthy weight then, [assumes the voice of the service, cheerfully] 'ta-ra!' It was nothing else afterwards." (Serena)*

Serena felt her treatment was inherently incomplete due to her treating service's assumption that improvements in her weight indicated wellness. For her, an improvement in her weight had triggered her PTT and discharge into the absence of support despite continuing to be unwell. Serena alludes to feelings of anger and disbelief towards what felt like an over-simplification of her experience of AN, while seeming to characterise her service as flippant, facetious, and dismissive as they terminated her care.

By centring improvements in weight as the focus of treatment, Kevin felt that professionals were able to consider their treatment successful and complete once the weight targets set had been met. To Kevin, weight gain in treatment for AN was a tick box exercise for professionals that enabled them to discharge him easily: *"[It] just seems to be a tick-y box, sort of an ideal way for you to then be discharged."* He alluded to the weight focus of services as intentional by design, intended to meet the needs and limitations of services rather than truly and holistically treating IwAN. He added: *"It was, it was about the weight, a* ***target*** *weight rather than identifying where that anorexia… had actually come from."* Kevin felt that the system's failure to address his AN's roots meant that his illness remained embedded, thriving amidst the service's preoccupation with weight.

Similarly to Kevin, Serena saw AN treatment programmes' focus on weight as a way to make treatment *"easier"* for professionals and circumnavigate complexity: *"if we just literally strip ourselves down as a human body [...] it's easier – it's a lot more straightforward"*. Louise echoed this experience of being stripped down and reduced to a number, sharing: *"they make you literally strip yourself down to weigh yourself, it's… not a* *nice process.”* For Serena, her treating teams’ reliance on *“medications”*, *“diets”* and *“fluids”* meant that they could avoid acknowledging and treating *“the **whole** picture”* and could evade responsibility for treating her psychologically: *“physically, you’re in a better place. So there’s nothing else that needs to be done.”* Serena alludes to this enabling the AN-treating system to prematurely discharge her under the guise of successful treatment.

“Just Left… to Fend for Ourselves”: Being Abandoned to Anorexia

Participants experienced PTT as abandoning them to their untreated, ineffectively treated, or incompletely treated AN, and spoke about the costs and long-term impact of this. Eleven years after his clinician-initiated discharge, Kevin managed to re-engage with ED services and process his grief for *“having lived a life for so many years with anorexia”* due to the premature termination of his treatment. He shared how this *“allow[ed]”* him *“to feel let down, to feel bitter, and to feel angry”* for services abandoning him to the *“grip”* of the illness. Kevin recalled the aftermath of his PTT from the ED service:

> *“Then anorexia was just… it gripped… straight away. It has it- had its freedom to walk - because I was so afraid to go back to the gym in case my legs collapsed again. So I began walking. (Sighs heavily).” (Kevin)*

Kevin described the speed and inevitability with which AN resumed its hold over his life following clinician-initiated PTT. Here, he alluded to AN as a separate, physical entity that had been gifted with freedom by the ED service’s decision to discharge him prematurely. That same decision appears to have, conversely, cost Kevin his own freedom. AN seemed to adapt to his deeply felt fear of returning to a state of rhabdomyolysis – a condition that had hospitalised him, nearly cost him his kidney, and initiated his ED inpatient admission – and change the means by which it over-exercised his body, circumnavigating Kevin’s instinct to protect himself from harm. His sigh seemed to convey a profound emotional and physical exhaustion. He shared the costs of his abandonment, just a few of which are included here:

"That discharge… led to a ***long****… many, many years of anorexia just being so present 24/7"; "it took me out of life, disengaged me from everything that I had"; "a dislocated toe which needs operating on, but now it's gone far beyond operating."*

Like Kevin, Serena felt abandoned following PTT events – *"I'm just being abandoned"* - but she also alluded to a sense of defeat. In the absence of support, Serena seemed left to navigate her *"battle"* against AN alone:

> *"I've… tried to come up with my own coping strategies and they're somewhat… they are a lot healthier, but there's so many unhealed parts that I'm still struggling with today because I… that was never treated and I think… I think that's where… I… (becomes tearful) I hurt a lot more? (Pause). Because… I just* ***wish****, I just* ***wish*** *that wasn't a part of my life." (Serena)*

Serena seems to allude to her AN feeling like an open, unhealed wound. Not having been equipped to "*battle"* AN alone through treatment prior to discharge, Serena seemed to feel overwhelmed by how much of her AN persevered and how significantly it continued to affect her life in the present day. She summarised this powerfully: *"so, I'm gone"*; Serena's abandonment to her AN seemed to have cost her her sense of self. To this day, Serena is left exhausted by her daily fight with AN, leaving her with a sense of failure and defeat: *"am I not doing enough to quieten that voice down?"* However, similarly to Kevin, Serena also recognised: *"how I was looked after wasn't adequate",* and located responsibility within the AN-treating system. This resonates with Louise's experience following PTT:

> *"Now, looking back… there's definitely elements of the thoughts that… it's… some days are still there. […] That I think maybe if my treatment would have been finished off nicely… might not still be as impactful to me." (Louise)*

She continued to share that she wants to be able to feel happy, *"you kind of can't be",* because of AN's ongoing presence. She expressed resignation to AN's perseverance, conceptualising it as having become a part of her brain that she must find a way of navigating life alongside. For her, AN had become, *"that little other area of my brain that's just been there for so long throughout my life."* For Louise, there was a sense that her PTT had abandoned her to a life alongside AN.

Rose's experiences of PTT included repeatedly waiting for therapeutic treatment to resume after consecutive clinicians abandoned her for reasons unrelated to Rose and the treatment itself; multiple professionals were allocated to her care before *"disappearing"* on long term sick leave or commencing maternity leave. Rose's stuckness on waitlists after those multiple instances of clinician-initiated PTT felt *"like abandonment"* to her. Rose also noted that it was not only her who had been abandoned to AN and left feeling fearful for her future, but her mother, too: *"She had absolutely **no** support and **I** had **no** support. So it was kind of… just left… to fend for ourselves."* Being left to *"fend"* for herself was an experience shared by Samantha, although for her this was a struggle she faced alone: *"I was just literally left to fend… fend for myself"* following her self-preserving self-initiated PTT from inpatient treatment, adding that services made, "*no attempt to aid me in that process*." Here, both Rose and Samantha alluded to the desperation and exhaustion they felt in the face of abandonment to their AN in the absence of support following PTT.

GET Three: *"Have you any idea…? The damage that you've caused?"*: Being Harmed by the Helpers

This GET speaks to participants' experiences of harm resulting from the actions of professionals around their PTT events. The title for this subtheme borrows from Kevin's experience; he shared how he would imagine encountering his old therapist in town and having the opportunity to challenge her: *"have you any idea…? The damage that you've caused?"*. In contrast, this GET also encompasses experiences of fortune and luck; experiences that participants associated with encountering *"good" (Rose)* professionals.

"Screaming, Shouting" to be Heard: The Silencing of Experiential Knowledge

An experience shared by all participants was that of their own experiential knowledge as individuals living with AN not just going unheard but being silenced by professionals around their PTT events, leading to harm. The name for this subtheme captures Amy's experience of inpatient treatment in the lead-up to a PTT event: *"I'm… I'm screaming, shouting because I need you to hear me."* Her words seemed to convey both desperation and a sense of futility. Amy received treatment in a CAMHS ED inpatient setting as an undiagnosed neurodivergent individual who endured *"the obvious systemic racism"* innate to healthcare systems. Unlike her treating team, Amy was an expert in herself and would voice her needs: *"I knew myself quite well. I knew what was helpful and what wasn't helpful".* The system, in contrast, seemed to repudiate her self-knowledge: *"I wasn't allowed to stim".* Despite communicating her struggles with the rigidity of her treatment and the absence of accommodations for her sensory differences, Amy endured a profound emotional and physiological pain throughout her treatment that led to agonising meltdowns:

> *"I think they just saw that as a very strange kind of mental health presentation that they ended up diagnosing as bipolar, ironically, when I was 14, which to any clinician now sounds wild, doesn't it? I don't have bipolar, just to clarify (laughs). […] They… they saw it how they saw it." (Amy)*

Amy's own voice went unheard in her treatment while professionals' misconceptions appeared to be privileged. Amy shared that she absconded from the CAMHS unit out of desperation to feel *"normal"* - a plea that went unheard by professionals - and was subsequently transferred to a *"more secure"* and *"PICU-like"* non-ED-specialist setting. For her, the PTT of her CAMHS admission was her *"punishment"* for absconding. Amy considered the costs of her experiential insight being silenced: *"at the EDU [eating disorder unit], I still had a reasonably strong sense of self and who I was […] my values were* *stronger"*, whereas, at the highly restrictive unit, *"my identity had completely fizzled, so I didn't really know what I cared about anymore by that point and what was important".* The PTT of Amy's CAMHS ED admission, which appeared to have been the culmination of the silencing of her experiential knowledge about her needs and difficulties, seemed to have led to the destruction of Amy's sense of self.

Kevin shared Amy's experience of his self-knowledge being silenced ahead of a PTT event:

> *"I went in [to treatment], very much – can you help me? This is what's happening. You know, very… I was honest. And just saying that I was… you know, I was wanting to be a boy… and if I ate anything, I would get my periods and I would get my breasts back. You know,* ***please*** *don't take this boy away from me." (Kevin)*

Kevin trusted his treating team with his self-knowledge and his hope, seeking their professional guidance and support. However, his treating team appeared to silence his self-knowledge, prioritising their own treatment goals:

> *"I would say I'm just…. I don't want to be, you know… I just want to be a boy. I just want to be a boy. I just want to be a boy, want to be a boy. And it would be… why have you lost a pound in a week? […] It just got to the target weight and then it was discharged." (Kevin)*

For Kevin, the urgency and desperation of his pleas to be heard went unheard. Here, his words powerfully convey how professionals' silencing of his voice had left him living within an intolerable, other body that was not his own – *"it"*. Kevin had given *"****everything*** *over"* to the ED professionals but had been left with a broken trust: *"it took many, many,* ***many*** *years for me to be able to trust in, in, in, in anyone, never mind the services again."* This was an experience shared by Rose, who, following a PTT event, shared losing her *"faith in the* *service and* ***belief*** *that treatment could help at all."* Rose described her experiences of a private therapist whose care she self-discharged from early in treatment:

> *"No, you know, you haven't heard me and you've kind of* ***decided*** *a narrative… in your head, without really listening to what I'm saying. So yeah, invalidated and unheard. Kind of like… I was quite* ***angry****." (Rose)*

Rose seemed to feel powerless over her own life story as it was in the hands of the therapist. Rose later reiterated her anger, adding that this experience left her feeling *"hopeless, because I was hoping to have some sort of meaningful support. […] I felt very kind of like isolated and alone"*.

"I Don't Have a Single Choice in the World": Powerlessness

This subtheme encompasses participants feelings of powerlessness due to professionals' actions around their PTT events. Amy recalled how she felt following the PTT of her ED inpatient admission having been relocated to the PICU-like setting:

> *"That was horrible… [Pause]… I think I was… because I was so far away from home, and… I… I couldn't... I couldn't leave? (Laughs, then begins crying). So… I think it's just an overwhelming feeling of being trapped… and feeling out of control. […] I just- I don't have a single choice in the world." (Amy)*

For Amy, her new admission seemed to leave her feeling isolated and powerless. Her initial laughter seemed disbelieving before it appeared to turn into a grief for her younger self.

Rachel recalled an encounter with a nurse prior to the PTT of her day patient treatment:

> *"She just forced us along there [a corridor] and it… it felt like a power trip. It felt like, I feel a little bit like, (assumes the voice of the nurse) 'I haven't got…*

> *I'm not as in control as I want to be, so I'm going to prove (plays with necklace chain) I've got power by forcing you to do what I want you to do'." (Rachel)*

Rachel's body language seemed like a means of self-soothing as she recalled her powerlessness against the nurse; she appeared to relive past feelings of fear and anxiety when recalling the event. Her repetition of the word *"forced"* added emphasis to her powerlessness and carried connotations of coercion and oppression at the professional's hands. Rachel shared that, during this episode of treatment, it felt like the professionals *"thought that I chose to behave that way"* and believed they needed to *"teach me"* a lesson, suggestive of a punitive experience. Samantha shared a similar reflection, alluding to her relationship with the ED service as punitive and infantilising around a PTT event, *"like they're a parent and I'm the naughty child"*, adding that the relationship was *"authoritative rather than caring"*. Kevin described a similar *"superiority"* from some professionals involved in his care and added that it felt like *"us and them"*: patients against staff, separated by a significant power imbalance.

Serena experienced powerlessness in her desperate *"fight"* to access treatment after an episode of PTT:

> *"I honestly don't think- if my dad hadn't battled for me… I don't think I'd possibly even be here. I don't think I'd have lived. (Begins crying). And… and that's quite…. hard to think that… if he hadn't have fought, would they have even done anything?" (Serena)*

The actions of professionals left Serena powerless to fight for her own life. While her father took up the battle for her survival on a new front, Serena was left trying to make sense of the knowledge that the professionals might have let her die. Her father's battle with services may have been the only reason she survived to this day and recognition of this seemed deeply painful.

"The **Neglect***": Being Met with Lack of Compassion and Understanding*

All participants held experiences of professionals lacking compassion towards- and understanding of- AN which they associated with feelings of neglect. For some participants, this neglect directly led to PTT events. For others, this neglect was, in part, why the systemically approved termination of their treatment felt inherently premature for them; they had not received acceptable or *"adequate" (Serena)* treatment.

> *"I think, looking back at the- at times, the* ***neglect****. I can feel… sadness and anger at times. You know, when I think of all of us, you know, individually as well and… and I think knowing… knowing that… (Long pause)… I don't know how many of us have recovered from that time, really." (Kevin)*

Kevin felt anger towards the professionals who were involved in his and his peers' care. His pause seemed to carry a significant emotional weight; for him and many of his peers, their treatment from those professionals had not led them to recovery, and seemed to have left Kevin with an unresolvable sadness and grieving an undefined loss.

For Samantha, the name of the service she had accessed felt incongruent with her experiences: "*outpatient… care? - we'll use that term loosely"*:

> *"I think they didn't want me to die from my eating disorder. Do I think that that was about them having any care for me? No, not necessarily. And that was because- it's because it's their job to tick box." (Samantha)*

Samantha experienced the professionals involved in her outpatient service as neglecting their caring role and approaching her as a *"tick box"* exercise: reductive and dehumanising. Similarly, Kevin experienced the caring professionals he encountered as merely asking, "*the questions that they had to ask on a tick-y box. And then their shift was done. […] Everybody was doing their roles, I suppose, to the best of what their roles were...? But following… a shift, a role. A job given by somebody else."* Kevin appeared to empathise with the limitations of the professionals' roles while recognising the systemic neglect and deferral of responsibility that contributed to his PTT.

Rose's parents had sought private therapy for her while she was repeatedly returned to NHS waitlists following PTT events. She conveyed experiences of neglect and infantilisation that she associated with her private therapist's lack of compassion and understanding:

> *"Saying to my parents, oh, well, if you- just, eventually she'll eat like… eventually she'll realise […] You just need to sort of basically, in not as many words, but get on and just do it and grow up." (Rose)*

This misconceptualisation of AN as behavioural led Rose to challenge the therapist's claim of holding specialist knowledge:

> *"I'm not really sure this person was sort of qualified to be saying what she was saying, or to be claiming that she was an eating disorder sort of specialist." (Rose)*

Rose subsequently withdrew from the therapy and ended her own treatment early to avoid harm. Her health was subsequently left to continue declining while she awaited support via the NHS.

Like Rose, Rachel experienced many of the professionals involved in her care as lacking *"any idea about eating disorders."*

> *"I feel like there are already preconceived ideas about… who I am, what I'm like…. There… It doesn't feel like there's any openness to really… or any openness or interest in really knowing me. All they see is a person with an eating disorder or an eating disorder that's attached to a person but that person has no value in and of themselves. They are just an eating disorder." (Rachel)*

Rachel encountered professionals who seemed to neglect her core self, only able to perceive her as her AN. When connecting with her experience of how professionals perceived her, her language shifted from the personal to the detached; *"I"* became *"they"*, suggestive of staffs' erasure of her self-concept feeling depersonalising. She experienced this as intentional and the result of the professionals' disinterest in- and lack of compassion towards- her. Rachel emphasised the absence of *"openness"* from these professionals, seeming to accentuate the closedness and immovability of their preconceptions. Samantha shared this experience and encapsulated how she was positioned as an individual with AN during treatment, stating, *"I [was] the sick person"*, and describing her treatment as, "*done at me rather than with me… and there was no… there was no… person in that. They were treating my eating disorder. They weren't engaging with me as a person."* Like many other participants, Samantha's experience of professionals around PTT events included neglect through othering and dehumanisation.

"Had the Wind Just Been Blown in the Other Direction…": *Feeling Lucky for Receiving Good Care*

This subtheme encompasses participants' experiences of receiving good care from professionals, which they universally described as *"lucky"* or *"fortunate"*. They often contextualised within the wider systemic barriers that prevent good care and contrasted these with their negative, harmful encounters with other professionals around their PTT events. Samantha emphasised how *"very lucky"* she felt to have seen her *"super honest"* therapist, adding:

> *"Had the wind just been blown in the other direction, I may never have even got in front of... another professional and that kind of narrative that was being given to me could have been… the story. And I could be dead." (Samantha)*

Samantha accentuated the role of chance in her survival. It had been her then partner who had found a private therapist and Samantha described how she had attended the first appointment to *"appease"* them: *"I wanted him to know, even when I died, that we tried everything. So I was kind of going along as a tick box exercise"*. Following a PTT event and the absence of support, she had believed her death was inevitable. Her use of the phrase *"tick box exercise"* mirrors her earlier description of the way in which NHS professionals had approached her care, in both cases evoking a sense of dispassionately going through a series of motions. Samantha continued to emphasise the role of luck in encountering *"a professional with that level of skill",* as it transpired she had found in her private therapist: *"Obviously that was to… to some degree just chance"*.

Samantha's experience of being lucky for having found a good, compassionate, skilled professional was shared by Rachel:

> *"It's luck in whether you happen to click with the therapist or not, but… she was very skilled and very… kind and compassionate and… she was an amazing therapist. She had lots of skills she had… she did so many things to help me… […] Just felt incredibly fortunate." (Rachel)*

Rachel, too, emphasised the role of luck and good fortune in her having a positive, helpful experience with a professional. To both her and Samantha, compassion and skills were attributes that were uncommon in the professionals they encountered, leaving these positive experiences, in contrast, feeling like exceptions to the rule that they needed to feel grateful for. Sarah, similarly, described her experience of a therapist as: *"**incredible**. She was so good and compassionate, but also she knew what she was doing."* The meaning that Sarah gave to this was that she was, *"very lucky because it was private"*; she felt fortunate for being in the financial position to evade treatment through the NHS, where her experiences had taught her that clinicians were *"hurtful"*.

GET Four: *"Dual Identity… A Privilege and an Honour"*: The Gifts of Dual Experience of Anorexia

The name of this GET borrows from Rachel's description of her dual experience. It is a theme that names that which was embedded throughout participants' interviews.

"Professionally, the Sense that I Make of That is…": Consulting a Professional Lens

While all participants spoke to their lived and living experiences of PTT as IwAN, all participants also appeared to consult their professional lenses to reflect upon their experiences and seek additional understanding or alternative ways of making sense of them. The majority of the participants approached their interviews from the position of being an individual with lived or living experience of AN, seemingly inviting their professional lenses in for consultation and then returning to their lived or living experiences. The participants appeared to signpost these consultations by naming their shift in lens, as though differentiating the meaning that their lived experienced and professional parts gave to their experiences: *"now, professionally, I think…" (Samantha)*, *"now, as a clinician, it makes me…" (Rachel)*, *"as a clinician…" (Sarah)*, *"as a support worker…" (Louise)*, *"where I'm at [in training] now, I feel…" (Serena)*. The participants then seemed to signpost their return to their lived experienced lenses following their internal professional consultations (*"in my personal experience…" (Louise)*, *"back then…" (Kevin)*, *"what I experienced at the time…" (Samantha)*). The participants appeared to take great care around these shifts in lens; they appeared to consciously invite their professional reflections in at specific points during their interviews, while seemingly ensuring that their lived and living experiences as IwAN were given the space and time to be heard and understood in their own right. Unlike other participants, Amy, contrastingly, proactively advised the PR that she would be relying upon her professional lens during her interview; at the start of her interview, Amy informed the PR that she could describe *"what happened clinically"* but that she wished to remain emotionally *"detached"* from her lived and living experiences:

> *"It's really hard- it it's really hard to kind of be in touch with myself, I guess. [...] I can't really look at it any other way but clinically... I think the only way to think about it is from that perspective." (Amy)*

Amy appeared to emphasise the emotional discomfort that her lived and living experiences caused her, alluding to a need for emotional distance from them. Like the other participants, however, Amy still appeared to shift between her professional lens and lived experienced lens throughout her interview; her professional position seemingly signposted through her use of clinical terminology (for example: *"my formulation would be..."*), and her lived experienced position seemingly recognisable through shifts in her use of language and emotional expression (for example: *"So it... (crying)... it's for- I think I was just really angry with myself. Sorry."*). When Amy reflected upon the meaning she gave to her experiences of PTT as an undiagnosed neurodivergent individual, she recognised that, *"none of that should have really happened"*, while also acknowledging, *"they [professionals] didn't have the information, I suppose, that* ***I do*** *now [...] That understanding might have entirely changed things."* Here, Amy contrasted her professional knowledge with the knowledge and literature that were available to the professionals involved in her care during preceding years. She lamented *"how easy it could have potentially been"* should professionals have had the training and knowledge to identify her needs as a patient, but appeared careful to avoid centring blame in staff for the lack of associated research at the time. She concluded, *"what we know about neurodiversity now just wasn't what they knew about it then"*, highlighting improvements in professionals' understanding of the links between neurodivergence and EDs.

Sarah spoke of the *"perfect storm"* of systemic challenges facing IwAN today, noting that they *"really need help, but yet the help that we know is forever shrinking"*, clarifying that she was alluding to difficulties with funding, service provision, and the limited intended outcomes of treatment approaches themselves. She appeared to signpost her shift to her professional lens as she shared:

> *"As a* ***clinician****, that's really depressing. And it's hard to carry that. I don't know how people do carry that when they have to go and support people knowing that this doesn't necessarily align with what I feel like I could do or what we could do as a service." (Sarah)*

While Sarah had previously voiced anger and dismay at professionals when speaking to her lived experiences, she also appeared to voice compassion for- and share- the systemic challenges that they face. She held both positions simultaneously. Like Samantha, Rose, Amy, Rachel, and Louise, when consulting her professional lens, Sarah used plural pronouns of *"we"*, *"our"* and *"us"*, as opposed to separating herself from other professionals. She noted that *"we're taught"* that social and community considerations are highly *"important"*, but that *"we don't do that"* because of systemic limitations. Sarah, like other participants, saw herself as part of the system that she believed was harmful to IwAN – a potentially morally injurious position.

When reflecting upon the mismanagement of her PTT, Samantha shared: *"as a professional, I think it's shocking."* This was an experience shared by Rachel: "*As a clinician, it made me really angry*". Samantha observed that the meaning she gave to her experiences has changed over time due to her own development as a professional. While she felt this provided her with insight into why professionals conducted themselves in the way that they did, she noted that this did not always reflect favourably upon them:

> *"I'd like to think that my professional knowledge makes me more understanding than I was at the time, but I actually think it makes me less understanding… because I'm like, they should have had the skills." (Samantha)*

Throughout her interview, Samantha appeared to struggle to locate responsibility for her painful and life-threatening PTT experiences, recognising that they were the result of systemic difficulties but also considering the degree to which the professionals themselves were accountable.

> *"Now, professionally, the sense I make of that is that those professionals […] did not have the knowledge of the actual reality of living with an eating disorder. They might have known, you know, the medications and the blood tests […] but I don't think that they actually comprehended." (Samantha)*

Samantha felt that professionals' understanding of the lived experience of AN was notably lacking. She also alluded to the medicalised nature of AN treatment approaches, highlighting that this was insufficient.

"I Can See…": Seeing the System

The name from this subtheme borrows from Serena's consultation with her professional lens. When reflecting upon the meaning she gave to her negative experiences of PTT, she considered her experiences systemically, repeating the phrase, *"I can see…"* as she spoke to her observations. This subtheme encompasses participants' experiences of being able to *"see"* the reality of the systems they were treated in, experienced PTT within, and now work within through the insight of their dual experience.

Serena reflected:

> *"Because I've worked in this field, I can see, you know, it's not that many individuals […] are in there for selfish reasons. They're there because they*

> *want to care. But there isn't enough to back those people that care and that have the passion to care… because of the powers that be that control the purses and control the funding for research and expansion and development. I can see that." (Serena)*

Serena, whose experiences of PTT were marked by ongoing *"battles"* with treatment systems and professionals, also saw and experienced the challenges that those professionals faced in the hands of the systems they worked within. Throughout her interview, Serena was unable to speak to any positive experiences with the staff she encountered during her treatment journey, yet she still appeared cautious of centring blame within them, instead challenging the treatment system. This contrasts with her experiences of professionals centring blame for her illness and treatment difficulties within her. Serena alluded to perceiving AN professionals as unsupported and at the mercy of those with decision-making authority. She also considered the impact of this lack of support and funding on professionals' knowledge alongside current treatment recommendations, noting that staff lack:

> *"… the understanding, either, of how to appropriately… treat each individual with an eating disorder, because although we're under the same umbrella of eating disorder, those individuals who have experienced anorexia, we're all still very different people. So we can't blanket treatment for everybody." (Serena)*

Serena saw that systemic limitations meant that professionals were not equipped with the knowledge to provide individualised treatment, contributing to IwANs' experiences of PTT. She alluded to the limitations inherent to standardised treatment guidelines as a barrier to individualised care and a cause of PTT, and recognised that one treatment approach cannot meet the needs of every individual with AN. When reflecting upon alternatives, she swiftly returned to a more hopeless, frustrated position: *"That requires a lot of money and resources,* *to which the NHS is already at a stretch. So how on earth is it going to be able to do that adequately?"* Serena was angry with the systemic limitations inherent in AN treatment and their role in the premature termination of her treatment. She named and understood the rationale for standardised guidelines and protocols in the NHS, but consolidating this knowledge with her personal and professional experiences seemed difficult and, at times, painful: *"I can see* ***why****. It just feels so unfair."*

Sarah, similarly, alluded to the powerlessness of ED professionals working within the NHS: *"They have to stick to very specific treatment protocols [...] and that's the only thing they can do."*

> *"That rigidity makes me sad because from my own experiences, if you're* ***solely*** *focusing on food and body and weight and recording [weight and food intake], that's the thing that put me off therapy and* ***stopped*** *me and* ***stopped*** *other people who I've looked after." (Sarah)*

Sarah saw, the protocolised, standardised nature of treatments and care for AN as both preventing IwAN from accessing treatment and contributing to self-initiated PTT. Her repetition and emphasis of ***"stopped"*** carried connotations of experience of such approaches feeling silencing and suppressive. Like Serena, Sarah recognised the NHS' need to follow protocols and focus on outcome measures to record, standardise and evaluate treatment, yet also noted: *"The irony that the rigidity within anorexia is paralleled within services makes me feel a bit sad."* For Sarah, the system's need to ensure the safety and efficacy of their AN treatments appeared to be replicating the inflexibility of AN; something that is both dangerous and deadly in the context of the illness itself. Her words seemed to carry a sense of hopelessness for AN-treating systems and the prevention of PTT.

"On the Other Side": A New Knowledge

The name of this subtheme is borrowed from Samantha, who reflected upon the moment she *"realised"* she held both lived experience and taught knowledge: *"and now I've got this new skill"*. For Samantha, it seemed her dual experience combined to create a new, strengthened skillset: *"I actually think it strengthens me [as a professional]"*. She described it as something she *"look[s] after and reflect[s] upon"* with *"good supervision"*, suggestive of it being a quality that she treasures and nourishes. Samantha described herself as *"working really hard"* to *"**not** exist in"* the professional or patient *"binary"* and own her dual knowledge. She considered dual experience as the creation of a new knowledge:

> *"I think it's really important that we start to learn more about… the reality that those things coexist and that actually… people that have got experience of both have maybe got some knowledge that people with only lived experience or people with only clinical experience don't have because of the way that we might make sense of it?" (Samantha)*

This contrasts with how Samantha's dual experience was received by other professionals:

> *"I… distinctly was given the message that I… should hide?- my lived… my lived experience now that I was a professional. Like you'd sort of crossed some sort of bridge and you were on the other side." (Samantha)*

Here, Samantha alluded to an 'us and them' divide. For her, becoming a professional seemed to require the metaphorical death of her lived experienced self; it was perceived by other professionals as unwelcome and shameful.

In contrast to her own experience of some professionals, Sarah shared the compassion and insight she held in her own work. She recalled her first role working professionally with others with AN: *"I remember **feeling** [their] shame"*. Sarah appeared to deeply empathise with her clients' experiences, sharing their emotional burdens. She noted that PTT was *"palpable"* and that she *"could almost predict it coming"* based upon which therapist an

IwAN had been allocated to or the therapeutic modality they were going to receive. She recalled the feedback she received from those she cared for: *"you're very **genuine**. You **genuinely** care. And I do wonder if part of that is… because it is **genuine**."* Sarah's emphasis of genuineness was suggestive of this being something lacking from those individuals' previous experiences of care and treatment. She associated her genuineness with her lived experience, noting that this enabled her to deeply connect with her clients.

6.0 Discussion

6.1 Overview

This chapter will explore the present study's findings, situating them within the current landscape of literature relevant to the themes that emerged. It will critically review the study, consider future directions and clinical and wider implications, before drawing to a close with overall conclusions. (RJE 8).

6.2 Summary of Findings

The present study sought to explore IwDEANs' experiences of PTT and the meaning that they gave to them in depth. It hoped to elucidate the phenomenon of PTT through the experiences of this under-researched population (Curry and Andriopoulou, 2023). All participants held personal experience of PTT, and six of the study's eight participants had multiple PTT experiences during their treatment journeys. While the participants' experiences of PTT varied broadly – across different treatment settings, at different ages, initiated by different parties – their experiences shared four key, central themes. These were inclusive of encountering systemic barriers, being within treatment systems that seemed to serve AN better than it served the needs of the individual themselves, encountering harmful professionals, and the gifts of their dual experience of AN in relation to making sense of those experiences.

6.3 Situating the Present Findings within Wider Literature

6.3.1 Systemic Gaps and Margins

A common experience amongst the present participants was that of falling into the gaps and margins between AN-treating systems, and this either leading to- or being the result of- PTT events. The participants identified these as systemic difficulties. Vinchenzo et al.'s (2022) findings suggested a similar conclusion, with the researchers remarking on PTT's 'intertwined-ness' with service-level factors. Pehlivan et al. (2022), analogously, conceptualised PTT as a clinician and healthcare delivery factor contributing to the poor treatment outcomes and high relapse rates often seen with IwAN. The researchers called for an evaluation of both the implementation of current ED treatments and elucidation of gaps in service delivery, noting the cost ineffectiveness of the treatment system as it currently stands.

A subset of the present participants experienced falling into the gaps between CAMHS and adult services, both initiating PTT and causing their AN to worsen. Research suggests that onset of AN may be most common during adolescence with an average duration reported to range between six and a half and fourteen years (Fernandez-Aranda et al., 2021; Treasure et al., 2005; Zerwas et al., 2013). As such, young IwAN often undergo transition between CAMHS and adult services (Lockertsen et al., 2021). Research suggests that this transition is commonly poorly managed (Lockertsen et al., 2021) and that PTT is a common outcome for young people with ED undergoing the process due to the inflexibility and misalignment of the two treatment systems (Broad et al., 2017). This systemic difficulty is not exclusive to EDs; Singh et al.'s (2010) study found that less than 5% of young people experiencing a mental health difficulty had a satisfactory transition between their respective CAMHS and adult services. Lockertsen et al. (2021) advocate that good collaboration between the two services is essential in supporting young people with AN to manage the transition successfully, yet note that significant systemic gaps persevere, perpetuate harm, and cause PTT.

Kazdin et al.'s (2017) review addressed 'critical gaps' in the treatment of EDs. The researchers highlighted a significant research-practice gap present in the field, resulting from the discrepancy between what is known about effective treatment and that which is actually provided to IwAN. While this reflects the present participants' experiences of the application of weight-based criteria and lapses in continuity of care, Kazdin et al.'s (2017) review differs from the present study in that they advocated for the robust following of ED treatment protocols. In contrast, the present participants felt frustrated with the limitations of current treatments and experienced positive professional interactions where their professionals thought outside of standard, *"blanket" (Serena)* treatment protocols.

As experienced by the present participants, NHS England (2024) noted that IwAN and other EDs frequently encounter poor transitions between services, facing delays and disruptions in their care. NHS England's (2024) report also called for professionals to work collaboratively to provide holistic, tailored care, and be trained to care for commonly co-occurring conditions to avoid gaps in care; the report recognised ongoing systemic challenges across these domains in the treatment of AN. Kastner et al.'s (2021) study of the initiation of treatment for AN highlighted similar barriers and facilitators as the present study's findings relating to PTT, naming systemic challenges and negative experiences of professionals. The researchers noted that the barriers and facilitators they identified were modifiable through the systemic change of AN-treating healthcare systems.

6.3.2 The Systemic Feeding of AN

All participants spoke to encountering systemic difficulties in relation to PTT events and had experiences where these had served to worsen their illness and prognosis rather than treating it to a point of remission or personal or clinical 'recovery'. In the present study, participants alluded to this as a systemic feeding of AN that left them abandoned to their untreated or incompletely treated illness following PTT. Within this theme, participants shared experiences of treatment services conceptualising AN as a solely physical illness marked by significantly low weight and subsequently deeming IwAN as 'well' once weight had been partially restored. This is consistent with existing qualitative explorations of the lived experiences of IwAN and PTT, where literature documents the negative impact of AN-treating systems' focus on weight improvements as a measure of wellness. The findings from the present study closely align with those of Babb et al.'s (2022) meta-synthesis. The authors found that their research into the treatment experiences of IwAN highlighted a systemic focus on weight restoration with ‘little regard’ for the psychological impact of treatment. Like the present study, they found that participants commonly shared experiences of being discharged from services once they had reached their target weight despite having made minimal or no psychological progress. The researchers’ identification of feelings of aloneness and the inevitability of relapse in IwAN post-discharge echo the present study’s subtheme of ‘abandonment’ to AN.

However, it is notable that the present participants identified the experience of being discharged following improvements in weight without having received *“adequate”* (Serena) psychological support as PTT – a novel conceptualisation of the phenomenon that has not previously been captured in ED literature. Serena, Kevin, Amy, Louise and Rachel conceptualised parts of their treatment as having been prematurely terminated because their treatment had ended before they felt it was complete: after weight improvements, yet before their AN had been meaningfully or holistically treated. Services’ focus on weight is well documented in literature across recent decades (eg. Babb et al., 2022; Chang et al., 2023; Redgrave et al., 2015; Roots et al., 2006). As recognised by the present participants, weight restoration is a key requirement of AN treatment due to the medical risks associated with low body weight (NICE, 2022) and studies suggest that early weight gain in treatment may be important for long-term prognosis (Bargiacchi et al., 2019). SLRs have found that, while AN treatment can temporarily improve weight, IwAN remain at an ‘exceedingly’ high risk of early relapse post-treatment due to ongoing, untreated psychological distress (Khalsa et al., 2017). Further research suggests that the assumption that weight restoration is a proxy for psychological recovery from AN is not empirically supported (Murray, 2018), and that the systemic focus on weight as opposed to ‘being well’ comes at the detriment of good practice and client-centred care (Johns et al., 2019).

Given that the aetiology of- and predictors of recovery from AN- are uncertain, some US-based researchers note that there is inadequate evidence upon which to set current standards of care internationally and challenge the notion that a ‘one-size-fits-all’, weight-based approach to treatment can adequately support IwAN (Kaye and Bulik, 2021). Furthermore, AN-treating services’ the conceptualisation of AN as a predominantly weight-based illness appears misaligned with the illness’ diagnostic criteria. Both the Diagnostic and Statistical Manual of Mental Disorders, fifth edition (DSM-V: APA, 2013) and ICD-11 (WHO, 2022) are clear that a diagnosis of AN can only be made in the presence of both physiological (eg. restriction of nutritional intake, low weight or in weight restoration from low weight) and psychological (eg. an intense fear of weight gain, persistent behaviours that interfere with weight gain) symptoms, meaning that individuals considered to be presenting with AN are inherently in psychological difficulty (Murray et al., 2018). In addition, research suggests that the psychological difficulties associated with AN frequently persevere following weight restoration (Barko and Moorman, 2023). The meaning the present study’s participants gave to the AN-treating system’s focus on weight is that they are streamlining their treatment requirements in order to facilitate quicker and more definably attainable outcomes. This is supported by Vinchenzo et al.’s (2022) suggestion that explorations of PTT in AN research highlight the limitations of current treatment approaches and raise the question of who benefits from the system in its current state.

Participants’ experiences of their psychological difficulties being neglected around PTT events also aligns with existing literature. A recent meta-analysis of 35 randomised controlled trials of treatments for AN suggested that, while improvements in weight were generally observed in the short-term, there was no effect on psychological outcomes (Murray et al., 2018). Recent literature has therefore suggested that weight-centred conceptualisations of AN and its ‘recovery’ are reductionist, and challenged the notion that ‘more weight’ constitutes ‘less illness’ (Barko and Moorman, 2023). Researchers recognise that weight continues to be the primary and prioritised index of recovery from AN, relied upon by treatment trials, long term follow-up studies, and treatment services to evaluate efficacy (Murray et al., 2018), yet IwAN and a growing body of empirical evidence continue to advocate that weight restoration or improvement does not equate to wellness or ‘recovery’ (eg. Chang et al., 2023; Ince et al., 2025). Auger et al.’s (2021) longitudinal study into deaths of IwAN found that suicide was among the three leading causes of death, further suggestive of the importance of psychological support in AN treatment. Babb et al. (2022) highlighted the importance of ED services adopting an individualised approach to the treatment of IwAN and a holistic approach to care as advocated for by the present participants. Similar to the present study, the researchers’ findings were also suggestive of a need for AN-treating services to support IwAN to uncover and address the underlying causes of their illness, consistent with Vinchenzo et al.’s (2022) conclusions.

Research continues to note the inconclusive and conflicting evidence base for psychological therapies for AN (Bulik et al., 2015), a lack of ‘gold standard’ effective therapies (Murray et al., 2017), and an absence of data supporting the rationale for current therapeutic treatment recommendations in the context of evidence suggesting that no existing approach is reliably superior to the other (Solmi et al., 2021). While research highlights the importance of psychological support in AN treatment, it also suggests that current therapies are of limited efficacy. Wider AN research has noted that the therapeutic relationship may be a stronger predictor of positive outcomes than the therapeutic modality itself and that strong therapeutic alliances have been associated with the prevention of PTT, weight improvements, AN symptom reduction, and decreases in depressive symptomology and AN cognitions (Graves et al., 2017; Zaitsoff et al., 2015), highlighting the importance of professionals’ compassion towards- and understanding of- AN.

6.3.3 Being Harmed by the Helpers

The present study's participants universally held experiences of encountering harmful professionals proximate to their PTT events. Themes documented in existing literature align with those that were prevalent for the present participants. Vinchenzo et al.'s (2022) study of PTT experiences in IwAN found difficulties with the actions of professionals to be a prevalent theme across ten publications, describing this subtheme as 'feeling misunderstood or unheard'. While Vinchenzo et al. (2022) focused on instances of self-initiated PTT, participants across the review's included studies shared experiences of professionals lacking receptiveness to individual needs, sensitivity to lived experiences of AN, and understanding of AN more broadly, aligning with the present findings. Vinchenzo et al. (2022) advocated the importance of strong IwAN-professional relationships where professionals are responsive to IwANs' needs, noting that this was currently lacking in the clinical field and contributing to PTT.

The experience of professionals lacking knowledge and understanding of AN is well documented in literature and researchers commonly conclude that further training is needed in order to improve treatment experiences and reduce phenomena inclusive of PTT (Chang et al., 2023; Johns et al., 2019; Jones et al., 2013; Ramjan, 2004; Wu and Chen, 2021). Furthermore, the consistency of such findings over recent decades may suggest that the under-training of specialist professionals remains systemic and unaddressed. Research suggests that inexperienced and under-trained professionals can hold stigmatising beliefs about IwAN (Thompson-Brenner et al., 2012) and has found that only one third of professionals report having received four or more hours of ED-related training over the preceding five years (Anderson et al., 2017). Numerous studies evidence a lack of trust between IwAN and their treating professionals due to professional misconceptions of AN (eg. Reas et al., 2021; Thompson-Brenner et al., 2012; Vandereycken & Devidt, 2010). Studies have found that IwAN may be more likely to receive negative reactions from the professionals involved in their care than other patients due to staff preconceptions about the illness being a choice, the result of behavioural difficulties, and innate to the individual (Reas et al., 2021; Thompson-Brenner et al., 2012). Currin et al. (2009) suggested that professionals' stigmatisation of AN may result from pessimistic perceptions of AN prognosis, and Reas et al. (2021) associated this stigma with professionals' misconception that IwAN have control over their illness. Kastner et al. (2021) suggested that professionals who trivialise AN or neglect IwAN are a 'weakness within the healthcare system' – a systemic weakness – that can contribute to the worsening of AN symptoms and cause those individuals future difficulties in returning to services due to broken trust. In the present study, however, the actions of such professionals were commonly attributed to a lack of knowledge and compassion that they appeared to view as a systemic (rather than individual) problem; contributing to a systemic dearth of compassion that created a suppressive power imbalance that established an 'us and them' – IwAN vs. professionals – divide. While this phrase does not commonly appear verbatim in AN literature, it is commonly alluded to (eg. Graham et al., 2020; Sibeoni et al., 2017). Johns et al. (2019), for example, found that the systemic disempowerment of IwAN in treatment led to a loss of identity, needing to 'put on an act' as the 'perfect patient' to perform compliance and avoid punishment, and enter an imbalanced power dynamic with professionals. The researchers posited that, should power relations be more balanced in treatment, outcomes may improve, and advocated that professionals avoid misusing power and control in pursuit of treatment agendas. The meaning that the present participants gave to their positive experiences of professionals was that they were *'lucky'* or *'fortunate'*. While this does not appear to be a conceptualisation of encounters with *'good'* professionals that is directly reflected in existing literature, the large body of evidence suggestive of harmful experiences of professionals both surrounding PTT events and in treatment more broadly (eg. Johns et al., 2019) might be viewed as supporting this finding.

While the present participants recognised the harm their treating professionals had caused them, many also consulted with their professional lenses and spoke to the difficulties that professionals face. These experiences are also supported by existing literature. Studies suggest that professionals' lack of knowledge can leave them feeling hopeless about themselves and IwAN, concerned about their lack of competence, and burnt-out by systemic difficulties within AN-treating services (eg. Devery, et al., 2018; Monteleone et al., 2024; Thompson-Brenner et al., 2012). Research also connotes that healthcare professionals who experience burnout are less likely to respond appropriately to patient needs, resulting in negative outcomes for both parties (Hage et al., 2021). While Hage et al.'s (2021) Norwegian study suggested that levels of burnout amongst specialist ED professionals may be lower than previously thought, the researchers also found that ED-specific factors such as risk due to low weight and ego-syntonicity, and staff preconceptions about the nature of EDs are strong predictors of emotional exhaustion, cynicism, and a reduced sense of personal accomplishment.

6.3.4 The Gifts of Dual Experience of AN

All participants consulted their professional lenses to contribute additional sense-making to their lived experiences of PTT. Each participant had their own, unique relationship with this lens. They used this lens to reflect upon their experiences of PTT, respecting them while contributing further context to them and situating them systemically on wider, macro levels. This phenomenon is evidenced in wider existing literature, which suggests that dual-experienced individuals' dual relationship with mental health treating systems provides them with a unique degree of experiential insight that can be utilised in their sense-making of their experiences (Adame, 2011), often attributed to their situation within the somewhat liminal space between ‘us’ and ‘them’: professionals and their clients (eg. Cleary and Armour, 2022). This aligns with the present participants’ prevalent experiences of being able to truly *“see”* the systems responsible for treating AN; seeing the systems through both their lived experiential and professional lenses, and often holding space for both perspectives simultaneously.

Participants reported valuing the insight offered to them as dual-experienced individuals, which is congruent with Curry and Andriopoulou’s (2023) study of IwDEANs’ experiences of treatment. The researchers found that their participants experienced their dual relationship with AN as enabling a novel type of understanding and empathy that was not shared by their colleagues. This resonates with the present study’s finding that participants considered their dual experience as a new form of knowledge conducive of a novel skillset that facilitated their professional work. This finding is also supported by wider literature outside the AN or ED fields. As evidenced by this project’s SLR, FTPs experienced their dual experiences as providing them with a new, organic, visceral knowledge that complimented their professional work.

6.4 Critical Review

The present study facilitated the capturing of experiences of PTT from IwDEAN. A strength of the study was its capture of a broad range of this population’s experiences. It enabled participants to bring their own conceptualisations of PTT, facilitating AN literature in furthering its understanding of the phenomena with the experiences and sense-making offered by this population. Based upon participants’ feedback, the PR’s insider researcher position fostered a supportive, understanding interview context in which they felt able to trust them with their experiences. Multiple participants described their involvement in the study as therapeutic and expressed gratitude for the opportunity to speak to their experiences, suggestive of the study being of multi-directional value.

While the study had ensured its recruitment criteria encompassed IwAN who did not hold a formal diagnosis of the illness out of recognition that such voices are commonly excluded from research, all participants who self-identified for the study held current or historic formal diagnoses. The study's recruitment criteria also included individuals with atypical diagnoses so as not to perpetuate the discrimination against- and exclusion of- such experiences in research (Harrop et al., 2023), yet only one participant held the experience of atypical AN (AAN) and it was within the context of fluctuating between AN and AAN presentations. As such, AAN experiences were notably underrepresented in the present study, and the experiences of individuals navigating PTT events without a formal diagnosis or within transdiagnostic settings were not captured. While the reason for this underrepresentation is unknown in the context of the present study, research suggests that the DSM-V (APA, 2013) changes to AAN diagnostic criteria, whilst being more inclusive of differing body weights, may have left healthcare professionals unclear as to who the diagnosis might be applicable for (Birgegard et al., 2023). Research also suggests that individuals with AAN, who typically present at higher weights compared to IwAN due to diagnostic boundaries, are more likely to encounter weight stigma when seeking support which prevents their diagnosis (Cunning and Rancourt, 2024). As such, it may be that individuals who meet AAN diagnostic criteria may remain undiagnosed even after seeking support and subsequently be unable to access care or treatment (Harrop et al., 2023). It is therefore possible that the stigma, lack of diagnostic clarity, and difficulties accessing care commonly encountered by this population may have prevented individuals self-identifying for participation in the present study.

Such research may also contribute to understanding the underrepresentation of male experiences in the present study. Studies suggest that current estimates of UK men experiencing an ED are an underrepresentation due to difficulties regarding clinicians' ability to recognise EDs in men, historically incorrect conceptualisations of EDs as female illnesses, stigma, and barriers hindering males from help-seeking and presenting at primary care services (Coopey and Johnson, 2022; Maloney et al., 2024). Research, similarly, highlights the treatment barriers and stigma encountered by transgender and gender diverse IwAN and wider ED presentations (Sun et al., 2025). While little research to date has explored this population's experiences of accessing mental health professions, existing literature suggests that they also encounter barriers, stigma, harassment, violence and abuse in wider professional organisations (Collins et al., 2015). Such findings may explain why this population is minimally represented in the present study.

Additionally, the overwhelming majority of the study's participants were white British, meaning that minoritised ethnicities were significantly underrepresented. While it is not possible to be certain within the context of the present study, research suggests that this may be a reflection of the difficulties that minoritised individuals face when seeking and accessing treatment for AN (Acle et al., 2021) as previously discussed. As both experienced by a participant in the present study and evidenced in research, minoritised individuals are routinely subjected to the oppression and harm of systemic racism within mental healthcare systems (Reyes-Rodriguez and Franko, 2020). This systemic racism continues to thrive in professional settings, routinely serving as a barrier against minoritised individuals entering- and having equitable access within- mental health professions and training courses (eg. Francis and Scott, 2023; Wood, 2020).

IPA is an intrinsically interpretative methodology, and Smith et al. (2021) recognise that any two researchers' analyses of a data set may therefore look quite different. Additionally, IPA studies rely on participant self-report and may be subject to bias or error (Jobe and Mingay, 1991). Participants also self-identified and may therefore have had their own motivations for contributing to the study, potentially introducing bias (Turner et al., 2021). Inherent to the methodology is recognition that the PR's own contexts and experiences interact with the research data during analysis and that this should be named, embraced, and appropriately bracketed to produce a high quality IPA study (Nizza et al., 2021), but this may also be conceptualised as introducing bias (Smith et al., 2021). However, IPA's purposiveness and phenomenological focus facilitated the deep experiential analysis of the present participants' experiences, meaningfully contributing to the advancement of research in its field. Great care was taken to ensure the quality and validity of the present study (see '*Methodology*' section), which met CASP's (2018) qualitative criteria for appraisal of research in addition to comfortably aligning with Yardley's (2000) adjunctive criteria.

6.5 Clinical Implications

The overarching meaning that participants gave to their experiences of PTT was that they were the result of systemic difficulties within the AN-treating system. This study therefore joins a growing body of literature calling for urgent systemic change and improvements (eg. Brown et al., 2025). In recognition of the funding limitations faced by UK healthcare systems in the present economic climate (eg. Boltri et al., 2024; Gilsbach et al., 2022), the following section will focus on clinical implications that may be navigable within this context.

To date, AN literature has predominantly framed PTT as an IwAN-initiated event that poses challenges for the AN-treating system. The present participants' experiences appear to call for a shift from this narrative, instead bringing attention to the systemic difficulties within treatment settings that impact upon IwAN and predicate PTT events. This attention shift has implications for future research efforts, which might take the form of the AN-treating system turning its gaze inwards to examine its own role in PTT events and associated experiences. The need to address the systemic barriers and gaps frequently encountered by IwAN around PTT events is well recognised but has yet to be successfully actioned (NHS

England, 2024). This may have implications for service policy, where changes that permit increased flexibility around inter-service transfers of care might mitigate some iatrogenic harm while further, action-focused research takes place.

The present findings also have implications for staff training needs, which the present participants' experiences indicated is an immediate priority with a view to improving understandings and compassion towards IwAN and mitigating avoidable iatrogenic harm surrounding PTT events and within treatment more broadly. The present participants, along with the individuals whose experiences were captured within the present SLR, named the value of holding both lived experience and professional insight, and attributed this to a capacity for a deeper empathy with their clients. This suggests that improved training should not just be informed by-, but designed- and led- by individuals with lived or living experience of AN, so as to provide professionals with insight into the lived or living realities of the illness and experiences of the AN-treating system. This may, additionally, help to foster a shared language between IwAN and professionals that is rooted in experiential knowledge and which may contribute to the reduction of the gap between 'us' and 'them'. Such training should be mandatory for all professionals studying healthcare qualifications, so as to begin fostering a systemic culture shift away from misunderstandings of- and stigma towards- IwAN.

Research supports the present study's finding that AN-treating systems' weight-centred criteria for treatment access and discharge serve the system as opposed to IwAN, further suggesting that this part of the system is maintained by funding limitations (Kazdin et al., 2018; Vinchenzo et al., 2022). While the present findings suggest that these criteria can be experienced by IwAN as harmful and can predicate PTT events, often leading to a requirement of further treatment, clinical implications relating to the system's management of funding fall outside the scope of that which can be suggested by the present study's findings.

The participants' experiences of abandonment following PTT events, however, are suggestive of an absence of effective and meaningful post-treatment support, which may be more readily addressable. Given IwANs' previously discussed high relapse rates and the limited efficacy of currently available treatments (Gregertsen et al., 2019; Jagielska and Kacperska, 2017), individual AN services might consider reviewing their post-treatment support processes. For services where post-treatment support is offered, client-led evaluations of their efficacy may be prudent. For services where this falls outside of their commission, reviews of their inter-service communication following discharge might support them to ensure that other levels of the healthcare system are aware of IwANs' potential relapse risks and recovery needs.

6.6 Suggestions for Future Research

In the present study, the participants consulted both their lived and living experiences of AN and their professional lenses to make sense of their experiences of PTT. As such, they were both the 'us' and the 'them' within the 'them and us' socially constructed divide that they described encountering surrounding their PTT experiences. The IwDEAN population remains under researched but may provide further insight into key challenges in AN treatment, service provision and access to services. Warren et al.'s (2013) study into job satisfaction and burnout in ED professionals found that approximately half of their sample reported either a personal history of ED or high levels of ED symptoms. Hage et al. (2021) concluded that this may mean individuals with dual experience of EDs, inclusive of IwDEAN, may be a sizeable population. In addition to contributing IwDEAN experiences to AN literature, future research might consider quantitatively studying the size and demographics of the population to further contextualise those individuals' experiences.

6.7 Conclusion

The present study explored, in depth, IwDEANs' experiences of PTT and the meaning that they give to them. The study was conducted ethically and with methodological rigour, and was designed with the needs of its participant population at the forefront; EbE input was included at all stages of its conceptualisation and the participants themselves were invited to contribute to the direction of the study. Four GETs were identified, inclusive of: systemic barriers: becoming lost in the gaps and margins; the systemic feeding of AN; being hurt by the helpers; and the gifts of dual experience of AN. This study was conducted by an insider researcher, allowing for an additional level of depth of analysis of participants' experiences, while the study's methodological rigour ensured that each participant's voice remained centred throughout analytical processes. Even so, the research team acknowledges that the interpretation that they have presented is but one possible interpretation. The study's findings have contributed voices of IwDEAN to discourses around PTT and, more broadly, to discourses about the current state of UK-based AN-treating systems and the professionals within them. It contributed a novel, adjunctive perspective to these conversations through the experiences of its previously under-researched population, and facilitated their voices and experiences in becoming seen and heard by the wider research community. These dual-experienced voices, inclusive of the PR's, do not serve to replace those of lived and living experience or those of professionals in the field, but instead take their place alongside them.

As this report draws to a close, it feels important to return to the experiences of the study's participants. While the present study does not reflect favourably upon the AN-treating systems' role in PTT, it is notable that many of its participants retained hope for systemic change that might prevent the replication of their experiences for others with AN. To borrow Samantha's words once more, the present study concludes that, as AN professionals and researchers, *"we need to do better"*. An ever-growing body of research, now inclusive of the present study, suggests that IwAN and professionals have quite significantly differing takes on the difficulties associated with AN; described by Barko and Moorman (2023) as speaking different languages. The present study found that this extended to a lack of shared understanding around not just PTT causes and experiences, but its definition. Both appear, however, united alongside IwDEAN in a struggle to navigate AN-treating systems as they currently stand. This study and its participants therefore join existing research in calling for urgent systemic change in the treatment of AN that is responsive to voices and needs of lived and living experience of AN.

References

Abbate-Daga, G., Amianto, F., Delsedime, N., De-Bacco, C., & Fassino, S. (2013). Resistance to treatment in eating disorder: A critical challenge. *BMC Psychiatry, 13*, 294. https://doi.org/10.1186/1471-244X-13-294

Acle, A., Cook, B.J., Siegfried, N., & Beasley, T. (2021). Cultural considerations in the treatment of eating disorders among racial/ethnic minorities: A systematic literature review. *Journal of Cross-Cultural Psychology, 52*(5). https://doi.org/10.1177/00220221211017664

Adame, A.L. (2011). Negotiating discourses: The dialectical identities of survivor-therapists. *The Humanistic Psychologist, 39*(4), 324-337. https://doi.org/10.1080/08873267.2011.618038

Aikawa, A., & Yasui, N.Y. (2017). Becoming a consumer-provider of mental health services: Dialogical identity development in prosumers in the United States of America and Japan. *American Journal of Psychiatric Rehabilitation, 20*(2), 175-191. https://doi.org/10.1080/15487768.2017.1302368

All-Party Parliamentary Group on Eating Disorders. (2021). *Breaking the cycle: An inquiry into eating disorder research funding in the UK.* All-Party Parliamentary Group on Eating Disorders. https://beat.contentfiles.net/media/documents/APPG_Research_Funding_inquiry_report.pdf

All-Party Parliamentary Group on Eating Disorders. (2025). *The right to health: People with eating disorders are being failed.* All-Party Parliamentary Group on Eating Disorders. https://www.yumpu.com/en/document/read/69681888/appg-report-the-right-to-health-final-one-all-checked

American Psychiatric Association. (2013). Feeding and eating disorders. In *Diagnostic and statistical manual of mental disorders* (5th ed., text rev.). https://doi.org/10.1176/appi.books.9780890425787

American Psychological Association. (2025). Empirical. In *APA Dictionary of Psychology*. Retrieved June 8, 2025, from https://dictionary.apa.org/empirical

Anderson, K., Accurso, E.C., Kinasz, K.R., & Le Grange, D. (2017). Residents' and fellows' knowledge and attitude about eating disorders at an academic medical centre. *Academic Psychiatry, 41,* 381-384. https://doi.org/10.1007/s40596-016-0578-z

Arcelus, J., Mitchell, A.J., Wales, J., & Nielsen, S. (2011). Mortality rates in patients with anorexia nervosa and other eating disorders. A meta-analysis of 36 studies. JAMA Psychiatry, 68(7), 724-731. https://doi.org/10.1001/archgenpsychiatry.2011.74

Asaria, A. (2023). 'Terminal anorexia': A lived experience perspective. Journal of Eating Disorders, 11(107). https://doi.org/10.1186/s40337-023-00823-x

Auger, N., Potter, B.J., Ukah, U.V., Low, N., Israel, M., Steiger, H., Healy-Profitos, J., Paradis, G. (2021). Anorexia nervosa and the long-term risk of mortality in women. *World Psychiatry, 20*(3), 448-449. https://doi.org/10.1002/wps.20904

Ayrolles, A., Clarke, J., Dechaux, M., Lefebvre, A., Cohen, A., Stordeur, C., Peyre, H., Bargiacchi, A., Godart, N., Watson, H., & Delorme, R. (2023). Inpatient target discharge weight for early-onset anorexia nervosa: Restoring premorbid BMI percentile to improve height prognosis. *Clinical Nutrition ESPEN, 54I,* 150-156. https://doi.org/10.1016/j.clnesp.2023.01.025

Babb, C., Jones, C.R.G., & Fox, J.R.E. (2022). Investigating service users' perspectives of eating disorder services: A meta-synthesis. *Clinical Psychology & Psychotherapy, 29*(4), 1276-1296. https://doi.org/10.1002/cpp.2723

Bailey-Straebler, S., Glasofer, D.R., Ojeda, J., & Attia, E. (2024). Equitable access to evidence-based treatment for eating disorders for patients with low-income: Identifying barriers and exploring solutions. *The Cognitive Behaviour Therapist, 17*(5). https://doi.org/10.1017/S1754470X24000023

Bailie, H.A., & Tickle, A. (2015). Effects of employment as a peer support worker on personal recovery: A review of qualitative evidence. *Mental Health Review Journal, 20*(1). https://doi.org/10.1108/MHRJ-04-2014-0014

Bakarat, S., McLean, S.A., Bryant, E., Le, A., Marks, P., National Eating Disorder Research Consortium., Touyz, S., & Maguire, S. (2023). Risk factors for eating disorders: Findings from a rapid review. *Journal of Eating Disorders, 11*(8). https://doi.org/10.1186/s40337-022-00717-4

Bandini, S., Antonelli, G., Moretti, P., Pampanelli, S., Quartesan, R., & Perriello, G. (2006). Factors affecting dropout in outpatient eating disorder treatment. *Eating and Weight Disorders – Studies on Anorexia, Bulimia and Obesity, 11*, 179-184. https://doi.org/10.1007/BF03327569

Bardone-Cone, A.M., Harney, M.B., Maldonado, C.R., Lawson, M.A., Robinson, D.P., Smith, R., & Tosh, A. (2010). Defining recovery from an eating disorder: Conceptualisation, validation, and examination of psychosocial functioning and psychiatric comorbidity. *Behaviour Research and Therapy, 48*(3), 194-202. https://doi.org/10.1016/j.brat.2009.11.001

Bargiacchi, A., Clarke, J., Paulsen, A., & Leger, J. (2019). Refeeding in anorexia nervosa. *European Journal of Pediatrics, 178,* 413-422. https://doi.org/10.1007/s00431-018-3295-7

Barko, E.B., & Moorman, S.M. (2023). Weighing in: qualitative explorations of weigh restoration as recovery in anorexia nervosa. *Journal of Eating Disorders, 11*(14). https://doi.org/10.1186/s40337-023-00736-9

Beames, J.R., Kikas, K., O'Gradey-Lee, M., Gale, N., Werner-Seider, A., Boydell, K.M., & Hudson, J.L. (2021). A new normal: Integrating lived experience into scientific data syntheses. *Frontiers in Psychiatry, 12*. https://doi.org/10.3389/fpsyt.2021.763005

Bergamin, J., Luigjes, J., Kiverstein, J., Bockting, C.L., & Denys, D. (2022). Defining autonomy in psychiatry. *Frontiers in Psychiatry, 13*. https://doi.org/10.3389/fpsyt.2022.801415

Bhaskar, R. (1993). *Dialectic: The pulse of freedom.* Verso.

Bhaskar, R. (2016). *Enlightened common sense: The philosophy of critical realism.* Routledge.

Bhattacharya, P. (2022). "And now I know how you feel…": Lived experience of surviving mental illness as a prosumer. *Psychological Services, 19*(1), 19-20. https://doi.org/10.1037/ser0000484

Birgegard, A., Forsen Mantilla, E., Breithaupt, L.E., Borg, S., Sanzari, C.M., Padalecki, S., Hedlund, E., & Bulik, C.M. (2023). Proposal for increasing diagnostic clarity in research and clinical practice by renaming and reframing atypical anorexia nervosa as "restrictive eating disorder" (RED). *Eating Behaviours*, *50.* https://doi.org/10.1016/j.eatbeh.2023.101750

Bjork, T., Bjorck, C., Clinton, D., & Sohlberg. S. (2009). What happened to the ones who dropped out? Outcome in eating disorder patients who complete or prematurely terminate treatment. *European Eating Disorders Review, 17*(2), 109-119. https://doi.org/10.1002/erv.911

Boland, A., Cherry, M.G., & Dickson, R. (2017). *Doing a systematic review: A student's guide.* Sage.

Boltri, M., Brusa, F., Apicella, E., & Mendolicchio, L. (2024). Short- and long-term effects of Covid-19 pandemic on health care system for individuals with eating disorders. *Frontiers in Psychiatry, 15.* https://doi.org/10.3389/fpsyt.2024.1360529

Boomsma-van Holten, M., Weerman, A., Karbouniaris, S., & Van Os, J. (2023). The use of experiential knowledge in the role of a psychiatrist. *Frontiers in Psychiatry, 14.* https://doi.org/10.3389/fpsyt.2023.1163804

Boyd, J.E., Graunke, B., Frese, F.J., Jones, J.T.R., Adkins, J.W., & Bassman, R. (2016). State psychology licensure questions about mental illness and compliance with the Americans with Disabilities Act. *American Journal of Orthopsychiatry, 86*(6), 620-631. https://doi.org/10.1037/ort0000177

Boyd, J.E., Zeiss, A., Reddy, S., & Skinner, S. (2016). Accomplishments of 77 VA mental health professionals with a lived experience of mental illness. *American Journal of Orthopsychiatry, 86*(6), 610-619. https://doi.org/10.1037/ort0000208

Branley-Bell, D., Talbot, C.V., Downs, J., Figueras, C., Green, J., McGilley, B., & Murphy-Morgan, C. (2023). It's not all about control: Challenging mainstream framing of eating disorders. *Journal of Eating Disorders, 11*(25). https://doi.org/10.1186/s40337-023-00752-9

Braun, V., & Clarke, V. (2022). Toward good practice in thematic analysis: avoiding common problems and becoming a knowing researcher. *International Journal of Transgender Health, 24*(1), 1-6. https://doi.org/10.1080/26895269.2022.2129597

Brayboy, B.M., & Deyhle, D. (2000). Insider-outsider: Researchers in American Indian communities. *Theory into Practice, 39*(3), 163-169. https://doi.org/10.1207/s15430421tip3903_7

Brelet, L., Flaudias, V., Desert, M., Guillaume, S., Llorca, P-M., & Boirie, Y. (2021). Stigmatization towards people with anorexia nervosa, bulimia nervosa, and binge eating disorder: A scoping review. *Nutrients, 13*(8), 2834. https://doi.org/10.3390/nu13082834

British Medical Journal. (2021). The PRISMA 2020 statement: An updated guideline for reporting systematic reviews. *The BMJ, 372*(71). https://doi.org/10.1136/bmj.n71

British Psychological Society. (2017). *Practice Guidelines.* The British Psychological Society. https://explore.bps.org.uk/content/report-guideline/bpsrep.2017.inf115

British Psychological Society. (2021). *BPS Code of Human Research Ethics.* The British Psychological Society. https://www.bps.org.uk/guideline/bps-code-human-research-ethics

Broad, K.L., Sandhu, V.K., Sunderji, N., & Charach, A. (2017). Youth experiences of transition from child mental health services to adult mental health services: A qualitative thematic synthesis. *BMC Psychiatry, 17*(1). https://doi.org/10.1186/s12888-017-1538-1

Brocki, J.M., & Wearden, A.J. (2006). A critical evaluation of the use of interpretative phenomenological analysis (IPA) in health psychology. *Psychology & Health, 21*(1), 87-108. https://doi.org/10.1080/14768320500230185

Brown, R., Murphy-Morgan, C., Downs, J., & Branley-Bell, D. (2025). A call for strategy on eating disorders: The need for a comprehensive eating disorder strategy in England and specific guidance for the remote delivery of eating disorder services. *Journal of Eating Disorders, 13*(54). https://doi.org/10.1186/s40337-025-01224-y

Bulik, C.M. (2015). Towards a science of eating disorders: Replacing myths with realities: the fourth Birgit Olsson lecture. *Nordic Journal of Psychiatry, 70*(3). https://doi.org/10.3109/08039488.2015.1074284

Burke, F., Higgins, M., & MacGinley, M. (2024). "I'll do it on my own, but I'm never alone": Lived experience and practitioner perspectives of autonomy in longstanding and severe eating disorder treatment and recovery – a rapid evidence review. *Journal of Eating Disorders, 12*(208). https://doi.org/10.1186/s40337-024-01164-z

Burnham, J. (2012). Developments in social GRRRAAACCEEESSS: Visible-invisible and voiced-unvoiced. In I.B. Krause (Ed.), *Culture and reflexivity in systemic psychotherapy: Mutual perspectives.* Karnac Books.

Calugi, S., El Ghoch, M., Conti, M., & Dalle Grave, R. (2018). Preoccupation with shape or weight, fear of weight gain, feeling fat and treatment outcomes in patients with anorexia nervosa: A longitudinal study. *Behaviour Research and Therapy, 105*, 63-68. https://doi.org/10.1016/j.brat.2018.04.001

Cardi, V., Mallorqui-Bague, N., Albano, G., Monteleone, A.M., Fernandez-Aranda, F., & Treasure, J. (2018). Social difficulties as risk and maintaining factors in anorexia nervosa: A mixed-method investigation. *Frontiers in Psychiatry, 9.* https://doi.org/10.3389/fpsyt.2018.00012

Cass, K., McGuire, C., Bjork, I., Sobotka, N., Walsh, K., & Mehler, P.S. (2020). Medical complication of anorexia nervosa. *Psychosomatics, 61*(6), 625-631. https://doi.org/10.1016/j.psym.2020.06.020

Chang, Y-S., Liao, F-T., Huang, L-C., & Chen, S-L. (2023). The treatment experience of anorexia nervosa in adolescents from healthcare professionals' perspective: A qualitative study. *International Journal of Environmental Research and Public Health, 20*(1), 794. https://doi.org/10.3390/ijerph20010794

Chapuis-de-Andrade, S., Moret-Tatay, C., Breno Costa, D., Abreu da Silva, F., Irigaray, T.Q., & Lara, D.R. (2019). The association between eating-compensatory behaviours and affective temperament in a Brazilian population. *Frontiers in Psychology, 10*. https://doi.org/10.3389/fpsyg.2019.01924

Chavez, C. (2008). Conceptualizing from the inside: Advantages, complications, and demands on insider positionality. *The Qualitative Report, 13*(3), 474-494. https://doi.org/10.46743/2160-3715/2008.1589

Cleary, R., & Armour, C. (2022). Exploring the role of practitioner lived experience of mental health issues in counselling and psychotherapy. *Counselling & Psychotherapy Research, 22*(4), 1100-1111. https://doi.org/10.1002/capr.12569

Clemente-Suarez, V.J., Ramirez-Goerke, M.I., Redondo-Florez, L., Beltran-Velasco, A.I., Martin-Rodriguez, A., Ramos-Campo, D.J., Navarro-Jimenez, E.N., Yanez-Sepulveda, R.Y., Tornero-Aguilera, J.F. (2023). The impact of anorexia nervosa and the basis for non-pharmacological interventions. *Nutrients, 15*(11). https://doi.org/10.3390/nu15112594

Collins, J.C., McFadden, C., Rocco, T.S., & Mathis, M.K. (2015). The problem of transgender marginalisation and exclusion: Critical actions for human resource development. *Human Resource Development Review, 14*(2). https://doi.org/10.1177/1534484315581755

Conchar, C., & Repper, J. (2014). Walking wounded or wounded healer? Does personal experience of mental health problems help or hinder mental health practice? A review of the literature. *Mental Health and Social Inclusion, 18*(1), 35-44. https://doi.org/10.1108/MHSI-02-2014-0003

Coniglio, K.A., Christensen, K.A., Haynos, A.F., Rienecke, R.D., & Selby, E.A. (2019). The posited effect of positive affect in anorexia nervosa: Advocating for a forgotten piece of a puzzling disease. *International Journal of Eating Disorders, 52*(9), 971-976. https://doi.org/10.1002/eat.23147

Cooke, A., Smith, D., & Booth, A. (2012). Beyond PICO: The SPIDER tool for qualitative evidence synthesis. *Qualitative Health Research, 22*(10): 1435-1443. https://doi.org/10.1177/1049732312452938

Cooper, Z., & Dalle Grave, R. (2017). Eating disorders: Transdiagnostic theory and treatment. In S.G. Hofmann & G.J.G. Asmundson (Eds.), *The Science of Cognitive Behavioural Therapy* (pp. 337-357). Elsevier Academic Press. https://doi.org/10.1016/B978-0-12-803457-6.00014-3

Coopey, E., & Johnson, G. (2022). "The male elephant in the room": A qualitative evidence synthesis exploring male experiences of eating disorders. *Journal of Eating Disorders, 10*(131). https://doi.org/10.1186/s40337-022-00614-w

Corbin Dwyer, S., & Buckle, J.L. (2009). The space between: On being an insider-outsider in qualitative research. *International Journal of Qualitative Methods, 8*(1), 54-63. https://doi.org/10.1177/160940690900800105

Covidence. (2024). A practical guide: Protocol development for systematic reviews. Covidence, Veritas Health Innovation Ltd.

Covidence. (2025). Covidence systematic review software. Veritas Health Innovation. www.covidence.org

Cripps, S., Pugh, M., & Serpell, L. (2024). Experiences of externalisation in recovery from anorexia nervosa: A reflexive thematic analysis. *Journal of Eating Disorders, 12*(157). https://doi.org/10.1186/s40337-024-01087-9

Critical Appraisal Skills Programme. (2018). CASP qualitative checklist. https://casp-uk.net

Crow, S.J. (2023). Terminal anorexia nervosa cannot currently be identified. *International Journal of Eating Disorders, 56*(7), 1329-1334. https://doi.org/10.1002/eat.23957

Cunning, A., & Rancourt, D. (2024). Stigmatization of anorexia nervosa versus atypical anorexia nervosa: An experimental study. *Stigma and Health, 9*(3), 249-257. https://doi.org/10.1037/sah0000432

Currin, L., Waller, G., & Schmidt, U. (2009). Primary care physicians' knowledge of and attitudes toward the eating disorders: Do they affect clinical actions? *International Journal of Eating Disorders, 42*(5)*,* 453-458. https://doi.org/10.1002/eat.20636

Curry, E.E., & Andriopoulou, P. (2023). "Dual-experiences" of treatment for anorexia nervosa: An interpretative phenomenological analysis of experience of treatment by service providers who are recovered service users. *Mental Health Review Journal*, *28*(4), 396-413. https://doi.org/10.1108/mhrj-02-2022-0010

Dawson, L., Rhodes, P., & Touyz, S. (2014). The recovery model and anorexia nervosa. *Australian and New Zealand Journal of Psychiatry, 48*(11), 1009-1016. https://doi.org/10.1177/0004867414539398

Dejong, H., Broadbent, H., & Schmidt, U. (2012). A systematic review of dropout from treatment in outpatients with anorexia nervosa. *International Journal of Eating Disorders, 45*(5), 635-647. https://doi.org/10.1002/eat.20956

Devery, H., Scanlan, J.N., & Ross, J. (2018). Factors associated with professional identity, job satisfaction and burnout for occupational therapists working in eating disorders: A mixed methods study. *Australian Occupational Therapy Journal, 65*(6), 523-532. https://doi.org/10.1111/1440-1630.12503

Du Plessis, C., Whitaker, L., & Hurley, J. (2020). Peer support workers in substance abuse treatment services: A systematic review of the literature. *Journal of Substance Use, 25*(3), 225-230. https://doi.org/10.1080/14659891.2019.1677794

Duggan, H.C., Hardy, G., & Waller, G. (2025). Cognitive-behavioural therapy (CBT) for outpatients with anorexia nervosa: A systematic review and meta-analysis of clinical effectiveness. *Cognitive Behavioural Therapy,* 1-46. https://doi.org/10.1080/16506073.2025.2465745

Duvall, A., & Hanson, O. (2024). Peer support and beyond: The role of lived experience in a new era of eating disorder treatment. *Focus, 22*(3), 333-338. https://doi.org/10.1176/appi.focus.20240002

Eatough, V., & Smith, J.A. (2017). Interpretative phenomenological analysis. In C. Willig and W. Stainton-Rogers (Eds.), *Handbook of qualitative psychology* (2nd ed.). Sage.

Eddy, K.T., Tabri, N., Thomas, J.J., Murray, H.B., Keshaviah, A., Hastings, E., Edkins, K., Krishna, M., Herzog, D.B., Keel, P.K., & Franko, D.L. (2017). Recovery from anorexia nervosa and bulimia nervosa at 22-year follow-up. *Journal of Clinical Psychiatry, 78*(2), 184-189. https://doi.org/10.4088/JCP.15m10393

Eiring, K., Wiig Hage, T., & Reas, D.L. (2021). Exploring the experience of being viewed as “not sick enough”: A qualitative study of women recovery from anorexia nervosa or atypical anorexia nervosa. *Journal of Eating Disorders, 9*(1), 142. https://doi.org/10.1186/s40337-021-00495-5

Elbaky, G.B.A., Hay, P.J., le Grange, D., Lacey, H., Crosby, R.D., & Touyz, S. (2014). Pre-treatment predictors of attrition in a randomised controlled trial of psychological therapy for severe and enduring anorexia nervosa. *BMC Psychiatry, 14*, 69. https://doi.org/10.1186/1471-244X-14-69

Elwyn, R. (2023). A lived experience response to the proposed diagnosis of terminal anorexia nervosa: Learning from iatrogenic harm, ambivalence and enduring hope. *Journal of Eating Disorders, 11*(2). https://doi.org/10.1186/s40337-022-00729-0

Evans, J., & Papoulias, S. (2020). Between funder requirements and ‘jobbing scientists’: The evolution of patient and public involvement in a mental health biomedical research centre – a qualitative study. *Research Involvement and Engagement, 6*(12). https://doi.org/10.1186/s40900-020-00185-7

Federici, A., & Kaplan, A.S. (2008). The patient's account of relapse and recovery in anorexia nervosa: A qualitative study. *European Eating Disorders Review, 16*(1), 1-10. https://oid.org/10.1002/erv.813

Fernandez-Aranda, F., Treasure, J., Paslakis, G., Aguera, Z., Gimenez, M., Granero, R., Sanchez, I., Serrano-Troncoso, E., Gorwood, P., Herpertz-Dahlmann, B., Bonin, E-M., Monteleone, P., & Jimenez-Murcia, S. (2021). The impact of duration of illness on treatment nonresponse and drop-out: Exploring the relevance of enduring eating disorder concept. *European Eating Disorders Review, 29*(3), 499-513. https://doi.org/10.1002/erv.2822

Findlay, L. (2021). Thematic analysis: The 'good', the 'bad' and the 'ugly'. *European Journal for Qualitative Research in Psychotherapy, 11,* 103-116. https://doi.org/10.24377/EJQRP.article3062

Fletcher, A.J. (2017). Applying critical realism in qualitative research: Methodology meets method. *International Journal of Social Research Methodology, 20*(2), 181-194. https://doi.org/10.1080/13645579.2016.1144401

Forbes, D.A. (2020). Futility in adolescent anorexia nervosa and the question of withdrawal of care. *Journal of Paediatrics and Child Health, 56*(1), 5-7. https://doi.org/10.1111/jpc.14659

Francis, D., & Scott, J. (2023). Racial equity and decolonisation within the DClinPsy: How far have we come and where are we going? Trainee clinical psychologists' perspectives of the curriculum and research practices. *Clinical Psychology Forum, 336,* 32-42. https://doi.org/10.53841/bpscpf.2023.1.366.32

Franzen, U., Backmund, H., & Gerlinghoff, M. (2004). Day treatment group programme for eating disorders: reasons for drop-out. *European Eating Disorders Review, 12*(3), 153-158. https://doi.org/10.1002/erv.515

Friesen, A.G. (2022). Changeover – how my lived experience changed my life, my work as a psychiatrist, and how it resulted in the establishment of a support group for prosumers in Germany. *Psychological Services, 19*(1), 55-57. https://doi.org/10.1037/ser0000487

Fuchs, T. (2022). The disappearing body: Anorexia as a conflict of embodiment. *Eating and Weight Disorders: Studies on Anorexia, Bulimia and Obesity, 27*, 109-117. https://doi.org/10.1007/s40519-021-01122-7

Giddens, A. (1986). *The constitution of society.* University of California Press.

Giel, K.E., Bremer, J., Riess-Stumm, S., Gregg, B., Fritz, A., Klemm, I., Daugelat, M-C., Schag, K., & the SUSTAIN Study Group. (2024). Enriching a randomized controlled treatment trial for anorexia nervosa by lived experience – chances and effects of a lived experience council in the SUSTAIN study. *International Journal of Eating Disorders, 57*(6), 13000-1310. https://doi.org//10.1002/eat.24050

Gillard, S., Foster, R., White, S., Barlow, S., Bhattacharya, R., Binfield, P., Eborall, R., Faulkner, A., Gibson, S., Goldsmith, L.P., Simpson, A., Lucock, M., Marks, J., Morshead, R., Patel, S., Priebe, S., Repper, J., Rinaldi, M., Ussher, M., & Worner, J. (2022). The impact of working as a peer worker in mental health services: A longitudinal mixed methods study. *BMC Psychiatry, 22*(373). https://doi.org/10.1186/s12888-022-03999-9

Gillard, S.G., Edwards, C., Gibson, S.L., Owen, K., & Wright, C. (2013). Introducing peer worker roles into UK mental health service teams: A qualitative analysis of the organisational benefits and challenges. *BMC Health Services Research, 13*(188). https://doi.org/10.1186/1472-6963-13-188

Gilsbach, S., Plana, M.T., Castro-Fornieles, J., Gatta, M., Paulson Karlsson, G., Flamarique, I., Raynaud, J-P., Riva, A., Solberg, A-L., van Elburg, A.A., Wentz, E., Nacinovich, R., & Herpertz-Dahlmann, B. (2022). Increase in admission rates and symptom severity of childhood and adolescent anorexia nervosa in Europe during the Covid-19 pandemic: Data from specialised eating disorder units in different European countries. *Child and Adolescent Psychiatry and Mental Health, 16*(46). https://doi.org/10.1186/s13034-022-00482-x

Gordon, K.H., Brattole, M.M., Wingate, L.R., & Joiner, T.E. (2006). The impact of client race on clinician detection of eating disorders. *Behaviour Therapy, 37*(4), 319-325. https://doi.org/10.1016/j.beth.2005.12.002

Gorski, P.S. (2013). What is critical realism? And why should you care? *Contemporary Sociology. 42*(5), 658. https://doi.org/10.1177/0094306113499533

Graham, M.R., Tierney, S., Chisholm, A., & Fox, J.R.E. (2020). The lived experience of working with people with eating disorders: A meta-ethnography. *International Journal of Eating Disorders, 53*(3), 422-441. https://doi.org/10.1002/eat.23215

Graves, T.A., Tabri, N., Thompson-Brenner, H., Franko, D.L., Eddy, K.T., Bourion-Bedes, S., Brown, A., Constantino, M.J., Fluckiger, C., Forsberg, S., Isserlin, L., Couturier, J., Paulson Karlsson, G., Mander, J., Teufel, M., Mitchell, J.E., Crosby, R.D., Prestano, C., Satir, D.A., & Thomas, J.J. (2017). A meta-analysis of the relation between therapeutic alliance and treatment outcome in eating disorders. *The International Journal of Eating Disorders, 50*(4), 323-340. https://doi.org/10.1002/eat.22672

Greene, M.J. (2014). On the inside looking in: Methodological insights and challenges in conducting qualitative insider research. *The Qualitative Report, 19*(29), 1-13. http://nsuworks.nova.edu/tqr/vol19/iss29/3

Gregertsen, E.C., Mandy, W., & Serpell, L. (2017). The egosyntonic nature of anorexia: An impediment to recovery in anorexia nervosa treatment. Frontiers in Psychiatry, 8. https://doi.org/10.3389/fpsyg.2017.02273

Gregertsen, E.C., Mandy, W., Kanakam, N., Armstrong, S., & Serpell, L. (2019). Pre-treatment patient characteristics as predictors of drop-out and treatment outcomes in individual and family therapy for adolescents and adults with anorexia nervosa: A systematic review and meta-analysis. *Psychiatry Research, 271*, 484-501. https://doi.org/10.1016/j.psychres.2018.11.068

Hage, T.W., Ro, K.I., & Ro, O. (2021). Burnout among staff on specialised eating disorder units in Norway. *Journal of Eating Disorders, 9*(138). https://doi.org/10.1186/s40337-021-00473-x

Halling, S. & Carroll, A. (1999). Existential-phenomenological psychology. In D. Moss (Ed.), *Humanistic and transpersonal psychology. A historical and biographic sourcebook* (pp. 95-124). Westport: Greenwood Press/Greenwood Publishing.

Hambleton, A., Pepin, G., Le, A., Maloney, D., Touyz, S., & Maguire, S. (2022). Psychiatric and medical comorbidities of eating disorders: Findings from a rapid review of the literature. Journal of Eating Disorders, 10(132). https://doi.org/10.1186/s40337-022-00654-2

Hamilton, S., Pinfold, V., Cotney, J., Couperthwaite, L., Matthews, J., Barret, K., Warren, S., Corker, E., Rose, D., Thornicroft, G., & Henderson, C. (2016). Qualitative analysis of mental health service users' reported experiences of discrimination. *Acta Psychiatrica Scandinavica, 134*(446), 14-22. https://doi.org/10.1111/acps.12611

Haripersad, Y.V., Kannegiesser-Bailey, M., Morton, K., Skeldon, S., Shipton, N., Edwards, K., Newton, R., Newell, A., Stevenson, P.G., & Martin, A.C. (2021). Outbreak of anorexia nervosa admissions during the COVID-19 pandemic. *Archives of Disease in Childhood, 106*(3), Article e15. https://doi.org/10.1136/archdischild-2020-319868

Harris, J.I., Barnes, T., Boyd, J.E., & Joseph, K.M. (2022). Workplace bullying among mental health providers with lived experience of a mental health challenge. *Psychological Services, 19*(1), 58-65. https://doi.org/10.1037/ser0000499

Harrop, E.N., Hutcheson, R., Harner, V., Mensinger, J.L., & Lindhorst, T. (2023). "You don't look anorexic:" Atypical anorexia patient experiences of weight stigma in medical care. *Body Image, 46,* 48-61. https://doi.org/10.1016/j.bodyim.2023.04.008

Hartman-Munick, S.M., Silverstein, S., Guss, C.E., Lopez, E., Calzo, J.P., & Gordon, A.R. (2021). Eating disorder screening and treatment experiences in transgender and gender diverse young adults. *Eating Behaviours, 41.* https://doi.org/10.1016/j.eatbeh.2021.101517

Hatoum, A.H., Burton, A.L., Berry, S.L., & Abbott, M.J. (2023). Psychometric properties of self-report measures of eating disorder cognitions: A systematic review. *Journal of Eating Disorders, 11.* https://doi.org/10.1186/s40337-023-00947-0

Hausner, E., Waffenschmidt, S., Kaiser, T., & Simon, M. (2012). Routine development of objectively derived search strategies. *Systematic Reviews, 1*(19). Httpt://doi.org/10.1186/2046-4053-1-19

Hogg, C., & Kemp, N. (2020). *Statement on clinical psychologists with lived experience of mental health difficulties.* The British Psychological Society. www.bps.org.uk/sites/www.bps.org.uk/files/Policy/Policy%20-%20Files/Statement%20on%20clinical%20psychologists%20with%20lived%20experience%20of%20mental %20health%20difficulties.pdf

Hoste, R.R., Zaitsoff, S., Hewell, K., le Grange, D. (2007). What can dropouts teach us about retention in eating disorder treatment studies? *International Journal of Eating Disorders, 40*(7), 668-671. https://doi.org/10.1002/eat.20421

Huet, V., & Holttum, S. (2016). Art therapists with experience of mental distress: Implications for art therapy training and practice. *International Journal of Art Therapy, 21*(3), 95-103. https://doi.org/10.1080/17454832.2016.1219755

Ince, B., Phillips, M.D., Dalton, B., Irish, M., Webb, H., Mercado, D., McCombie, C., Zenasni, Z., Shearer, J., Potts, L., Peachey, G., Au, K., Kern, N., Clark-Stone, S., Connan, F., Johnston, A.L., Lazarova, S., Zadeh, E., Tomlin, S., Battisti, F., Ioannidis, K., Newell, C., Pathan, T., Wales, J., Cashmore, R., Marshall, S., Arcelus, J., Robinson, P., Byford, S., Landau, S., Lawrence, V., Himmerich, H., Treasure, J., & Schmidt, U. (2025). Stepping into day treatment approach versus inpatient treatment for adults with anorexia nervosa: The DAISIES RCT. *Health Technology Assessment.* https://doi.org/10.3310/FTJP6744

Information Commissioner's Office. (2024). *Principles: Storage Limitations.* https://ico.org.uk/for-organisations/uk-gdpr-guidance-and-resources/data-protection-principles/a-guide-to-the-data-protection-principles/the-principles/storage-limitation/?q=research

Jagielska, G., & Kacperska, I. (2017). Outcome, comorbidity and prognosis in anorexia nervosa. *Psychiatria Polska, 51*(2), 205-218. https://doi.org/10.12740/PP/64580

Jobe, J.B., & Mingay, D.J. (1991). Cognition and survey measurement: History and overview. *Applied Cognitive Psychology, 5*(3), 175-192. https://doi.org/10.1002/acp.2350050303

Johns, G., Taylor, B., John, A., & Tan, J. (2019). Current eating disorder healthcare services – the perspectives and experiences of individuals with eating disorders, their families and health professionals: Systematic review and thematic synthesis. *BJPsych Open, 5*(4). https://doi.org/10.1192/bjo.2019.48

Jones, W.R., Saeidi, S., & Morgan, J.F. (2013). Knowledge and attitudes of psychiatrists towards eating disorders. *European Eating Disorders Review, 21*(1), 84-88. https://doi.org/10.1002/erv.2155

Jordan, J., McIntosh, V.V.W., Carter, F.A., Joyce, P.R., Frampton, C.M.A., Luty, S.E., McKenzie, J.M., Carter, J.D, & Bulik, C.M. (2017). Predictors of premature termination from psychotherapy for anorexia nervosa: Low treatment credibility, early therapy alliance, and self-transcendence. *International Journal of Eating Disorders, 50*(8), 979-983. https://doi.org/10.1002/eat.22726

Josselson R., & Hammack, P.L. (2021). *Essentials of narrative analysis.* American Psychological Association. https://doi.org/10.1037/0000246-000

Karbouniaris, S., Boomsma-van Holten, M., Oostindier, A., Raats, P., Prins-Aardema, C.C., Weerman, A., Wilken, J.P., & Abma, T.A. (2023). Explorations on the use of lived experiences by psychiatrists: Facilitators and barriers. *Mental Health and Social Inclusion, 27*(1), 66-80. https://doi.org/10.1108/MHSI-07-2022-0049

Karbouniaris, S., Weerman, A., Dunnewind, B., Wilken, J.P., & Abma, T.A. (2022). Professionals harnessing experiential knowledge in Dutch mental health settings. *Mental Health and Social Inclusion, 26*(1), 75-88. https://doi.org/10.1108/MHSI-08-2021-0054

Karlsson, S., Friberg, W., Rask, M., & Tuvesson, H. (2021). Patients' experiences and perceptions of recovering from anorexia nervosa while having contact with psychiatric care: A literature review and narrative synthesis of qualitative studies. *Issues in Mental Health Nursing, 42*(8), 709-719. https://doi.org/10.1080/01612840.2020.1847222

Kastner, D., Weigel, A., Buchholz, I., Voderholzer, U., Lowe, B., & Gumz, A. (2021). Facilitators and barriers in anorexia nervosa treatment initiation: A qualitative study on the perspectives of patients, carers and professionals. *Journal of Eating Disorders, 9*(28). https://doi.org/10.1186/s40337-021-00381-0

Kaye, W.H., & Bulik, C.M. (2021). Treatment of patients with anorexia nervosa in the US – a crisis in care. *Caring for the Critically Ill Patient, 78*(6), 591-592. https://doi.org/10.1001/jamapsychiatry.2020.4796

Kazdin, A.E., Fitzsimmons-Craft, E.E., & Wilfley, D.E. (2017). Addressing critical gaps in the treatment of eating disorders. *International Journal of Eating Disorders, 50*(3), 170-189. https://doi.org/10.1002/eat.22670

Kelly, A.C., Vimalakanthan, K., & Carter, J.C. (2014). Understanding the roles of self-esteem, self-compassion, and fear of self-compassion in eating disorder pathology: An examination of female students and eating disorder patients. Eating Behaviours, 15(3), 388-391. https://doi.org/10.1016/j.eatbeh.2014.04.008

Kenny, T.E., Trottier, K., & Lewis, S.P. (2022). Lived experience perspectives on a definition of eating disorder recovery in a sample of predominantly white women: A mixed method study. *Journal of Eating Disorders, 13*(10), 149. https://doi.org/10.1186/s40337-022-00670-2

Khalsa, S.S., Portnoff, L.C., McCurdy-McKinnon, D., & Feusner, J.D. (2017). What happens after treatment? A systematic review of relapse, remission, and recovery in anorexia nervosa. *Journal of Eating Disorders, 5*(20). https://doi.org/10.1186/s40337-017-0145-3

Kiely, L., Conti, J., & Hay, P. (2023). Conceptualisation of severe and enduring anorexia nervosa: A qualitative meta-synthesis. *BMC Psychiatry, 23*(606). https://doi.org/10.1186/s12888-023-05098-9

Kiely, L., Conti, J., & Hay, P. (2024). Severe and enduring anorexia nervosa and the proposed "terminal anorexia" category: An expanded meta synthesis. *Eating Disorders: The Journal of Treatment and Prevention, 33*(4), 460-491. https://doi.org/10.1080/10640266.2024.2379635

Kinnaird, E., & Cooper, M. (2023). Exploring the relationship between clinical and personal models of recovery in anorexia nervosa: A mixed methods study. *European Eating Disorders Review, 32*(2), 244-256. https://doi.org/10.1002/erv.3037

Kurdak, H., Tiyekli, E., Ozcan, S., Ozer, Z.Y., Nur Topuz, A., (2023). Eating disorders, primary care, and stigma: An analysis of research trends and patterns. *Frontiers in Psychiatry, 14*. https://doi.org/10.3389/fpsyt.2023.1243922

LaMarre, A., Wozney, L., Obeid, N., Kumar, S., Jones, S., Dimitropoulos, G, & Couturier, J. (2024). Peer mentors' experiences of delivering peer support for individuals with eating disorders: Giving back and supporting processes of change. *Eating Disorders: The Journal of Treatment and Prevention,* 1-15. https://doi.org/10.1080/10640266.2024.2420419

Lasserson, T.J., Thomas, J., & Higgins, J.P.T. (2021). Starting a Review [last updated August 2021]. In J.P.T. Higgins, J. Thomas, J. Chandler, M. Cumpston, T. Li, M.J. Page, & V.A. Welch (Eds.), *Cochrane Handbook for Systematic Reviews of Interventions* (version 6.5). Cochrane.

Laverty, S.M. (2003). Hermeneutic phenomenology and phenomenology: A comparison of historical and methodological considerations. *International Journal of Qualitative Methods, 2*(3), 21-35. https://doi.org/10.1177/160940690300200303

Lewis, H.K., & Foye, U. (2021). From prevention to peer support: A systematic review exploring the involvement of lived-experience in eating disorder interventions.

Mental Health Review Journal, 27(1), 1-17. https://doi.org/10.1108/MHRJ-04-2021-0033

Lian, Q., Zuo, X., Mao, Y., Luo, S., Zhang, S., Tu, X., Lou, C., & Zhou, W. (2017). Anorexia nervosa, depression and suicidal thoughts among Chinese adolescents: A national school-based cross-sectional study. Environmental Health and Preventative Medicine, 22(30). https://doi.org/10.1186/s12199-017-0639-2

Linardon, J., Wade, T.D., De La Piedad Garcia, X., & Brennan, L. (2017). The efficacy of cognitive-behavioural therapy for eating disorders: A systematic review and meta-analysis. *Journal of Consulting and Clinical Psychology, 85*(11), 1080-1094. https://doi.org/10.1037/ccp0000245

Lockertsen, V., Wellhaven Holm, L.A., Nilsen, L., Ro, O., Burger, L.M., & Rossberg, J.I. (2021). The transition process between child and adolescent mental services and adult mental health services for patients with anorexia nervosa: A qualitative study of the parents' experiences. *Journal of Eating Disorders, 9*(45). https://doi.org/10.1186/s40337-021-00404-w

Lockwood, C., Munn, Z., & Porritt, K. (2015). Qualitative research synthesis: methodological guidance for systematic reviewers utilising meta-aggregation. *International Journal of Evidence-Based Healthcare, 13*(3), 179-187. https://doi.org/10.1097/xeb.0000000000000062

Long, H.A., French, D.P., & Brooks, J.M. (2020). Optimising the value of the critical appraisal skills programme (CASP) tool for quality appraisal in qualitative evidence synthesis. *Research Methods in Medicine & Health Sciences, 1*(1). https://doi.org/10.1177/2632084320947559

Lopez-Aybar, L., Gonzales, L., & Kanani, A. (2024). Prosumers' experiences of stigma dimensions within the clinical psychology field. *Psychological Services, 21*(2), 369-378. https://doi.org/10.1037/ser0000765

Lubieniecki, G., Fernando, A.N., Randhawa, A., Cowlishaw, S., & Sharp, G. (2024). Perceived clinician stigma and its impact on eating disorder treatment experiences: A systematic review of the lived experience literature. *Journal of Eating Disorders, 12*(161). https://doi.org/10.1186/s40337-024-01128-3

MacLellan, J., Surey, J., Abubakar, I., & Stagg, H.R. (2015). Peer support workers in health: A qualitative metasynthesis of their experiences. *PLoS One, 10*(10). https://doi.org/10.1371/journal.pone.0141122

Mahon, J. (2000). Dropping out from psychological treatment for eating disorders: What are the issues? *European Eating Disorders Review, 8*(3), 198-216. https://doi.org/10.1002/(SICI)1099-0968(200005)8:3<198::AID-ERV356>3.0.CO;2-3

Majid, U., & Vanstone, M. (2018). Appraising qualitative research for evidence syntheses: A compendium of quality appraisal tools. *Qualitative Health Research, 28*(13), 2115-2131. https://doi.org/10.1177/1049732318785358

Maloney, R., Lunney, L., Lennox, O-M., Vaughan, E., & Kelly, C. (2024). Stigma experience of men with eating disorders: A scoping review. *Journal of Social Care, 4*(4). https://doi.org/10.21427/tcqd-k745

Martinez-Gonzalez, L., Fernandez-Villa, T., Jose Molina, A., Delgado-Rodriguez, M., & Martin, V. (2020). Incidence of anorexia nervosa in women: A systematic review and meta-analysis. *International Journal of Environmental Research and Public Health, 17*(11), 3824. https://doi.org/10.3390/ijerph17113824

Masson, P.C., & Sheeshka, J.D. (2009). Clinicians' perspective on the premature termination of treatment in patients with eating disorders. *Eating Disorders: The Journal of Treatment & Prevention, 17*(2), 109-125. https://doi.org/10.1080/10640260802714548

Masson, P.C., Perlman, C.M., Ross, S.A., & Gates, A.L. (2006). Premature termination of treatment in an inpatient eating disorder programme. *European Eating Disorders Review, 15*(4), 275-282. https://doi.org/10.1002/erv.762

Matter, L., Thiebaud, M-R., Huas, C., Cebula, C., & Godart, N. (2012). Depression, anxiety and obsessive-compulsive symptoms in relation to nutritional status and outcome in severe anorexia nervosa. *Psychiatry Research, 200*(2-3), 513-517. https://doi.org/10.1016/j.psychres.2012.04.032

Medway, M., & Rhodes, P. (2016). Young people's experience of family therapy for anorexia nervosa: A qualitative meta-synthesis. *Advances in Eating Disorders, 4*(2), 189-207. https://doi.org/10.1080/21662630.2016.1164609

Melles, H., & Jansen, A. (2023). Transdiagnostic fears and avoidance behaviours in self-reported eating disorders. *Journal of Eating Disorders, 11*(1), 19. https://doi.org/10.1186/s40337-023-00745-8

Merriam, S.B., Johnson-Bailey, J., Lee, M-Y., Key, Y., Ntseane, G., & Muhamad, M. (2001). Power and positionality: Negotiating insider/outsider status within and across cultures. *International Journal of Lifelong Education, 20*(5), 405-416. https://doi.org/10.1080/02601370120490

Mewes, R., Tagay, S., & Senf, W. (2008). Weight curves as predictors of short-term outcome in anorexia nervosa inpatients. *European Eating Disorders Review, 16*(1), 37-43. https://doi.org/10.1002/erv.807

Microsoft. (2024). *Security and Microsoft Teams.* https://learn.microsoft.com/en-us/microsoftteams/teams-security-guide

Miller, K.D., & Tsang, E.W.K. (2011). Testing management theories: Critical realist philosophy and research methods. *Strategic Management Journal, 32*(2), 139-158. https://doi.org/10.1002/smj.868

Mills, R., Hyam, L., & Schmidt, U. (2023). A narrative review of early intervention for eating disorders: Barriers and facilitators. *Adolescent Health, Medicine and Therapeutics, 14*, 217-235. https://doi.org/10.2147/AHMT.S415698

Montague, J., Phillips, E., Holland, F., & Archer, S. (2020). Expanding hermeneutic horizons: Working as multiple researchers and with multiple perspectives. *Research Methods in Medicine & Health Sciences, 1*(1), 25-30. https://doi.org/10.1177/2632084320947571

Monteleone, A.M., Carfagno, M., Barone, E., Cascino, G., Pittocco, A., Brandi, C., Landolfi, L., Toni, C., Sampogna, G., & Fiorillo, A. (2024). Attitudes and gaps in knowledge of the diagnosis, treatment, and psychopathology of eating disorders among different health professionals. *Journal of Eating Disorders, 28*(12). https://doi.org/10.1186/s40337-024-01053-5

Monteleone, A.M., Pellegrino, F., Croatto, G., Cargagno, M., Hilbert, A., Treasure, J., Wade, T., Bulik, C.M., Zipfel, S., Hay, P., Schmidt, U., Castellini, G., Favaro, A., Fernandez-Aranda, F., Shin, J.I., Voderholzer, U., Ricca, V., Moretti, D., Busatta, D., Abbate-Daga, G., Ciullini, F., Cascino, G., Monaco, F., Correll, C.U., Solmi, M. (2022). Treatment of eating disorders: A systematic meta-review of meta-analyses and network meta-analyses. *Neuroscience and Biobehavioural Reviews, 142.* https://doi.org/10.1016/j.neubiorev.2022.104857

Moran, D. (2000). *Introduction to Phenomenology.* Routledge.

Moser, A., & Korstjens, I. (2017). Series: Practical guidance to qualitative research. Part 1: Introduction. *European Journal of General Practice,23*(1), 271-273. https://doi.org/10.1080/13814788.2017.1375093

Munn, Z., Peters, M.D.J., Stern, C., Tufanaru, C., McArthur, A., & Aromataris, E. (2018a). Systematic review or scoping review? Guidance for authors when choosing between a systematic or scoping review approach. *BMC Medical Research Methodology, 18*(143). https://doi.org/10.1186/s12874-018-0611-x

Munn, Z., Stern, C., Aromataris, E., Lockwood, C., & Jordan, Z. (2018b). What kind of systematic review should I conduct? A proposed typology and guidance for systematic reviewers in the medical and health sciences. *BMC Medical Research Methodology, 18*(5). https://doi.org/10.1186/s12874-017-0468-4

Muratore, A.F., & Attia, E. (2021). Current therapeutic approaches to anorexia nervosa: State of the art. *Clinical Therapeutics*, 43(1), 85-94. https://doi.org/10.1016/j.clinthera.2020.11.006

Murray, S.B., Loeb, K.L., & Le Grange, D. (2018). Treatment outcome reporting in anorexia nervosa: Time for a paradigm shift? *Journal of Eating Disorders, 6*(10). https://doi.org/10.1186/s40337-018-0195-1

Music, S., Elwyn, R., Fountas, G., Gnatt, I., Jenkins, Z.M., Malcolm, A., Miles, S., Neill, E., Simpson, T., Ob Yolland, C., & Phillipou, A. (2021). Valuing the voice of lived experience of eating disorders in the research process: Benefits and considerations. *Australia and New Zealand Journal of Psychiatry, 56*(3), 216-218. https://doi.org/10.1177/0004867421998794

Naeem, M., Ozuem, W., Howell, K., & Ranfagni, S. (2024). Demystification and actualisation of data saturation in qualitative research through thematic analysis. *International Journal of Qualitative Methods, 23.* https://doi.org/10.1177/16094069241229777

Naples, N.A. (1996). The outsider phenomenon. In C.D. Smith & W. Kornblum (Eds.), *In the field: readings on the field research experience.* Praeger.

Naples, N.A. (2003). *Feminism and method: Ethnography, discourse analysis, and activist research.* Routledge.

National Institute for Health and Care Excellence (2020). Eating disorders: recognition and treatment. https://www.nice.org.uk/guidance/ng69

National Library of Medicine. (2024). *MeSH.* https://www.ncbi.nlm.nih.gov/mesh/

NHS Cambridge and Peterborough Foundation Trust. (2023). *Lone Worker Policy.* https://www.google.co.uk/url?sa=t&rct=j&q=&esrc=s&source=web&cd=&ved=2ahUKEwiH24S0tcaCAxWcQUEAHebgBBwQFnoECA0QAQ&url=https%3A%2F%2Fwww.dtgp.cpft.nhs.uk%2FFileHandler.ashx%3Fid%3D654&usg=AOvVaw1xW6KuCJ-qemyYw2-Mw6Uz&opi=89978449

NHS England. (2024). *Specialised adult eating disorder inpatient service: consultation guide.* https://www.england.nhs.uk/long-read/specialised-adult-eating-disorder-inpatient-service-consultation-guide/

Nickel, K., Joos, A., Tebartz van Elst, L., Matthis, J., Holovics, L., Endres, D., Zeeck, A., Hartmann, A., Tuscher, O., Maier, S. (2018). Recovery of cortical volume and thickness after remission from acute anorexia nervosa. *International Journal of Eating Disorders, 51*(9), 1056-1069. https://doi.org/10.1002/eat.22918

Nizza, I.E., Farr, J., & Smith, J.A. (2021). Achieving excellence in interpretative phenomenological analysis (IPA): Four markers of high quality. *Qualitative Research in Psychology, 18*(3), 369-386. https://doi.org/10.1080/14780887.2020.1854404

Norris, M.L., Hiebert, J.D., Katzman, D.K., Canadian Paediatric Society. (2024). Determining treatment goal weights for children and adolescents with anorexia nervosa. *Canadian Paediatric Society, 23*(8), 511. https://doi.org/10.1093/pch/pxy133

Noyes, J., Booth, A., Flemming, K., Garside, R., Harden, A., Lewin, S., Pantoja, T., Hannes, K., Cargo, M., & Thomas, J. (2018). Cochrane qualitative and implementation methods group guidance paper 3: Methods for assessing methodological limitations, data extraction and synthesis, and confidence in synthesised qualitative findings. *Journal of Clinical Epidemiology, 97,* 49-58. https://doi.org/10.1016/j.jclinepi.2017.06.020

Otte, I., Werning, A., Nossek, A., Vollmann, J., Juckel, G., & Gather, J. (2020). Challenged faced by peer support workers during the integration into hospital-based mental health-care teams: Results from a qualitative interview study. *International Journal of Social Psychiatry, 66*(3). https://doi.org/10.1177/0020764020904764

Oxley, L. (2016). An examination of interpretative phenomenological analysis (IPA). *Educational and Child Psychology, 33*(3), 55-62. https://doi.org/10.53841/bpsecp.2016.33.3.55

Pehlivan, M.J., Miskovic-Wheatley, J., Le, A., Maloney, D., National Eating Disorders Research Consortium., Touyz, S., & Maguire, S. (2022). Models of care for eating disorders: Findings from a rapid review. *Journal of Eating Disorders, 10*(166). https://doi.org/10.1186/s40337-022-00671-1

Pereira, T., Lock, J., & Oggins, J. (2006). Role of therapeutic alliance in family therapy for adolescent anorexia nervosa. *International Journal of Eating Disorders, 39*(8), 677-684. https://doi.org/10.1002/eat.20303

Puckett, L., Grayeb, D., Khatri, V., Cass, K., & Mehler, P. (2021). A comprehensive review of complications and new findings associated with anorexia nervosa. *Journal of Clinical Medicine, 10*(12), 2555. https://doi.org/10.3390/jcm10122555

Ramjan, L.M. (2004). Nurses and the ‘therapeutic relationship’: Caring for adolescents with anorexia nervosa. *Journal of Advanced Nursing, 45*(5), 495-503. https://doi.org/10.1046/j.1365-2648.2003.02932.x

Reas, D.L., Isomaa, R., Gulliksen, K.S., & Levallius, J. (2021). Clinicians as a critical link: Understanding health professionals' beliefs and attitudes toward anorexia nervosa, bulimia nervosa, and binge eating disorder. *Scandinavian Journal of Psychology, 62*(6), 775-779. https://doi.org/10.1111/sjop.12777

Redgrave, G.W., Coughlin, J.W., Schreyer, C.C., Martin, L.M., Leonpacher, A.K., Seide, M., Verdi, A.M., Pletch, A., & Guarda, A.S. (2015). Refeeding and weight restoration outcomes in anorexia nervosa: Challenging current guidelines. *International Journal of Eating Disorders, 48*(7), 866-873. https://doi.org/10.1002/eat.22390

Reid, K., Flowers, P., & Larkin, M. (2005). *Exploring lived experience*. The British Psychological Society.

Repper, J., & Carter, T. (2011). A review of the literature on peer support in mental health services. Journal of Mental Health, 20(4), 392-411. https://doi.org/10.3109/09638237.2011.583947

Reyes-Rodriguez, M.L., & Franko, D. (2020). Cultural adaptations of evidence-based treatments for eating disorders. In C.C. Tortolani, A.B. Goldschmidt, & D. Le Grange (Eds.), *Adapting evidence-based eating disorder treatment for novel populations and settings.* Routledge.

Richards, C. (2010, January 10). Them and us in mental health services. *British Psychological Society.* https://www.bps.org.uk/psychologist/opinion-them-and-us-mental-health-services

Richardson, C., & Paslakis, G. (2021). Men's experiences of eating disorder treatment: a qualitative systematic review of men-only studies. *Journal of Psychiatric and Mental Health Nursing, 28*(2), 237-250. https://doi.org/10.1111/jpm.12670

Richardson, F.C., Fowers, B.J., & Guignon, C.B. (1999). *Re-envisioning psychology: Moral dimensions of theory and practice.* Jossey-Bass.

Rigaud, D., Pennacchio, H., Bizeul, C., Reveillard, V., & Verges, B. (2011). Outcome in AN adult patients: A 13-year follow-up in 484 patients. *Diabetes and Metabolism, 37*(4), 305-311. https://doi.org/10.1016/j.diabet.2010.11.020

Roe, D., Slade, M., & Jones, N. (2022). The utility of patient-reported outcome measures in mental health. *World Psychiatry, 21*(1), 56-57. https://doi.org/10.1002/wps.20924

Roots, P., Hawker, J., & Gowers, S. (2006). The use of target weights in the inpatient treatment of adolescent anorexia nervosa. *European Eating Disorders Review, 14*(5), 323-328. https://doi.org/10.1002/erv.723

Royal College of Psychiatrists. (2023). *Medical emergencies in eating disorders: Guidance on recognition and management.* Royal College of Psychiatrists.

Sardar, M.R., Greway, A., DeAngelis, M., Tysko, E.O., Lehmann, S., Wohlstetter, M., & Patel, R. (2015). Cardiovascular impact of eating disorders in adults: A single centre experience and literature review. *Heart Views, 16*(3), 88-92. https://doi.org/10.4103/1995-705X.164463

Schleider, J.L. (2024). The fundamental need for lived experience perspectives in developing and evaluating psychotherapies. *Journal of Consulting and Clinical Psychology, 91*(3), 119-121. https://doi.org/10.1037/ccp0000798

Schmidt, U., & Treasure, J. (2006). Anorexia nervosa: Valued and visible. A cognitive-interpersonal maintenance model and its implications for research and practice. *British Journal of Clinical Psychology, 45*(3), 343-366. https://doi.org/10.1348/014466505x53902

Schmidt, U., Treasure, J., & Allen, K. (2023). The Maudsley model of anorexia nervosa treatment for adults (MANTRA). In P. Robinson, T. Wade, B. Herpertz-Dahlmann, F. Fernandez-Aranda, J. Treasure & S. Wonderlich (Eds.), *Eating Disorders.* Springer.

Seidinger-Leibovitz, F.M., Malta, A.R., Rodrigues, L., Bastos, R.A., Thiene Leme, P.A., Silva, D.F.A., Turato, E.R., & Vieira, C.M (2020). Premature termination of treatment among adults attending treatment for eating disorders: A critical review. *Open Journal of Medical Psychology, 9*(3). https://doi.org/10.4236/ojmp.2020.93010

Selby, E.A., & Coniglio, K.A. (2020). Positive emotion and motivational dynamics in anorexia nervosa: A positive emotion amplification model (PE-AMP). *Psychological Review, 127*(5), 853-890. https://doi.org/10.1037/rev0000198

Shaheen, N., Shaheen, A., Ramadan, A., Hefnawy, M.T., Ramadan, A., Ibrahim, I.A., Hassanein, M.E., Ashour, M.E., & Flouty, O. (2023). Appraising systematic reviews: A comprehensive guide to ensuring validity and reliability. *Frontiers, 8.* https://doi.org/10.3389/frma.2023.1268045

Sibeoni, J., Orri, M., Colin, S., Valentin, M., Pradere, J., & Revah-Levy, A. (2017). The lived experience of anorexia nervosa in adolescence, comparison of the points of view of adolescents, parents and professionals: A metasynthesis. *International Journal of Nursing Studies, 65,* 25-34. https://doi.org/10.1016/j.ijnurstu.2016.10.006

Siddaway, A.P., Wood, A.M., & Hedges, L.V. (2019). How to do a systematic review: A best practice guide for conducting and reporting narrative reviews, meta-analyses, and meta-syntheses. *Annual Review of Psychology, 4*(70), 747-770. https://doi.org/10.1146/annurev-psych-010418-102803

Singh, S.P., Paul, M., Ford, T., Kramer, T., Weaver, T., McLaren, S., Hovish, K., Islam, Z., Belling, R., & White, S. (2010). Process, outcome and experience of transition from child to adult mental healthcare: Multiperspective study. *British Journal of Psychiatry, 197*(4), 305-312. https://doi.org/10.1192/bjp.bp.109.075135

Sinha, S., & Warfa, N. (2013). Treatment of eating disorder among ethnic minorities in western settings: A systemic review. *Psychiatria Danubina, 25*(2), 295-299. PMID: 23995197

Skowron, K., Kurnik-Lucka, M., Dadanski, E., Betkowska-Korpala, B., & Gil, K. (2020). Backstage of eating disorder – about the biological mechanisms behind the symptoms of anorexia nervosa. *Nutrients, 12*(9), 2604. https://doi.org/10.3390/nu12092604

Sly, R. (2009). What's in a name? Classifying 'the dropout' from treatment for anorexia nervosa. *European Eating Disorders Review, 17*(6), 405-407. https://doi.org/10.1002/erv.964

Sly, R., & Bamford, B. (2011). Why are we waiting? The relationship between low admission weight and end of treatment weight outcomes. *European Eating Disorders Review, 19*(5), 407-410. https://doi.org/10.1002/erv.1061

Sly, R., Morgan, J.F., Mountford, V.A., & Lacey, J.H. (2013). Predicting premature termination of hospitalised treatment for anorexia nervosa: The roles of therapeutic alliance, motivation, and behaviour change. *Eating Behaviours, 14*(2), 119-123. https://doi.org/10.1016/j.eatbeh.2013.01.007

Sly, R., Mountford, V.A., Morgan, J.F., & Lacey, J.H. (2014). Premature termination of treatment for anorexia nervosa: Difference between patient-initiated and staff-initiated discharge. *International Journal of Eating Disorders, 47*(1), 40-46. https://doi.org/10.1002/eat.22190

Smith, A.R., Zuromski, K.L., & Dodd, D.R. (2017). Eating disorders and suicidality: what we know, what we don't know, and suggestions for future research. *Current Opinions in Psychology, 22*, 63-67. https://doi.org/10/1016/j.copsyc.2017.08.023

Smith, J.A, & Osborn, M. (2015). Interpretative phenomenological analysis as a useful methodology for research on the lived experience of pain. *British Journal of Pain, 9*(1), 41-42. https://doi.org/10.1177/2049463714541642

Smith, J.A. (1996). Beyond the divide between cognition and discourse: Using interpretative phenomenological analysis in health psychology. *Psychology & Health, 11*(2), 261-271. https://doi.org/10.1080/08870449608400256

Smith, J.A. (2010). Evaluating the contribution of interpretative phenomenological analysis. *Health Psychology Review, 5*(1), 9-27. https://doi.org/10.1080/17437199.2010.510659

Smith, J.A., & Nizza, I.E. (2022). *Essentials of interpretative phenomenological analysis.* American Psychological Association. https://doi.org/10.1037/0000259-000

Smith, J.A., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis: theory, method and research.* Sage Publications.

Smith, J.A., Flowers, P., & Larkin, M. (2021). *Interpretative phenomenological analysis: theory, method and research* (2nd ed.). Sage Publications.

Smith, S., & Woodside, D.B. (2021). Characterising treatment-resistance anorexia nervosa. *Frontiers in Psychiatry, 11.* https://doi.org/10.3389/fpsyt.2020.542206

Smith, S., Sutandar, K., & Woodside, B. (2023). Premature termination of inpatient eating disorder treatment: Does timing matter? *Journal of Eating Disorders, 11*(1), 210. https://doi.org/10.1186/s40337-023-00934-5

Smithuis, L., Kool-Goudzwaard, N., de Man-Van Ginkel, J.M., Van Os-Medendorp, H., Berends, T., Dingemans, A., Claes, L., Van Elburg, A.A., & Van Meijel, B. (2018). Self-injurious behaviour in patients with anorexia nervosa: A quantitative study. Journal of Eating Disorders, 6. https://doi.org/10.1186/s40337-018-0214-2

Solmi, M., Wade, T.D., Byrne, S., Del Giovane, C., Fairburn, C.G., Ostinelli, E.G., De Crescenzo, F., Johnson, C., Schmidt, U., Treasure, J., Favaro, A., Zipfel S., &

Cipriani, A. (2021). Comparative efficacy and acceptability of psychological interventions for the treatment of adult outpatients with anorexia nervosa: A systematic review and network meta-analysis. *Lancet Psychiatry, 8*(3), 215-224. https://doi.org/10.1016/S2215-0366(20)30566-6

Stedal, K., Ely, A.V., Kurniadi, N., Lopez, E., Kaye, W.H., & Wierenga, C.E. (2018). A process approach to verbal memory assessment: Exploratory evidence of inefficient learning in women remitted from anorexia nervosa. *Journal of Clinical and Experimental Neuropsychology, 41*(6), 653-663. https://doi.org/10.1080/13803395.2019.1610160

Stockford, C., Stenfert Kroese, B., Beesley, A., & Leung, N. (2018). Severe and enduring anorexia nervosa: The personal meaning of symptoms and treatment. *Women's Studies International Forum, 68,* 129-138. https://doi.org/10.1016/j.wsif.2018.03.003

Stone, K.D., Dimitropoulos, G., & MacMaster, F.P. (2021). Food for thought: A dissonance between healthcare utilisation costs and research funding for eating disorders in Canada. *Journal of the Canadian Academy of Child and Adolescent Psychiatry. 30*(3), 197-203. PMID: 34381512

Stuart, M-C., Schiavo, R.S., Herzog, D.B., & Franko, D.L. (2008). Stereotypes, prejudice and discrimination of women with anorexia nervosa. *European Eating Disorders Review, 16*(4), 311-318. https://doi.org/10.1002/erv.849

Sun, N.Y., Guerra, S.E., & Keuroghlian, A.S. (2024). Eating disorders among transgender and gender diverse people: A qualitative analysis of Reddit threads. *Journal of Clinical Psychiatry, 86*(2), 134. https://doi.org/10.4088/JCP.24com15640

Takakura, S., Aso, C.S., Toda, K., Hata, T., Yamashita, M., & Sudo, N. (2019). Physical and psychological aspects of anorexia nervosa based on duration of illness: a cross-sectional study. *BioPsychoSocial Medicine, 13*(32). https://doi.org/10.1186/s13030-019-0173-0

Tay, S., Alcock, K., & Scior, K. (2018). Mental health problems among clinical psychologists: Stigma and its impact on disclosure and help-seeking. *Journal of Clinical Psychology, 74*(9), 1545-1555. https://doi.org/10.1002/jclp.22614

Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology, 8*(45). https://doi.org/10.1186/1471-2288-8-45

Thompson-Brenner, H., Satir, S.A., Franko, D.L., & Herzog, D.B. (2012). Clinician reactions to patients with eating disorders: A review of the literature. *Psychiatric Services, 63*(1). https://doi.org/10.1176/appi.ps.201100050

Treasure, J., Duarte, T.A., & Schmidt, S. (2020). Eating disorders. *Lancet, 395*(10227), 899-911. https://doi.org/10.1016/S0140-6736(20)30059-3

Tricco, A.C., Tetzlaff, J., Sampson, M., Fergusson, D., Cogo, E., Horsley, T., & Moher, D. (2008). Few systematic reviews exist documenting the extent of bias: A systematic review. *Journal of Clinical Epidemiology, 61*(5), 422-434. https://doi.org/10.1016/j.jclinepi.2007.10.017

Tuffour, I. (2017). A critical overview of interpretation phenomenological analysis: A contemporary qualitative research approach. *Journal of Healthcare Communications, 2*(4), 52. https://doi.org/10.4172/2472-1654.100093

Turner, K., Moses, J., & Neal, A. (2021). 'I think it does just opens it up and… you're not hiding it anymore': Trainee clinical psychologists' experiences of self-disclosing mental health difficulties. *Clinical Psychology & Psychotherapy, 29*(2), 733-743. https://doi.org/10.1002/cpp.2667

Ulven, O., Hjelen Stige, S., & Sorebo Danielsen, Y. (2025). Premature termination of eating disorder treatment – a qualitative study of therapist perspectives. *Journal of Eating Disorders, 13*(76). https://doi.org/10.1186/s40337-025-01268-0

University of Hertfordshire. (2025). Ethics approval: Studies involving human participants. https://ask.herts.ac.uk/ethics-approval

Van Eeden, A.E., Van Hoeken, D., & Hoek, H.W. (2021). Incidence, prevalence and mortality of anorexia nervosa and bulimia nervosa. *Current Opinion in Psychiatry, 34*(6), 515-524. https://doi.org/10.1097/YCO.0000000000000739

Vandereycken, W., & Devidt, K. (2010). Dropping out from a specialised inpatient treatment for eating disorder: The perception of patients and staff. *Eating Disorders, 18*(2), 140-147. https://doi.org/10.1080/10640260903585557

Vandereycken, W., & Pierloot, R., (1983). Drop-out during in-patient treatment of anorexia nervosa: A clinical study of 133 patients. *British Journal of Medical Psychology, 56*(2), 145-156. https://doi.org/10.1111/j.2044-8341.1983.tb01542

Vandewalle, J., Debyser, B., Beeckman, D., Vandecasteele, T., Van Hecke, A., & Verhaeghe, S. (2016). Peer workers' perceptions and experiences of barriers to implementation of peer worker roles in mental health services: A literature review. *International Journal of Nursing Studies, 60*, 234-250. https://doi.org/10.1016/j.ijnurstu.2016.04.018

Victor, S.E., Schleider, J.L., Ammerman, B.A., Bradford, D.E., Devendorf, A.R., Gruber, J., Gunaydin, L.A., Hallion, L.S., Kaufman, E.A., Lewis, S.P., & Stage, D.L. (2022). Leveraging the strengths of psychologists with lived experience of psychopathology. *Perspectives on Psychological Science, 17*(6). https://oid.org/10.1177/17456916211072826

Vierthaler, J.M., & Elliott, E.C. (2022). A shared lived experience of a psychologist battling a mental health crisis. *Psychological Services, 19*(1), 46-48. https://doi.org/10.1037/ser0000489

Viljoen, D., Ayton, A., Roberts, L., Twitchell, M., & Collins, L. (2023). Applying integrated enhanced cognitive behaviour therapy (I-CBTE) to severe and longstanding eating disorders (SEED) paper 2: An in-depth case study for clinicians. *Journal of Eating Disorders, 12*(1), 172. https://doi.org/10.1186/s40337-024-01116-7

Vinchenzo, C., Lawrence, V., & McCombie, C. (2022). Patient perspectives on premature termination of eating disorder treatment: A systematic review and qualitative synthesis. *Journal of Eating Disorders, 10*(9). https://doi.org/10.1186/s40337-022-00568-z

Vistorte, A.O.R., Ribeiro, W.S., Jaen, D., Jorge, M.R., Evans-Lacko, S., & de Jesus Mari, J. (2018). Stigmatising attitudes of primary care professionals towards people with mental disorders: A systematic review. *International Journal of Psychiatry in Medicine, 53*(4), 317-338. https://doi.org/10.1177/0091217418778620

Vitousek, K., Watson, S., & Wilson, G.T. (1998). Enhancing motivation for change in treatment-resistant eating disorders. *Clinical Psychology Review, 18*(4), 391-420. https://doi.org/10.1016/s0272-7358(98)00012-9

Walker, G., & Bryant, W. (2013). Peer support in adult mental health settings: A metasynthesis of qualitative findings. *Psychiatric Rehabilitation Journal, 36*(1), 28-32. https://doi.org/10.1037/h0094744

Waller, G., Schmidt, U., Treasure, J., Emmanuelli, F., Alenya, J., Crockett, J., & Murray, K. (2009). Ethnic origins of patients attending specialist eating disorders services in a multiethnic urban catchment area in the United Kingdom. *International Journal of Eating Disorders, 42*(1), 459-463. https://doi.org/10/1002/eat.20636

Wallier, J., Vibert, S., Berthoz, S., Huas, C., Hubert, T., & Godart, N. (2009). Dropout from inpatient treatment for anorexia nervosa: Critical review of the literature. *International Journal of Eating Disorders, 42*(7), 636-647. https://doi.org/10.1002/eat.20609

Walton, E., Bernardoni, F., Batury, V-L., Bahnsen, K., Lariviere, S., Abbate-Daga, G., Andres-Perpina, S., Bang, L., Bischoff-Grethe, A., Brooks, S.J., Campbell, I.C., Cascino, G., Castro-Fornieles, J., Collantoni, E., D'Agata, F., Dahmen, B., Danner, U.N., Favaro, A., Feusner, J.D., Frank, G.K.W.,…Ehrlich, S., (2022). Brain structure in acutely underweight and partially weight-restored individuals with anorexia nervosa: A coordinated analysis by the ENIGMA eating disorders working group. *Biological Psychiatry, 92*(9), 730-738. https://doi.org/10.1016/j.biopsych.2022.04.022

Warren, C.S., Schafer, K.J., Crowley, M.E.J., & Olivardia, R. (2013). Demographic and work-related correlates of job burnout in professional eating disorder treatment providers. *Psychotherapy, 50*(4), 553-564. https://doi.org/10.1037/a0028783

Weissman, R., Becker, A., Bulik, C., Frank, G., Klump, K., Steiger, H., Strober, M., Thomas, J., Waller, G., & Walsh, B. (2016). Speaking of that: Terms to avoid or reconsider in the eating disorders field. *International Journal of Eating Disorders, 49*(4), 349-353. https://doi.org/10.1002/eat.22528

Whitney, C., & Evered, J.A. (2022). The qualitative research distress protocol: A participant-centered tool for navigating distress during data collection. *International Journal of Qualitative Methods, 21.* https://doi.org/10.1177/16094069221110317

Willig, C. (2019). What can qualitative research contribute to psychological knowledge? *Psychological Methods, 24*(6), 796-804. https://doi.org/met0000218

Wood, N. (2020). Racism in clinical psychology within the heart of the old empire. *South African Journal of Psychology, 50*(4). https://doi.org/10.1177/0081236320968233

Woods, A., & Springham, N. (2011). On learning from being the in-patient. *International Journal of Arts Therapies, 16*(2), 60-68. https://doi.org/10.1080/17454832.2011.603697

World Health Organization. (2013). *Mental Health Action Plan 2013-2020.* World Health Organization.

World Health Organization. (2022). *ICD-11: International classification of diseases* (11th revision). https://icd.who.int/

Wu, W-L., & Chen, S-L. (2021). Nurses' perceptions on and experiences in conflict situations when caring for adolescents with anorexia nervosa: A qualitative study. *International Journal of Mental Health Nursing, 30*(S1), 1386-1394. https://doi.org/10.1111/inm.12886

Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology and Health. 15*(2), 215-228. https://doi.org/10.1080/08870440008400302

Zaitsoff, S., Pullmer, R., Cyr, M., & Aime, H. (2015). The role of the therapeutic alliance in eating disorder treatment outcomes: A systematic review. *Eating Disorders, 23*(2), 99-114. https://doi.org/10.1080/10640266.2014.96462

Zavella, P. (1996). Feminist insider dilemmas: Constructing ethnic identity with Chicana informants. In D.L. Wolf (Ed.), *Feminist dilemmas in fieldwork.* Westview Press.

Zerubavel, N., & O'Dougherty-Wright, M. (2012). The dilemma of the wounded healer. Psychotherapy, 49(4), 482-491. https://doi.org/10.1037/a0027824

Zerwas, S., Lund, B.C., Von Holle, A., Thornton, L.M., Berrettini, W.H., Brandt, H., Crawford, S., Fichter, M.M., Hami, K.A., Johnson, C., Kaplan, A.S., La Via, M., Mitchell, J., Rotondo, A., Strober, M., Woodside, D.B., Kaye, W.H., & Bulik, C.M. (2013). Factors associated with recovery from anorexia nervosa. *Journal of Psychiatric Research, 47*(7), 972-979. https://doi.org/j.jpsychires.2013.02.011

Appendix A

Reflexive Journal Entries

Please Note: In some places within the excerpts below, some additional information has been added retrospectively by the PR in square brackets with a view to providing the reader with additional clarity or context. Some extracts have been abbreviated (indicated by […]).

Entry 1:

A Journal Excerpt Relating to the Experience of Sharing Reflections:

While I have always been aware that I will share excerpts from this journal with the project's reader, there's a part of me that, now, feels reticent to do so. In fact, I think it's a little stronger than that – a part of me is resistant to doing so. I find myself feeling vulnerable, and sitting with an urge to protect myself. Saddeningly, it's taken little time to connect with that part of myself and ask it what it feels the need to protect me from and why. As an incoming Clinical Psychologist, a part of myself continues to fear clinicians. I think this is also a sentence that needs to be a little stronger – a part of me is terrified of them. […]

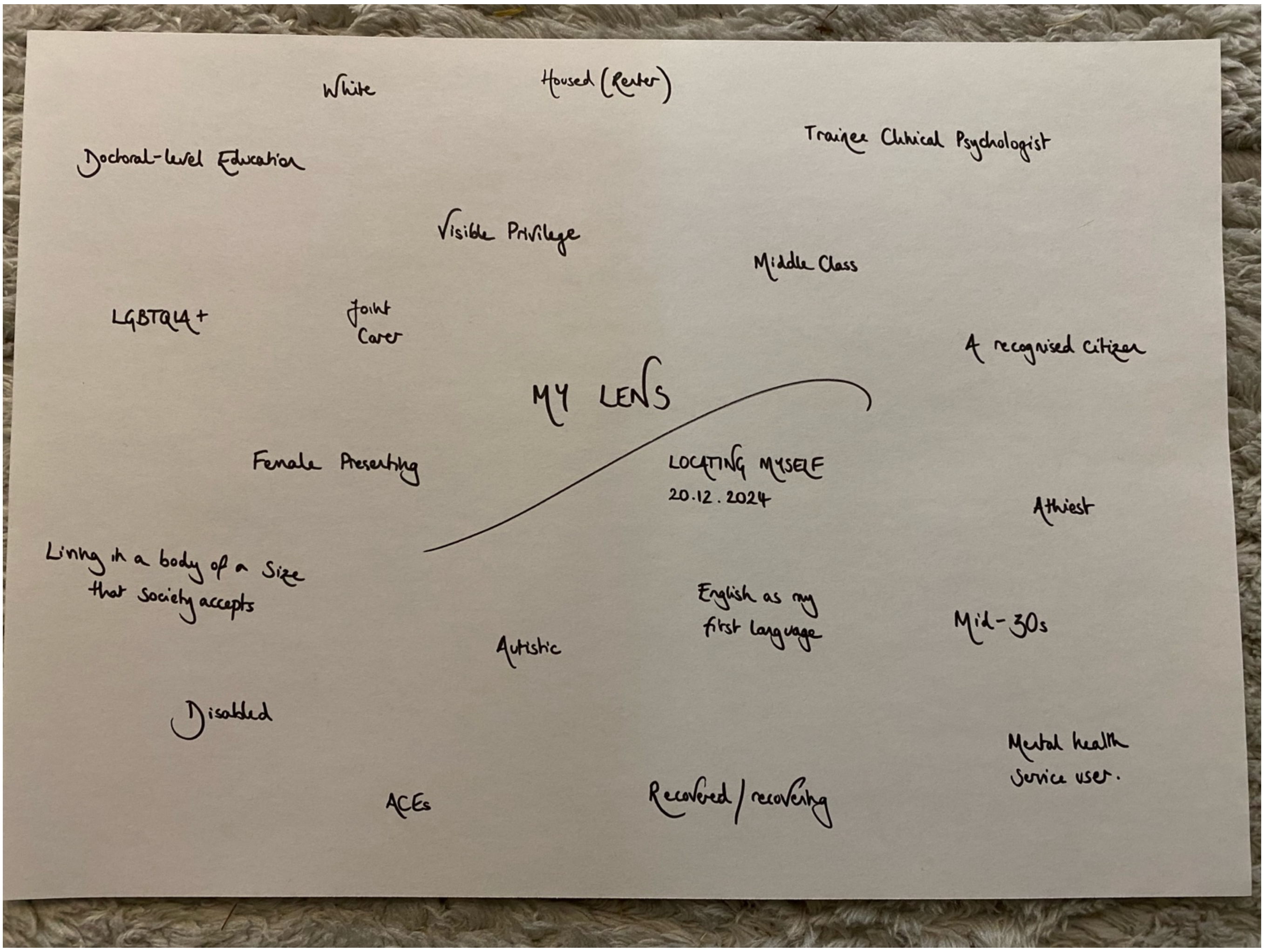
In sharing my reflections, I am sharing a part of myself with others. Others whom I do not know, and whose responses I cannot gauge. Once that part of myself is accessible to the others, they will process it – digest it. While not inherently a bad thing (there are many clinicians and individuals with lived experience out there whom I am excited to share our project with), it is this that brings me fear. It is in these sections of text that my voice of lived experience feels more present – I have, after all, used this book [reflexive journal] to reflect at length upon my own, personal experiences in relation to our [the research team's] work. It appears, however, that a part of me remains fearful consciously allowing myself to share that part of me. A part of me wants to somehow remove myself from my reflections. This makes me angry. Furious. Because another part of me stands for the very opposite. It also makes me deeply sad; I'm going to be asking our participants to do the same.

Entry 2:

A Journal Excerpt Relating to my Lens

I've been reflecting upon my previous entry [entry 1, above] since I wrote it. What *will* make this experience [sharing their dual experiences] different for our participants? Will they feel the same as I do now? And is it possible for me to support them to feel differently? I find myself feeling tentatively hopeful that my insiderness brings them a slight ease in discomfort, but I'm mindful that their experiences will still be, essentially (albethey in an analysed form and pseudoanonymised) with others upon publication.

Moreover, are there other aspects of me – my other points of intersectionality – that might contribute to a sense of discomfort or unease? Inevitably, certainly. Some aspects of the lens through which I interact with the world are highly visible. I walk through the world with a significant amount of visible privilege. I must carefully consider this throughout the entirety of the project. *(A photograph of the PR's mapping of their lens – created at the time of this journal entry - is included below. It was created after reflecting upon Burnham's (2012) Social GRRAAACCEEESSS, which the PR felt prompted to do following the present journal entry).*



White

Housed (Renter)

Trainee Clinical Psychologist

Doctoral-level Education

Visible Privilege

Middle Class

LGBTQIA+

Joint
Carer

A recognised citizen

MY LENS

Female Presenting

LOCATING MYSELF
20.12.2024

Athiest

Living in a body of a Size
that society accepts

English as my
first language

Mid-30s

Autistic

Disabled

Mental health
service user.

ACEs

Recovered / recovering

Entry 3:

A Journal Excerpt Relating to the Decision to Conduct a Literature Review of FTP Experiences as Opposed to PTT in AN:

Recent SLRs and meta-analyses of PTT studies in AN have been published, and I have struggled to design a review that meaningfully adds to research without duplicating existing efforts or producing a review that fails to meet the retrieved paper requirements of the Doctoral College. Existing reviews feel frustrating – many capture and perpetuate some of the stigmatising narratives around PTT in existing literature – but I can see that it is difficult to avoid this given the current evidence base. I had chosen to conduct an SLR of IwANs' experiences of PTT, but despite the best of efforts, it seems that such a study does not enable me to meet the Doctoral College's requirements due to a lack of existing literature (although the available literature is rich and valuable). My hands are tied. This does, however, further highlight a need for a study such as [the present empirical study].

An Excerpt from the Following Week:

I've now solidified the new review's proposal and I've committed to conducting a review of the experiences of FTPs. After numerous trial runs of my original review [experiences of PTT in AN treatment], I've decided to take a step back, reflect, and redirect – take the review in a different direction. I feel disappointed to lose the existing work, but also feel confident that this redirection better serves the project and the wider dual-experienced population [not just IwDEAN but individuals with dual experiences of other mental health difficulties], and would be of benefit to the research community.

My empirical study will recruit IwDEAN – individuals from a community inclusive of FTPs and individuals whose professional roles rely on the sharing of their lived or living experiences (such as peer support workers and lived experienced practitioners). But I've found that the vast majority of the research that's been available to me when drafting my introduction is from the peer support/lived experienced practitioners subset of the dual-experienced population. Comparatively, very little research explores the experiences of FTPs, and only a small subset of that research would be considered ‘truly’ empirical by the wider research community. There are some truly beautiful, powerful, poignant and heart-breaking FTP first-person narratives in publication – these have brought me much solace, strength, and shared anger as I’ve navigated my career to date – but I’ve found that these are so commonly lost or disregarded by the research community because of why or how they have been written.

I feel I cannot overlook this opportunity to contribute to research’s understanding of the wider dual-experienced community and contribute to capturing the fact that, within the population, there is so much diversity. So many points of intersectionality. Not all dual-experienced individuals have peer support roles: they exist within formally trained roles, too. The dual-experienced population is rich with experiences. I feel I cannot meaningfully embark on my empirical study without capturing and addressing this, and utilising this as a learning opportunity. I am so excited to learn of the findings of the review and see how they fit alongside peer support/lived experienced practitioner experiences. I’m excited to potentially contribute to the elucidation of our wider dual-experienced population. I hope to serve the wider dual-experienced population by adding to the empirical literature base and facilitate it in being more loudly heard within the research community.

An Excerpt from a Later Entry Relating to Worries about the Reception of the Present Literature Review:

Natalie supports my decision and rationale whole-heartedly, which increases my confidence slightly, but I’m struck by how fearful I am that my decision might be perceived as strange by my examiners. I don’t know who they will be or which lenses they might see and experience this project through. I can see how they might find my rationale somewhat protracted if their preference is for the neatest of narrative threads or if they are personally more distanced from dual-experienced [mental health] populations [as defined within the context of the present study] and find my review's concept trivial. I truly hope that is not the case. I find myself returning to the idea of the narrative 'funnel' that we've [the cohort] been advised to adopt throughout our theses. To me, there's a clear funnel. Perhaps not the obvious funnel-based choice, but a funnel nonetheless! I'm mindful that I keep seeking reassurance about this from my research team. I wonder why this is? Perhaps some internalised stigma finding its way in? Perhaps my autistic fear of my 'clear funnel' being an obscure adjunct to someone else?

Entry 4:

A Journal Excerpt Relating to the Decision to Conduct an SLR (as Opposed to a Scoping Review) and Difficulties with the SLR's Search Phrase:

Today, I have committed to running the SLR as planned. This decision has not been made lightly. I'm aware that it is arguable that the nature of my SLR research question might lend itself to a scoping review format: my question is intentionally less directive than might be considered more typical (perhaps, traditional?) for an SLR. Notably, however, there is a substantial precedent for such a question to be addressed within an SLR (eg. Lockwood et al., 2015; Munn et al., 2018a; Munn et al., 2018b (in addition to many published SLRs from psychological fields (including peer support workers (eg. MacLellan et al., 2015)) and more broadly), and the aim of the review is not to provide a broader, more descriptive overview of available evidence relating to FTPs (as might be expected of a scoping review), but to rigorously assess the quality of existing evidence and robustly synthesise and thematically analyse available data with the intention of systematically answering the research question, identifying the existing empirical evidence, informing future research within the field, and informing the development of my thesis. Given the lay of the land in FTP literature, it additionally feels important to contribute a methodologically rigorous literature review to the field. I consulted with [the doctoral research lead], [the research librarian], my research team, and buried myself in published SLRs and scoping reviews over the last three weeks prior to committing to the decision. It seems we are all in agreement that my logic and rationale are in keeping with SLR standards despite the question being a little less traditional.

[…] I also consulted with [the research librarian] regarding my final search phrase, expressing my concerns that it appeared unprofessional and chaotic despite being the product of much care and consideration. Although [they] initially looked a little surprised, [they] nodded sagely when I explained my findings re. the inconsistencies in labelling/titling/key wording literature in the field. I felt reassured after our conversation, although still find myself craving a more readily legible search phrase! Reflecting upon this in the SLR's discussion will hopefully be valuable for future research in the field (mine included). I am sure this is a difficulty commonly encountered by researchers when studying underrepresented populations or research topics.

Entry 5:

A Journal Excerpt Relating to the Experience of Participant Interviews:

I am fascinated by how each of the participants approaches their dual experience. One participant signposts a switch between their lived experience position and professional position by laughing. Another signposts the switch by verbally signposting which lens they are about to answer my question through. One, so far, seems to assimilate the two positions. Every one of them has reflected upon their memories of their emotional experiences with their professional lens, almost like an internal consultation. These consultations were signposted, too; each of them let me know that they were switching lenses. I'm trying not to jump too far ahead, but am mindful of needing to consider how to navigate and capture this during analysis. I wonder if it is something that I'll continue to see during the remaining participants' interviews?

Entry 6:

A Journal Excerpt Relating to the Experience of Analysis:

I feel ashamed to be writing here that I'm finding this process incredibly challenging. No, I think perhaps that's me moderating the part of me that holds the lived experiences that I share with our participants. Why am I so unused to allowing that part of me to be as it is? 'Challenging' is one of those academic 'fluff' words that's non-specific. Non-committal. Palatable. I'm finding this process devastating. I have found myself feeling tearful, furious, relieved, heartbroken, touched, hopeless, hopeful, exhausted, and invigorated. Yet I find I'm left with an overarching sense of hopelessness. Perhaps because participants whose experiences of PTT occurred decades ago are, systemically, no different to the participants whose experiences are living and present. Perhaps because eight strangers from across the UK had such similar experiences. Perhaps because some of my own experiences are shared by participants. Perhaps because so many of the participants attribute their survival to sheer luck. Perhaps because participants' positive experiences do not relate to PTT, and many of these were of their own making – their own pursuit.

I keep having to step away from analysis and distract myself every time I catch an undercurrent of hopelessness nestling itself in its familiar home in my chest. I can feel myself moving more slowly, more cautiously through participants' analyses. I will reach out to Natalie and let her know I need to shift our mini deadline [for analyses]. I must allow myself the time and space to centre the participants' experiences and, separately, to sit with and process my own.

Entry 7:

A Journal Excerpt Relating to the Experience of Analysis:

I am deeply struggling with [participant's name's] analysis. During their interview, I felt so ashamed of my own profession. […] But they felt differently. They had such pride in their profession and such hope for its future. They held such compassion. And I admire them so greatly. They have placed their trust in me and leant me their voice, and it is their experience – their wisdom, compassion, pride and hope – that must be heard clearly in this report. Amplified. And what an honour it is to do so. Analysis is proving more emotionally challenging than I could have anticipated, but what a gift it is to learn from these wonderful individuals.

Entry 8:

A Journal Excerpt Relating to the Experience of Writing the Research Report:

Another young person with anorexia has died. It's in the media. I'm unsure whether what I'm feeling right now is due to my grief, my rage, or my exhaustion. All of these are experiences shared by the study's participants. […] Every time I hear of news like this, I feel the world sinking.

I am devastated, furious and exhausted, but I fear this is unwelcome in research. I'm finding myself worrying about my languaging in the write-up: am I being too angry? Too critical? Too political? Too combative? My difficulty is that I believe it is right for me to be angry, critical, political and combative. Who am I serving if I moderate the study in this way? Would this not make me part of the problem? My written words are my primary means of communicating with the research community. What do I do? I know the answer to this. I will continue to strive for openness and curiosity. The researcher in me seeks knowledge and understanding. And to prioritise the voice of the participants being heard. My anger is not empirical. It has its place – absolutely. I see it, I feel it, I understand it. I will give it its space and time and respect what my brain and body are communicating with me. But my anger is mine to make sense of. This [the thesis] isn't its space. And that's okay. I'll check in with Natalie about his next month.

Appendix B

Search Phrase Trial Trail

Attempt One:

(“Dual*experienced clinicians” OR “Clinicians with dual experience” OR “Dual*experienced practitioners” OR “Practitioners with dual*experience” OR “Practitioners with liv* experience” OR “Lived experience practitioners” OR “Clinicians with liv* experience” OR “Liv* experience clinicians”)

AND (Clinician* OR Professional* OR Psychologist* OR Nurse* OR Doctor* OR psychiatrist* OR “Support worker*” OR Psychotherapist* OR Therapist* OR “Mental health professional*” OR “mental health practitioner*” OR Practitioner)

AND (“Mental illness” OR “Mental health” OR “Mental difficulties” OR “Mental disorder” OR “Psychological illness” OR “Psychological distress” OR “Psychological difficulties” OR “Psychiatric illness” OR “Psychiatric difficulties” OR “Psychiatric disorder” OR Psychosis OR “Hearing voices” OR Schizophren* OR “Eating disorders” OR “EDs” OR “Anorexia nervosa” OR “Bulimia nervosa” OR “Avoidant and restrictive food intake disorder” OR “ARFID” OR “Binge eating disorder” OR Diabulimi* OR “Body dysmorphic disorder” OR “Obsessive compulsive disorder” OR “OCD” OR “Obsessive compulsive behaviour” OR “Personality disorder” OR “Bipolar disorder” OR “Dissociative identity disorder” OR “Prolonged grief disorder” OR “Post-traumatic stress disorder” OR “Panic disorder” OR Phobia OR Addict* OR Depression OR Anxiety)

AND (Qualitative OR “Interpretative phenomenological analysis” OR “IPA” OR “Grounded theory” OR “Thematic analysis” OR “Narrative analysis” OR “Case study” OR “Ethnographic research” OR “Focus group” OR Interview*)

Attempt Two:

PR’s Notes – Less successful in retrieving relevant papers than attempt one.

(“Dual experience*” OR “dual identit*”)

AND (clinician* OR professional* OR psychologist* OR nurse* OR doctor* OR psychiatrist* OR “support worker*” OR psychotherapist* OR therapist* OR “mental health professional*” OR “mental health practitioner*” OR practitioner)

AND (“Mental illness” OR “Mental health” OR “Mental difficulties” OR “Mental disorder” OR “Psychological illness” OR “Psychological distress” OR “Psychological difficulties” OR “Psychiatric illness” OR “Psychiatric difficulties” OR “Psychiatric disorder” OR Psychosis OR “Hearing voices” OR Schizophren* OR “Eating disorders” OR “EDs” OR “Anorexia nervosa” OR “Bulimia nervosa” OR “Avoidant and restrictive food intake disorder” OR “ARFID” OR “Binge eating disorder” OR Diabulimi* OR “Body dysmorphic disorder” OR “Obsessive compulsive disorder” OR “OCD” OR “Obsessive compulsive behaviour” OR “Personality disorder” OR “Bipolar disorder” OR “Dissociative identity disorder” OR “Prolonged grief disorder” OR “Post-traumatic stress disorder” OR “Panic disorder” OR Phobia OR Addict* OR Depression OR Anxiety)

AND (Qualitative OR “Interpretative phenomenological analysis” OR “IPA” OR “Grounded theory” OR “Thematic analysis” OR “Narrative analysis” OR “Case study” OR “Ethnographic research” OR “Focus group” OR Interview*)

Attempt Three:

PR’s Notes – Large number of irrelevant papers, very few relevant papers. Known relevant papers missing.

(“Dual experience*” OR “dual identit*” OR “liv*experience*” OR “survivor”)

AND (clinician* OR professional* OR psychologist* OR nurse* OR doctor* OR psychiatrist* OR “support worker*” OR psychotherapist* OR therapist* OR “mental health professional*” OR “mental health practitioner*” OR practitioner*)

AND (“mental illness” OR “mental health” OR “mental difficulties” OR “mental disorder” OR “psychological illness” OR “psychological distress” OR “psychological difficulties” OR “psychiatric illness” OR “psychiatric difficulties” OR “psychiatric disorder” OR psychosis OR “hearing voices” OR schizophren* OR “eating disorders” OR “EDs” OR “anorexia nervosa” OR “bulimia nervosa” OR “avoidant and restrictive food intake disorder” OR “ARFID” OR “binge eating disorder” OR diabulimi* OR “body dysmorphic disorder” OR “obsessive compulsive disorder” OR “OCD” OR “obsessive compulsive behaviour” OR “personality disorder” OR “bipolar disorder” OR “dissociative identity disorder” OR "prolonged grief disorder" OR "post-traumatic stress disorder" OR "panic disorder" OR phobia OR addict* OR depression OR anxiety)

AND (qualitative OR "interpretative phenomenological analysis" OR "IPA" OR "grounded theory" OR "thematic analysis" OR "narrative analysis" OR "case study" OR "ethnographic research" OR "focus group" OR interview*)

Attempt Four:

PR's Notes – Retrieved only three relevant papers

("Dual experience*" OR "dual identit*" OR "liv*experience*")

AND (clinician* OR professional* OR psychologist* OR nurse* OR doctor* OR psychiatrist* OR "support worker*" OR psychotherapist* OR therapist* OR "mental health professional*" OR "mental health practitioner*" OR practitioner* OR "service provider*")

AND ("mental illness" OR "mental health" OR "mental difficulties" OR "mental disorder" OR "psychological illness" OR "psychological distress" OR "psychological difficulties" OR "psychiatric illness" OR "psychiatric difficulties" OR "psychiatric disorder" OR psychosis OR "hearing voices" OR schizophren* OR "eating disorders" OR "EDs" OR "anorexia nervosa" OR "bulimia nervosa" OR "avoidant and restrictive food intake disorder" OR "ARFID" OR "binge eating disorder" OR diabulimi* OR "body dysmorphic disorder" OR "obsessive compulsive disorder" OR "OCD" OR "obsessive compulsive behaviour" OR "personality disorder" OR "bipolar disorder" OR "dissociative identity disorder" OR "prolonged grief disorder" OR "post-traumatic stress disorder" OR "panic disorder" OR phobia OR addict* OR depression OR anxiety)

AND (qualitative OR "interpretative phenomenological analysis" OR "IPA" OR "grounded theory" OR "thematic analysis" OR "narrative analysis" OR "case study" OR "ethnographic research" OR "focus group" OR interview*)

Attempt Five:

PR's Notes: Minor improvements in retrieved papers – far from optimal.

("Dual experience*" OR "dual identit*" OR "liv*experience*")

AND (clinician* OR professional* OR psychologist* OR nurse* OR doctor* OR psychiatrist* OR "support worker*" OR psychotherapist* OR therapist* OR "mental health professional*" OR "mental health practitioner*" OR practitioner)

AND ("mental illness" OR "mental health" OR "mental difficulties" OR "mental disorder" OR "mental problem" OR "psychological problem" OR "psychological illness" OR "psychological distress" OR "psychological difficulties" OR "psychiatric illness" OR "psychiatric difficulties" OR "psychiatric disorder" OR psychosis OR "hearing voices" OR schizophren* OR "eating disorders" OR "EDs" OR "anorexia nervosa" OR "bulimia nervosa" OR "avoidant and restrictive food intake disorder" OR "ARFID" OR "binge eating disorder" OR diabulimi* OR "body dysmorphi*" OR "obsessive compulsive disorder" OR

"OCD" OR "obsessive compulsive behaviour" OR "personality disorder" OR "bipolar disorder" OR "dissociative identity disorder" OR "prolonged grief disorder" OR "post-traumatic stress disorder" OR "panic disorder" OR phobia OR addict* OR depression OR anxiety)

AND (qualitative OR "interpretative phenomenological analysis" OR "IPA" OR "grounded theory" OR "thematic analysis" OR "narrative analysis" OR "case study" OR "ethnographic research" OR "focus group" OR interview*)

Attempt Six:

PR's Notes – Retrieved some relevant papers though many still missing.

("Dual experience*" OR "dual identit*" OR "dual role*" OR "liv*experience*")

AND (clinician* OR professional* OR psycholog* OR nurse* OR doctor* OR psychiatrist* OR "support worker*" OR psychotherap* OR therapist* OR "mental health professional*" OR "mental health practitioner*" OR practitioner*)

AND ("mental illness" OR "mental health" OR "mental difficulties" OR "mental disorder" OR "mental problem" OR "psychological problem" OR "psychological illness" OR "psychological distress" OR "psychological difficulties" OR "psychiatric illness" OR "psychiatric difficulties" OR "psychiatric disorder" OR psychosis OR "hearing voices" OR schizophren* OR "eating disorders" OR "EDs" OR "anorexia nervosa" OR "bulimia nervosa" OR "avoidant and restrictive food intake disorder" OR "ARFID" OR "binge eating disorder” OR diabulimi* OR “body dysmorphi*” OR “obsessive compulsive disorder” OR “OCD” OR “obsessive compulsive behaviour” OR “personality disorder” OR “bipolar disorder” OR “dissociative identity disorder” OR “prolonged grief disorder” OR “post-traumatic stress disorder” OR “panic disorder” OR phobia OR addict* OR depression OR anxiety)

AND (qualitative OR “interpretative phenomenological analysis” OR “IPA” OR “grounded theory” OR “thematic analysis” OR “narrative analysis” OR “case study” OR “ethnographic research” OR “focus group” OR interview*)

Attempt Seven:

PR’s Notes – A large number of irrelevant results with very few relevant papers.

(“Dual experience*” OR “dual identit*” OR “dual role*” OR “lived experience*” OR “living experience*” OR prosumer*)

AND (clinician* OR professional* OR psycholog* OR nurse* OR doctor* OR psychiatrist* OR “support worker*” OR psychotherap* OR therapist* OR “mental health professional*” OR “mental health practitioner*” OR practitioner* OR “mental health worker*”)

AND (“mental illness” OR “mental health” OR “mental difficulties” OR “mental disorder” OR “mental problem” OR “psychological problem” OR “psychological illness” OR “psychological distress” OR “psychological difficulties” OR “psychiatric illness” OR “psychiatric difficulties” OR “psychiatric disorder” OR psychosis OR “hearing voices” OR schizophren* OR “eating disorders” OR “EDs” OR “anorexia nervosa” OR “bulimia nervosa” OR “avoidant and restrictive food intake disorder” OR “ARFID” OR “binge eating disorder” OR diabulimi* OR “body dysmorphi*” OR “obsessive compulsive disorder” OR “OCD” OR “obsessive compulsive behaviour” OR “personality disorder” OR “bipolar disorder” OR “dissociative identity disorder” OR “prolonged grief disorder” OR “post-traumatic stress disorder” OR “panic disorder” OR phobia OR addict* OR depression OR anxiety OR “self harm” OR “self injury” OR suicide*)

AND (qualitative OR “interpretative phenomenological analysis” OR “IPA” OR “grounded theory” OR “thematic analysis” OR “narrative analysis” OR “case study” OR “ethnographic research” OR “focus group” OR interview*)

Attempt Eight:

PR’s Notes – A large number of irrelevant results with very few relevant papers. I’ve noticed that relevant papers have inconsistent key wording/labelling re. methodologies and languaging to refer to the target population.

(“Dual experience*” OR “dual identit*” OR “dual role*” OR “dual experienced clinician*” OR “clinician* with dual experience*” OR “dual experience* practitioner*” OR “practitioner* with dual experience” OR “practitioner* with liv* experience*” OR “lived experience practitioner*” OR “clinicians with liv* experience*” OR “liv* experience* clinician*”)

AND (clinician* OR professional* OR psychologist* OR nurse* OR doctor* OR psychiatrist* OR “support worker*” OR psychotherapist* OR therapist* OR “mental health professional*” OR “mental health practitioner*” OR practitioner*)

AND (“mental illness” OR “mental health” OR “mental difficulties” OR “mental disorder” OR “mental problem” OR “psychological problem” OR “psychological illness” OR “psychological distress” OR “psychological difficulties” OR “psychiatric illness” OR “psychiatric difficulties” OR “psychiatric disorder” OR psychosis OR “hearing voices” OR schizophren* OR “eating disorders” OR “EDs” OR “anorexia nervosa” OR “bulimia nervosa” OR “avoidant and restrictive food intake disorder” OR “ARFID” OR “binge eating disorder” OR diabulimi* OR “body dysmorphi*” OR “obsessive compulsive disorder” OR “OCD” OR “obsessive compulsive behaviour” OR “personality disorder” OR “bipolar disorder” OR “dissociative identity disorder” OR “prolonged grief disorder” OR “post-traumatic stress disorder” OR “panic disorder” OR phobia OR addict* OR depression OR anxiety OR “self*harm” OR “self*injury” OR suicide*)

AND (qualitative OR “interpretative phenomenological analysis” OR “IPA” OR “grounded theory” OR “thematic analysis” OR “narrative analysis” OR “case study” OR “ethnographic research” OR “focus group” OR interview*)

Attempt Nine:

PR’s Notes – A significant improvement – a higher number of relevant papers and minimal irrelevant papers. Amalgamating lived experience with FTP role proved successful but is highly inelegant/feels very clunky.

(“Dual experience*” OR “dual experience* clinician*” OR “clinician* with dual experience*” OR “liv* experience clinician*” OR “clinician* with liv* experience*” OR “dual experience* practitioner*” OR “practitioner* with dual experience*” OR “practitioner* with liv* experience*” OR “liv* experience practitioner*” OR “professional* with dual experience*” OR “dual experience* professional*”OR “professional* with liv* experience*” OR “liv* experience* professional*”OR “psychologist* with dual experience*” OR “dual experience* psychologist*” OR “psychologist* with liv* experience*” OR “liv* experience* psychologist*” OR “nurse* with dual experience*” OR “dual experience* nurse*” OR “nurse* with liv* experience*” OR “liv* experience* nurse*” OR “psychiatrist* with dual experience*” OR “dual experience* psychiatrist*” OR “psychiatrist* with liv* experience*” OR “liv* experience* psychiatrist*” OR “doctor* with dual experience*” OR “dual experience* doctor*” OR “doctor* with liv* experience*” OR “liv* experience* doctor*” OR “psychotherapist* with dual experience*” OR “dual experience* psychotherapist*” OR “psychotherapist* with liv* experience*” OR “liv* experience* psychotherapist*” OR “therapist* with dual experience” OR “dual experience* therapist*” OR “therapist* with liv* experience*” OR “liv* experience* therapist*” OR “dual experience* mental health professional*”OR “mental health professional* with dual experience*” OR “mental health professional* with liv* experience*” OR “liv* experience* mental health professional*” OR “mental health practitioner* with dual experience*” OR “dual experience* mental health practitioner*” OR “mental health practitioner* with liv* experience*” OR “liv* experience* mental health practitioner*” OR “mental health worker* with dual experience*” OR “dual experience* mental health worker*” OR “mental health worker* with liv* experience*”OR “liv* experience* mental health worker*” OR “mental health provider* with dual experience*” OR “dual experience* mental health provider*” OR “mental health provider* with liv* experience*” OR “liv* experience* mental health provider*” OR “prosumer*”)

AND (“mental illness*” OR “mental health” OR “mental difficult*” OR “mental disorder*” OR “mental problem*” OR “psychological problem*” OR “psychological illness*” OR “psychological distress” OR “psychological difficult*” OR “psychiatric illness*” OR “psychiatric difficult*” OR “psychiatric disorder*” OR psychosis OR “hearing voices” OR schizophren* OR “eating disorders” OR “EDs” OR “anorexia nervosa” OR “bulimia nervosa” OR “avoidant and restrictive food intake disorder” OR “ARFID” OR “binge eating disorder” OR diabulimi* OR “body dysmorphi*” OR “obsessive compulsive” OR “OCD” OR “personality disorder” OR “bipolar disorder*” OR “dissociative identity disorder” OR “prolonged grief disorder” OR “post-traumatic stress disorder” OR “panic disorder” OR phobia* OR addict* OR depression OR anxiety* OR “self*harm” OR “self*injury” OR suicide*)

Attempt 10:

PR’s Notes - Changing the second part of the search phrase (removing diagnoses/symptoms) removed many relevant papers. This was tried to streamline the search phrase, but was unsuccessful.

(“Dual experience*” OR “dual experience* clinician*” OR “clinician* with dual experience*” OR “liv* experience clinician*” OR “clinician* with liv* experience*” OR “dual experience* practitioner*” OR “practitioner* with dual experience*” OR “practitioner* with liv* experience*” OR “liv* experience practitioner*” OR “professional* with dual experience*" OR "dual experience* professional*"OR "professional* with liv* experience*" OR "liv* experience* professional*"OR "psychologist* with dual experience*" OR "dual experience* psychologist*" OR "psychologist* with liv* experience*" OR "liv* experience* psychologist*" OR "nurse* with dual experience*" OR "dual experience* nurse*" OR "nurse* with liv* experience*" OR "liv* experience* nurse*" OR "psychiatrist* with dual experience*" OR "dual experience* psychiatrist*" OR "psychiatrist* with liv* experience*" OR "liv* experience* psychiatrist*" OR "doctor* with dual experience*" OR "dual experience* doctor*" OR "doctor* with liv* experience*" OR "liv* experience* doctor*" OR "psychotherapist* with dual experience*" OR "dual experience* psychotherapist*" OR "psychotherapist* with liv* experience*" OR "liv* experience* psychotherapist*" OR "therapist* with dual experience" OR "dual experience* therapist*"OR "therapist* with liv* experience*" OR "liv* experience* therapist*" OR "dual experience* mental health professional*"OR "mental health professional* with dual experience*" OR "mental health professional* with liv* experience*" OR "liv* experience* mental health professional*" OR "mental health practitioner* with dual experience*" OR "dual experience* mental health practitioner*" OR "mental health practitioner* with liv* experience*" OR "liv* experience* mental health practitioner*" OR "mental health worker* with dual experience*" OR "dual experience* mental health worker*" OR "mental health worker* with liv* experience*"OR "liv* experience* mental health worker*" OR "mental health provider* with dual experience*" OR "dual experience* mental health provider*" OR "mental health provider* with liv* experience*" OR "liv* experience* mental health provider*" OR "prosumer*")

AND ("mental illness*" OR "mental health" OR "mental difficult*" OR "mental disorder*" OR "mental problem*" OR "psychological problem*" OR "psychological illness*" OR “psychological distress” OR “psychological difficult*” OR “psychiatric illness*” OR “psychiatric difficult*” OR “psychiatric disorder*”)

Attempt 11:

PR’s Notes – Minor attempts to perfect the search phrase – no more successful at retrieving relevant papers than previous similar attempts.

(“Dual experience*” OR “dual experience* clinician*” OR “clinician* with dual*experience*” OR “liv* experience clinician*” OR “clinician* with liv* experience*” OR “dual experience* practitioner*” OR “practitioner* with dual experience*” OR “practitioner* with liv* experience*” OR “liv* experience practitioner*” OR “professional* with dual experience*” OR “dual experience* professional*”OR “professional* with liv* experience*” OR “liv* experience* professional*”OR “psychologist* with dual experience*” OR “dual experience* psychologist*” OR “psychologist* with liv* experience*” OR “liv* experience* psychologist*” OR “nurse* with dual experience*” OR “dual experience* nurse*” OR “nurse* with liv* experience*” OR “liv* experience* nurse*” OR “psychiatrist* with dual experience*” OR “dual experience* psychiatrist*” OR “psychiatrist* with liv* experience*” OR “liv* experience* psychiatrist*” OR “doctor* with dual experience*” OR “dual experience* doctor*” OR “doctor* with liv* experience*” OR “liv* experience* doctor*” OR “psychotherapist* with dual experience*” OR “dual experience* psychotherapist*” OR “psychotherapist* with liv* experience*” OR “liv* experience* psychotherapist*” OR “therapist* with dual experience” OR “dual experience* therapist*”OR “therapist* with liv* experience*” OR “liv* experience* therapist*” OR “dual experience* mental health professional*”OR “mental health professional* with dual experience*” OR “mental health professional* with liv* experience*” OR “liv* experience* mental health professional*” OR “mental health practitioner* with dual experience*” OR “dual experience* mental health practitioner*” OR “mental health practitioner* with liv* experience*” OR “liv* experience* mental health practitioner*” OR “mental health worker* with dual experience*” OR “dual experience* mental health worker*” OR “mental health worker* with liv* experience*”OR “liv* experience* mental health worker*” OR “mental health provider* with dual experience*” OR “dual experience* mental health provider*” OR “mental health provider* with liv* experience*” OR “liv* experience* mental health provider*” OR “prosumer*”)

AND (“mental illness*” OR “mental health” OR “mental difficult*” OR “mental disorder*” OR “mental problem*” OR “psychological problem*” OR “psychological illness*” OR “psychological distress” OR “psychological difficult*” OR “psychiatric illness*” OR “psychiatric difficult*” OR “psychiatric disorder*” OR psychos* OR “hearing voices” OR schizo* OR “delusional disorder” OR “eating disorder*” OR “anorexia nervosa” OR “bulimia nervosa” OR “avoidant and restrictive food intake disorder” OR “ARFID” OR “binge eating disorder” OR diabulimi* OR pica OR “rumination*regurgitation” OR “body dysmorphi*” OR “obsessive compulsive” OR “OCD” OR “perinatal mental health” OR “personality disorder*” OR “bipolar disorder*” OR “dissociative” OR “depersonali*ation*dereali*ation disorder” OR “trance disorder” OR “bodily distress disorder” OR “prolonged grief disorder*” OR “post-traumatic stress disorder*” OR “panic disorder*” OR *phobia* OR addict* OR depression OR depressive OR “mood disorder” OR “dysthymic disorder” OR anxiety* OR “fear*related disorder” OR “self*harm” OR “self*injury” OR suicid* OR “selective mutism”)

Attempt 12:

PR's Notes – Search included peer support workers – search run to see the effect of including peer support workers on retrieved papers.

(“Dual experience*” OR “dual experience* clinician*” OR “clinician* with dual*experience*” OR “liv* experience clinician*” OR “clinician* with liv* experience*” OR “dual experience* practitioner*” OR “practitioner* with dual experience*” OR “practitioner* with liv* experience*” OR “liv* experience practitioner*” OR “professional* with dual experience*” OR “dual experience* professional*”OR “professional* with liv* experience*” OR “liv* experience* professional*”OR “psychologist* with dual experience*” OR “dual experience* psychologist*” OR “psychologist* with liv* experience*” OR “liv* experience* psychologist*” OR “nurse* with dual experience*” OR “dual experience* nurse*” OR “nurse* with liv* experience*” OR “liv* experience* nurse*” OR “psychiatrist* with dual experience*” OR “dual experience* psychiatrist*” OR “psychiatrist* with liv* experience*” OR “liv* experience* psychiatrist*” OR “doctor* with dual experience*” OR “dual experience* doctor*” OR “doctor* with liv* experience*” OR “liv* experience* doctor*” OR “psychotherapist* with dual experience*” OR “dual experience* psychotherapist*” OR “psychotherapist* with liv* experience*” OR “liv* experience* psychotherapist*” OR “therapist* with dual experience” OR “dual experience* therapist*”OR “therapist* with liv* experience*” OR “liv* experience* therapist*” OR “dual experience* mental health professional*”OR “mental health professional* with dual experience*” OR “mental health professional* with liv* experience*” OR “liv* experience* mental health professional*” OR “mental health practitioner* with dual experience*” OR “dual experience* mental health practitioner*” OR “mental health practitioner* with liv* experience*” OR “liv* experience* mental health practitioner*” OR “mental health worker* with dual experience*” OR “dual experience* mental health worker*” OR “mental health worker* with liv* experience*”OR “liv* experience* mental health worker*” OR “mental health provider* with dual experience*” OR “dual experience* mental health provider*” OR “mental health provider* with liv* experience*” OR “liv* experience* mental health provider*” OR “prosumer*” OR “peer support worker”)

AND (“mental illness*” OR “mental health” OR “mental difficult*” OR “mental disorder*” OR “mental problem*” OR “psychological problem*” OR “psychological illness*” OR “psychological distress” OR “psychological difficult*” OR “psychiatric illness*” OR “psychiatric difficult*” OR “psychiatric disorder*” OR psychos* OR “hearing voices” OR schizo* OR “delusional disorder” OR “eating disorder*” OR “anorexia nervosa” OR “bulimia nervosa” OR “avoidant and restrictive food intake disorder” OR “ARFID” OR “binge eating disorder” OR diabulimi* OR pica OR “rumination*regurgitation” OR “body dysmorphi*” OR “obsessive compulsive” OR “OCD” OR “perinatal mental health” OR “personality disorder*” OR “bipolar disorder*” OR “dissociative” OR “depersonali*ation*dereali*ation disorder” OR “trance disorder” OR “bodily distress disorder” OR “prolonged grief disorder*” OR “post-traumatic stress disorder*” OR “panic disorder*” OR *phobia* OR addict* OR depression OR depressive OR “mood disorder” OR “dysthymic disorder” OR anxiety* OR “fear*related disorder” OR “self*harm” OR “self*injury” OR suicid* OR “selective mutism”)

Attempt 13:

PR’s Notes - 19,713 papers pulled on Scopus alone, very few relevant papers.

(“Dual experience*” OR “dual identit*” OR “dual role*” OR “lived experience*” OR “living experience*” OR “personal experience*”)

AND (clinician* OR professional* OR psycholog* OR nurse* OR doctor* OR psychiatrist* OR “support worker*” OR psychotherap* OR therapist* OR “mental health professional*” OR “mental health practitioner*” OR practitioner* OR “mental health worker*” OR provider* OR prosumer*)

AND (“mental illness*” OR “mental health” OR “mental difficult*” OR “mental disorder*” OR “mental problem*” OR “psychological problem*” OR “psychological illness*” OR “psychological distress” OR “psychological difficult*” OR “psychiatric illness*” OR “psychiatric difficult*” OR “psychiatric disorder*” OR psychos* OR “hearing voices” OR schizo* OR “delusional disorder” OR “eating disorder*” OR “anorexia nervosa” OR “bulimia nervosa” OR “avoidant and restrictive food intake disorder” OR “ARFID” OR “binge eating disorder” OR diabulimi* OR pica OR “rumination*regurgitation” OR “body dysmorphi*” OR “obsessive compulsive” OR “OCD” OR “perinatal mental health” OR “personality disorder*” OR “bipolar disorder*” OR “dissociative” OR “depersonali*ation*dereali*ation disorder” OR “trance disorder” OR “bodily distress disorder” OR “prolonged grief disorder*” OR “post-traumatic stress disorder*” OR “panic disorder*” OR *phobia* OR addict* OR depression OR depressive OR “mood disorder” OR “dysthymic disorder” OR anxiety* OR “fear*related disorder” OR “self*harm” OR “self*injury” OR suicid* OR “selective mutism”)

Attempt 14 (Final Search Phrase):

PR's Notes – Most successful attempt. Relevant papers retrieved, minimal irrelevant papers. The list of mental health difficulties is not exhaustive – it cannot be – but is sufficient and appropriate for the current landscape of empirical literature.

("Dual experience*" OR "dual experience* clinician*" OR "clinician* with dual experience*" OR "liv* experience clinician*" OR "clinician* with liv* experience*" OR "dual experience* practitioner*" OR "practitioner* with dual experience*" OR "practitioner* with liv* experience*" OR "liv* experience practitioner*" OR "professional* with dual experience*" OR "dual experience* professional*"OR "professional* with liv* experience*" OR "liv* experience* professional*" OR "psychologist* with dual experience*" OR "dual experience* psychologist*" OR "psychologist* with liv* experience*" OR "liv* experience* psychologist*" OR "nurse* with dual experience*" OR "dual experience* nurse*" OR "nurse* with liv* experience*" OR "liv* experience* nurse*" OR "psychiatrist* with dual experience*" OR "dual experience* psychiatrist*" OR "psychiatrist* with liv* experience*" OR "liv* experience* psychiatrist*" OR "doctor* with dual experience*" OR "dual experience* doctor*" OR "doctor* with liv* experience*" OR "liv* experience* doctor*" OR "psychotherapist* with dual experience*" OR "dual experience* psychotherapist*" OR "psychotherapist* with liv* experience*" OR "liv* experience* psychotherapist*" OR "therapist* with dual experience" OR "dual experience* therapist*" OR "therapist* with liv* experience*" OR "liv* experience* therapist*" OR "dual experience* mental health professional*"OR "mental health professional* with dual experience*" OR "mental health professional* with liv* experience*" OR "liv* experience* mental health professional*" OR "mental health practitioner* with dual experience*" OR "dual experience* mental health practitioner*" OR "mental health practitioner* with liv* experience*" OR "liv* experience* mental health practitioner*” OR “mental health worker* with dual experience*” OR “dual experience* mental health worker*” OR “mental health worker* with liv* experience*”OR “liv* experience* mental health worker*” OR “mental health provider* with dual experience*” OR “dual experience* mental health provider*” OR “mental health provider* with liv* experience*” OR “liv* experience* mental health provider*” OR prosumer*)

AND (“mental illness*” OR “mental health” OR “mental difficult*” OR “mental disorder*” OR “mental problem*” OR “psychological problem*” OR “psychological illness*” OR “psychological distress” OR “psychological difficult*” OR “psychiatric illness*” OR “psychiatric difficult*” OR “psychiatric disorder*” OR psychos* OR “hearing voices” OR schizo* OR “delusional disorder” OR “eating disorder*” OR “anorexia nervosa” OR “bulimia nervosa” OR “avoidant and restrictive food intake disorder” OR “ARFID” OR “binge eating disorder” OR diabulimi* OR pica OR “rumination*regurgitation” OR “body dysmorphi*” OR “obsessive compulsive” OR “OCD” OR “perinatal mental health” OR “personality disorder*” OR “bipolar disorder*” OR “dissociative” OR “depersonali*ation dereali*ation disorder” OR “trance disorder” OR “bodily distress disorder” OR “prolonged grief disorder*” OR “post-traumatic stress disorder*” OR “panic disorder*” OR *phobia* OR addict* OR depression OR depressive OR “mood disorder” OR “dysthymic disorder” OR anxiety* OR “fear*related disorder” OR “self*harm” OR “self*injury” OR suicid* OR “selective mutism”)

Appendix C

Evaluation of Qualitative Research Papers for Review using the Critical Appraisal Skills Programme (CASP, 2018) Qualitative Checklist

	Item 1	Item 2	Item 3	Item 4	Item 5	Item 6	Item 7	Item 8	Item 9	Item 10
Author	Was there a clear statement of the aims of the research?	Is qualitative methodology appropriate?	Was the research design appropriate to address the aims of the research?	Was the recruitment strategy appropriate to the aims of the research?	Was the data collected in a way that addressed the research issue?	Has the relationship between researcher and participants been adequately considered?	Have ethical issues been taken into consideration?	Was the data analysis sufficiently rigorous?	Is there a clear statement of findings?	How valuable is the research?
Adame (2011)	Yes	Yes	Yes	Yes, although the process adopted may have	Yes	Yes	No, they are not explicitly addressed in the report.	Yes	Yes	Valuable

	Item 1	Item 2	Item 3	Item 4	Item 5	Item 6	Item 7	Item 8	Item 9	Item 10
Author	Was there a clear statement of the aims of the research?	Is qualitative methodology appropriate?	Was the research design appropriate to address the aims of the research?	Was the recruitment strategy appropriate to the aims of the research?	Was the data collected in a way that addressed the research issue?	Has the relationship between researcher and participants been adequately considered?	Have ethical issues been taken into consideration?	Was the data analysis sufficiently rigorous?	Is there a clear statement of findings?	How valuable is the research?
				introduced some bias.						
Boosma-van Holten et al. (2023)	Yes	Yes (Mixed Methods Study)	Yes	Yes	Yes	No	Yes	Yes	Yes	Valuable
Boyd et al. (2016)	Yes	Yes	Yes	Yes	Yes	No	No: Ethical approval is	Yes	Yes	Valuable

	Item 1	Item 2	Item 3	Item 4	Item 5	Item 6	Item 7	Item 8	Item 9	Item 10
Author	Was there a clear statement of the aims of the research?	Is qualitative methodology appropriate?	Was the research design appropriate to address the aims of the research?	Was the recruitment strategy appropriate to the aims of the research?	Was the data collected in a way that addressed the research issue?	Has the relationship between researcher and participants been adequately considered?	Have ethical issues been taken into consideration?	Was the data analysis sufficiently rigorous?	Is there a clear statement of findings?	How valuable is the research?
							clear, but no considerations are elucidated.			
Cleary and Armour (2022)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Valuable

	Item 1	Item 2	Item 3	Item 4	Item 5	Item 6	Item 7	Item 8	Item 9	Item 10
Author	Was there a clear statement of the aims of the research?	Is qualitative methodology appropriate?	Was the research design appropriate to address the aims of the research?	Was the recruitment strategy appropriate to the aims of the research?	Was the data collected in a way that addressed the research issue?	Has the relationship between researcher and participants been adequately considered?	Have ethical issues been taken into consideration?	Was the data analysis sufficiently rigorous?	Is there a clear statement of findings?	How valuable is the research?
Curry and Andriopoulou (2023)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Valuable
Huet and Holttum (2016)	Yes	Yes	Yes	Yes	Yes	No	No: Ethical approval is clear, but no	Yes	Yes	Valuable

	Item 1	Item 2	Item 3	Item 4	Item 5	Item 6	Item 7	Item 8	Item 9	Item 10
Author	Was there a clear statement of the aims of the research?	Is qualitative methodology appropriate?	Was the research design appropriate to address the aims of the research?	Was the recruitment strategy appropriate to the aims of the research?	Was the data collected in a way that addressed the research issue?	Has the relationship between researcher and participants been adequately considered?	Have ethical issues been taken into consideration?	Was the data analysis sufficiently rigorous?	Is there a clear statement of findings?	How valuable is the research?
							considerations are elucidated.			
Karbouniaris et al. (2022)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Valuable
Karbouniaris et al. (2023)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Valuable

	Item 1	Item 2	Item 3	Item 4	Item 5	Item 6	Item 7	Item 8	Item 9	Item 10
Author	Was there a clear statement of the aims of the research?	Is qualitative methodology appropriate?	Was the research design appropriate to address the aims of the research?	Was the recruitment strategy appropriate to the aims of the research?	Was the data collected in a way that addressed the research issue?	Has the relationship between researcher and participants been adequately considered?	Have ethical issues been taken into consideration?	Was the data analysis sufficiently rigorous?	Is there a clear statement of findings?	How valuable is the research?
Lopez-Aybar et al. (2024)	Yes	Yes	Yes	Yes	Yes	No	No: Ethical approval is clear, but no considerations are elucidated.	Yes	Yes	Valuable
Turner et al. (2021)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Valuable

	Item 1	Item 2	Item 3	Item 4	Item 5	Item 6	Item 7	Item 8	Item 9	Item 10
Author	Was there a clear statement of the aims of the research?	Is qualitative methodology appropriate?	Was the research design appropriate to address the aims of the research?	Was the recruitment strategy appropriate to the aims of the research?	Was the data collected in a way that addressed the research issue?	Has the relationship between researcher and participants been adequately considered?	Have ethical issues been taken into consideration?	Was the data analysis sufficiently rigorous?	Is there a clear statement of findings?	How valuable is the research?
Woods and Springham (2011)	Yes	Yes	Yes	No: There was no formal recruitment strategy.	Yes	Yes	No	Yes	Yes	Valuable

Appendix D

CASP Qualitative Checklist Modifiers (Yardley, 2000)

	Yardley's (2000) Principles for Quality			
Author(s)	Sensitivity to Context	Commitment and Rigour	Transparency and Coherence	Impact and Importance
Adame (2011)	The researcher considered the languaging utilised to refer to the participant population in great depth. The researcher also acknowledged and explored the challenges encountered by the participant population as evidenced in research.	The researcher conducted an in-depth analysis of participant data and even considered the portrayal of participant quotes in the written report, opting for stanza form. Some rigour may have been lost due to the relationship between the researcher and their	The researcher clearly outlines their methodology and rationale for the study. The study is coherent – its aims align with its design. The report is accessible and clear.	The study explored an understudied population.

	Yardley's (2000) Principles for Quality			
Author(s)	Sensitivity to Context	Commitment and Rigour	Transparency and Coherence	Impact and Importance
		participants and reflexivity going unaddressed. The researcher does note, however difficulty in managing the space/word count permitted in publication and how this had affected what they have been able to report and how.		
Boosma-van Holten et al. (2023)	The researchers compassionately situated	Three forms of member-checking took place	The researchers' thoughts following interviews were	The study explored an understudied population.

	Yardley's (2000) Principles for Quality			
Author(s)	Sensitivity to Context	Commitment and Rigour	Transparency and Coherence	Impact and Importance
	their research population in literature to obtain an understanding of the population's context and gave their participants an active role in processing the study's data with a view to ensuring they accurately reflected the participants' meanings. The use of semi-structured interviews enabled the researchers to explore	throughout the study: all participants were invited to review summaries of their interviews and adjust them if necessary to best convey their intended meaning; participants were invited to looks for connections, share reflections and meaning, and refine the study's outcomes; all participants were invited to read and	documented and utilised in discussions to inform the analytical process. The researchers reported all aspects of their study in detail, providing rationales for each decision taken. Their study was coherent with their aims and methodology.	The study provided recommendations and considerations regarding the use of experiential knowledge in clinical practice based upon participants' experiences. The study contributes to the 'professionalisation' (the authors' terminology) of the use of experiential knowledge by psychiatrists.

	Yardley's (2000) Principles for Quality			
Author(s)	Sensitivity to Context	Commitment and Rigour	Transparency and Coherence	Impact and Importance
	novel lines of questioning and follow participants' narratives. Member-checking was undertaken at three stages of the study with a view to doing 'as much justice as possible' to what the respondents had to say.	comment on the article prior to manuscript submission with a view to doing 'as much justice as possible' to what the respondents had to say.		
Boyd et al. (2016)	The authors robustly situate the present participant population within existing literature	The study was rigorous in its design, although the researchers' relationship with the participants and	The researchers were transparent regarding their study's rationale, design	The study was novel and its findings suggested that the prosumer population may be helpful within the

	Yardley's (2000) Principles for Quality			
Author(s)	Sensitivity to Context	Commitment and Rigour	Transparency and Coherence	Impact and Importance
	prior to outlining their novel research endeavour.	reflexivity were not included.	and findings. The study is coherent.	VHA system. It highlighted clear pathways for future research.
Cleary and Armour (2022)	The researchers considered the dichotomy of their participant population and situated this within existing research relating to the challenges encountered by this population. They also considered the use of	The study was rigorous and addressed all aspects of its design, methods and findings as would be expected. Reflexivity was addressed, as was the relationship between the researchers and their participants. The	All aspects of the study were reported transparently and in depth. The study's design was coherent with its aims. The report was clear and accessible.	The researchers called for a cultural shift across mental health services whereby experiences of mental distress are no longer understood as being external and isolated to service-users.

	Yardley's (2000) Principles for Quality			
Author(s)	Sensitivity to Context	Commitment and Rigour	Transparency and Coherence	Impact and Importance
	language in reference to the present population.	methodology utilised was an in-depth analysis, demonstrating commitment to elucidating their phenomenon of study.		
Curry and Andriopoulou (2023)	The primary researcher was an insider researcher and belonged to the participant population. This context was shared with participants, and was utilised to inform the	The researchers considered reflexivity throughout the study in the form of supervision and a reflexive diary. Methodological processes	Methodological processes and reflexivity are transparent in the study's report. The study is coherent, and its design aligns with its aims.	The study explored the experiences of an understudied and stigmatised population.

	Yardley's (2000) Principles for Quality			
Author(s)	Sensitivity to Context	Commitment and Rigour	Transparency and Coherence	Impact and Importance
	study's design. Language use was discussed with each participant during their interview and the study was written in accordance with the participants' language preferences.	are clearly rationalised, outlined and cited.		
Huet and Holttum (2016)	The researchers considered the dual positionality of their participant population.	As part of their research protocol, the researchers developed a network of individuals belonging to the participant population	The study is coherent, and its design aligns with its aims. The study is transparently reported.	The findings of the study supported existing findings in literature, suggestive of the strengths

	Yardley's (2000) Principles for Quality			
Author(s)	Sensitivity to Context	Commitment and Rigour	Transparency and Coherence	Impact and Importance
		with a view to creating a research network and foster learning opportunities, demonstrating their commitment to their participant population. The study is rigorous in most aspects of its reporting, although fails to address the relationship between the researchers and their participants or		of the participant population.

	Yardley's (2000) Principles for Quality			
Author(s)	Sensitivity to Context	Commitment and Rigour	Transparency and Coherence	Impact and Importance
		the use (or lack thereof) of reflexivity.		
Karbouniaris et al. (2022)	The researchers adopted a participatory action research approach, and participants were included at all stages of the study's design. They considered the difficulties of the dual positionality of their participant population.	The researchers demonstrated their commitment to the study through their in-depth analyses and carefully considered study design in consultation with Experts by Experience.	The study is coherent, and its design aligns with its aims. The study's report does not, however, consider the relationship between the researchers and their participants, not did they speak clearly to the ethical considerations given in the context of the study.	The study highlighted a need for service culture to change to accommodate this population, and called for associated transformations of governance, policy and ethics.

	Yardley's (2000) Principles for Quality			
Author(s)	Sensitivity to Context	Commitment and Rigour	Transparency and Coherence	Impact and Importance
Karbouniaris et al. (2023)	The researchers adopted a participatory action research approach, and participants were included at all stages of the study's design. They considered the difficulties of the dual positionality of their participant population.	The researchers demonstrated their commitment to the study through their in-depth analyses and carefully considered study design in consultation with Experts by Experience.	The study is coherent, and its design aligns with its aims. The study's report does not, however, consider the relationship between the researchers and their participants, nor did they speak clearly to the ethical considerations given in the context of the study.	Informing the direction of future research with a view to overcoming the shame and stigma experienced by- and imposed upon- the participant population and discover the full potential of dual experiences in the context of practice, education and research.
Lopez-Aybar et al. (2024)	Attention was paid to the empirical landscape	As a mixed methods study, both statistical	The researchers were transparent in their	The study's findings have implications for clinical

	Yardley's (2000) Principles for Quality			
Author(s)	Sensitivity to Context	Commitment and Rigour	Transparency and Coherence	Impact and Importance
	suggestive of the experiences held by the participant population. Thought was given to the sigma these individuals are reported in research as encountering.	analyses and grounded theory were utilised to analyse participants' data. The reported methodology was clear and suggestive of rigour.	reporting of their study and its design was coherent with the study's aims.	psychology training programme evaluation and the adoption of recovery-orientated approaches within training and clinical settings. The findings suggested that prosumers within the field of clinical psychology experienced multiple forms of discrimination and engaged in stigma resistance.

	Yardley's (2000) Principles for Quality			
Author(s)	Sensitivity to Context	Commitment and Rigour	Transparency and Coherence	Impact and Importance
Turner et al. (2021)	The researchers carefully considered the difficulties encountered by their population of study as reported in research and reflected upon their own positionality.	Reflexive bracketing was used via supervision and the use of a reflexive journal to consider sociocultural, personal and research contexts that might affect analyses and findings. The researchers reported their deep immersion and engagement with participant transcripts, exhibiting commitment.	The researchers created a personal position statement for transparency, although this was not elucidated in the study's report and the relationship between the participant population and the researchers remained unknown. Analytical processed were documented to demonstrate transparency	The study explored an understudied population. The researchers reported that, anecdotally, several participants commented on the importance of the current study. The researchers additionally suggested that the study contributes to research into the populations' self-disclosure practices and might affect clinical

	Yardley's (2000) Principles for Quality			
Author(s)	Sensitivity to Context	Commitment and Rigour	Transparency and Coherence	Impact and Importance
			and evidence themes. Methodological choice illustrated coherence within the study's design.	psychology's professional practice.
Woods and Springham (2011)	A high amount of reflexivity is present throughout the study's report and illustrates how the needs of AW (the case study) were considered in its design. The researchers clearly state the intention of the paper and are clear	The case study upon which the paper is based, AW, was also a co-author of the paper. AW was involved in the study's design, analyses and findings. Both researchers were committed to accurately capturing data	The researchers are transparent about the development of the study, the choice of AW, the relationship between the researchers (inclusive of AW, the case study), and the intentions behind the paper. The study is	The study explored the experiences of someone with an understudied dual relationship with their professional role. The researchers empirically captured AW's experiences, enabling

	Yardley’s (2000) Principles for Quality			
Author(s)	Sensitivity to Context	Commitment and Rigour	Transparency and Coherence	Impact and Importance
	on its limitations and potential mis-representations of its findings in future studies.	and adapted their interview approach to facilitate this. It might be arguable that this study is less rigorous because of the nature of its conception and case study selection process.	coherent and its design aligns with its aims.	them to inform future research ventures.

Appendix E

Summary Table for Studies Included in the Systematic Literature Review

Author(s)	Location	Aims	Sample	Research Design and Method	Key Findings	Limitations
Adame (2011)	United States	To understand how the identity of psychiatric survivor influences approaches to therapy and the nature of the relationship between the two identities.	Five survivor-therapists were recruited via professional connections.	Narrative inquiry applied to semi-structured interviews. The researcher incorporated Lieblich et al.'s (1998) method of holistic-content analysis.	Salient themes included: - The foundational nature of survivor identity - The risks and benefits of self-disclosure - How survivor identity influences work as a therapist - "Us and Them" dichotomies.	The relationship between the researcher and their participants was not addressed. Limited generalisability (although not the intention of the study).

Author(s)	Location	Aims	Sample	Research Design and Method	Key Findings	Limitations
Boosma-van Holten et al. (2023)	The Netherlands	To gain insight into the concerns of psychiatrists using their lived experiences with mental health distress as a source of knowledge for patients, colleagues and themselves.	18 psychiatrists with lived experience as patients in mental health care systems.	Participants were interviewed utilising a semi-structured questionnaire. The interviews were analysed using qualitative narrative thematic synthesis.	The majority of participants reported using their lived experience implicitly in their contact with patients. Participants unanimously indicated that the use of experiential knowledge in their role in a personal decision. Safety and stability in their wider teams felt vital in facilitating the use of experiential knowledge.	Its small, homogenous participant population may mean the study lacks generalisability. Authors acknowledged the potential for selection bias due to the nature of the study, although recognised that multiple perspectives regarding the use of

Author(s)	Location	Aims	Sample	Research Design and Method	Key Findings	Limitations
					The authors recommended that psychiatrists with lived experience should be able to reflect on their lived experience from ‘a sufficient distance’ and should take patient factors into account when utilising their lived experience. Having personal lived experiences with a mental health difficulty affects the way psychiatrists think about and perform their profession.	lived experience in psychiatry, serving to improve the study’s reliability.

Author(s)	Location	Aims	Sample	Research Design and Method	Key Findings	Limitations
Boyd et al. (2016)	United States	'To document the existence of competently functioning mental health providers with lived experience of mental illness and to begin exploration of their contributions and their point of view, in an effort to shape future work.'	77 prosumers recruited via convenience sample, working for the Veterans Health Administration in the United States. The study described the participant population as 'prosumers'.	Mixed methods. Descriptive statistics for quantitative items. Descriptive coding applied iteratively to qualitative items as described by Saldana (2013).	Few participants reported having asked for accommodations at work, and two thirds reported not disclosing their lived experiences to their patients. On average, participants only disclosed their own lived experience to 16% of their colleagues. Qualitative data suggested that participants saw their lived experience as an asset, whether disclosed to others of not. Additional themes	The authors were very passionate about providing a means by which their participants' voices would be heard but did not clearly consider the researchers' relationship with the participant group. As such, it is possible that some bias may be present in the review.

Author(s)	Location	Aims	Sample	Research Design and Method	Key Findings	Limitations
		Research questions included: - The prevalence of prosumers. - Are prosumers in leadership positions? - How commonly do prosumers disclose to colleagues and patients?			included pride in their experiences. Some participants felt cautious about disclosure.	The researchers note that their sample was skewed by ‘the sampling frame’. They noted that some highly stigmatised mental health difficulties were not captured within their sample and are therefore not represented in the study’s findings.

Author(s)	Location	Aims	Sample	Research Design and Method	Key Findings	Limitations
		- Do prosumers typically need accommodations to do well? - Have the participants experienced discrimination? - Can they assume mentorship roles? - ‘If this invisible group is given a voice,				The qualitative data captured through the study was limited and was therefore not as rich as it might have been. The researchers acknowledge that their qualitative data was analysed subjectively rather than following a rigorous qualitative

Author(s)	Location	Aims	Sample	Research Design and Method	Key Findings	Limitations
		what does it have to say to the field?’				analytical methodology. Limited generalisability, although notably this was not the intention of the study.
Cleary and Armour (2022)	Northern Ireland	To explore the role of practitioner lived experience of mental health difficulties in counselling and psychotherapy.	Three participants (two qualified counsellors and one qualified psychotherapist) with lived experience of mental health difficulties were	IPA was applied to participants’ transcripts following individual semi-structured interviews.	Four themes were identified through analysis including: - Identity as a practitioner	The researchers identified that IPA is an inherently subjective methodology. The study interviewer was also an insider

Author(s)	Location	Aims	Sample	Research Design and Method	Key Findings	Limitations
			recruited as part of a small, homogenous sample. Two participants were White Irish and one participant was White British. Two were female, one was male. The mental health difficulties experienced by the participants were not disclosed in the study. The study described its participant population		- Self-disclosure as enhancing therapeutic relationships - Importance of supervision - Healing and recovery.	researcher, and the authors note that this may have fostered a tendency to prioritise certain themes. They described their analyses as subject to bias. Generalisability is limited due to the sample sizes utilised in IPA.

Author(s)	Location	Aims	Sample	Research Design and Method	Key Findings	Limitations
			as ‘practitioners with lived experience of mental health issues’.			Selection bias may also be a limitation, as self-nominating for the study may inter a particular degree of insight into the benefits and challenges of holding this dual identity. The perspectives of minoritised groups were not captured in the study.

Author(s)	Location	Aims	Sample	Research Design and Method	Key Findings	Limitations
Curry and Andriopoulou (2023)	United Kingdom	To explore the treatment experiences of individuals with dual experience of anorexia nervosa (defined as individuals who self-identify as 'recovered' from anorexia who have also been service providers treating anorexia).	Four United Kingdom-based female participants who self-identified as having dual experience of anorexia. Participants' professional positions included a Trainee Clinical Psychologist, a Trainee Psychotherapist, a Therapist, and a Therapeutic Support Worker.	IPA was applied to participants' transcripts following individual semi-structured interviews.	Analyses revealed four primary themes including barriers to accessing services, the impact of treating professionals' approaches, displacement of responsibility for treatment anorexia, and the value of dual experience of anorexia.	The researchers identified that IPA is an inherently subjective methodology. The primary researcher was an insider research. Some bias may therefore be present despite efforts to mitigate this. Generalisability is limited due to the

Author(s)	Location	Aims	Sample	Research Design and Method	Key Findings	Limitations
			The study described its participants as 'individuals with dual experience of anorexia'.			sample sizes utilised in IPA, although this is also not an aim of IPA. The experiences of minoritised groups and individuals identifying as male were not captured within the study.
Huet and Holttum (2016)	United Kingdom	To explore the experiences of art therapists with experience of mental	19 art therapists completed the study's questionnaire.	Data was collected via cross-sectional survey using a	That clinicians' experiences of mental distress could be drawn upon for the benefit of service users. That	A small-sample, survey-led study of the members of one particular art therapy

Author(s)	Location	Aims	Sample	Research Design and Method	Key Findings	Limitations
		distress to answer the research questions: - Did participants disclose their experience of mental distress at interview of during their art therapy training, and, if so, what was their experience of	Service user experience was defined as having received a mental health diagnosis and having needed to use mental health services before, during, or after training as an art therapist. Demographic information was not collected to ensure the anonymity of participants.	questionnaire with open-ended questions to enable participants to share their stories. Written responses were thematically coded. Descriptive statistics were provided.	further support was needed in clinical and training settings in order to facilitate the harnessing of lived and living experiences and the ‘bringing all parts of themselves’ together. A self-reported increase in empathy towards service users, and an awareness of one’s own limitations.	organisation. The demographics of the participants are not reported to protect their confidentiality.

Author(s)	Location	Aims	Sample	Research Design and Method	Key Findings	Limitations
		disclosing and the reactions to it? - What effects, if any, do participants perceive their experience of mental distress to have had on their practice?				
Karbouniaris et al. (2022)	The Netherlands	To explore the perspectives of mental health professionals who are in a process of	Participants were professionals across a variety of recovery orientated in- and out-patient settings who	A participatory action research approach. Thematic analysis (Braun and	The use of experiential knowledge held by the participants was found to affect four levels: their personal-professional	The researchers note that they recruited from a local population of specifically

Author(s)	Location	Aims	Sample	Research Design and Method	Key Findings	Limitations
		integrating their own experiential knowledge in their professional role.	held their own experiences of mental health difficulties. 12 female, three male participants, with ages ranging between 27 and 60. Professionals roles included nurses, social workers, and humanistic counsellors.	Clarke, 2006) was applied to participant interview transcripts.	development, their relationships with service users, their relationships with colleges, and the broader organisations that they worked within.	recovery-orientated services, meaning that the study's generalisability is limited. Data pertaining to the nature of participants' lived experiences of mental health difficulties was not captured to protect anonymity, but means that this was therefore not

Author(s)	Location	Aims	Sample	Research Design and Method	Key Findings	Limitations
						considered in analysis.
Karbouniaris et al. (2023)	The Netherlands	To explore the perspectives of psychiatrists with lived experiences of mental health difficulties, in addition to exploring their considerations when integrating the personal into the professional realm.	Eight psychiatrists with lived or living experiences of mental health difficulties were recruited. Ages ranged between 46 and 65 years.	A qualitative, participatory study. Data collections included participant observations during peer supervision sessions, three interviews, and a focus group.	The decision to become a psychiatrist was often related to participants' personal experiences with mental distress. Some felt the need to integrate their personal experiences into their professional work, although findings suggests that the use of lived experiences in participants' work was 'in early stages of development.	The study was conducted locally and there were not similar, comparable studies known at the time of publication. It utilised a small, homogenous sample size due to its qualitative methodology, and may therefore lack generalisability.

Author(s)	Location	Aims	Sample	Research Design and Method	Key Findings	Limitations
				Member checking was utilised. Thematic analysis was applied to participant interviews.	Findings suggested three main considerations.	
Lopez-Aybar et al. (2024)	United States	To assess prosumers' experiences of mental illness stigma within the field of clinical psychology. To answer the questions:	175 participants recruited by 'snowballing'. The participants were prosumers with any given psychiatric diagnosis as defined by DSM-V. Prosumers where either in their	Data was collected via qualitative, open-ended questionnaire items and quantitative measures of witness	Emergent qualitative themes included witnessed discrimination, anticipated stigma, internalised stigma, and stigma resistance.	The participant pool was majority white, cis-gender females, meaning that the experiences of minoritised individuals may not be represented. The study may therefore

Author(s)	Location	Aims	Sample	Research Design and Method	Key Findings	Limitations
		-What is the nature of stigmatising experiences relating to prosumer status within clinical psychology? -In what context and from whom do prosumers report experiences of stigma within the clinical psychology field?	doctoral training or post-qualification, living in the US, aged 18 or over, and English speaking. The majority of recruited participants were currently in training.	discrimination, microaggressions, internalised stigma, anticipated stigma, and stigma resistance. Grounded theory was utilised to analyse qualitative data and descriptive data analyses were conducted using SPSS.		not capture minoritised intersectionalities. Recruitment bias may have occurred due to the use of the 'snowballing' recruitment method. The researchers also acknowledge the potential for bias introduced by the ways in which participants represented their

Author(s)	Location	Aims	Sample	Research Design and Method	Key Findings	Limitations
						experiences. Participants may have self-identified based on their interest in the topic of study, meaning that some other positions/experiences have not been represented. The researchers acknowledge the subjectivity of grounded theory.

Author(s)	Location	Aims	Sample	Research Design and Method	Key Findings	Limitations
Turner et al. (2021)	United Kingdom	To develop a theory about how trainees approach and manage disclosures of lived/living experiences of mental health difficulties, and relating to factors which might precipitate or inhibit disclosure to psychology colleagues during training.	12 trainee clinical psychologists were recruited from accredited doctoral programmes in clinical psychology throughout the United Kingdom. 3 participants were male, 9 were female, with an age range between 26 and 37 years. Some participants held experiences of multiple	Participants participated in individual semi-structured interviews about their experiences of disclosure. Grounded theory methodology was applied to participants' interview transcripts.	Six core categories emerged, which comprised of further subcategories. The categories included: - Motivations (feeling the struggle and needing support, being understood, professional values and duty, influencing narratives).	Interviews relied on participant self-report and recollections of disclosure experiences and are thus subject to bias or error. Participants were self-selecting volunteers and may have had particular interest and motivations for participating. Skype interview may have

Author(s)	Location	Aims	Sample	Research Design and Method	Key Findings	Limitations
			mental health difficulties.	A constructivist approach was taken. Results were modelled pictorially to facilitate theoretical coding and build the grounded theory model.	- Enablers (trusting relationships, feeling 'safe', having an 'in-road'). - Barriers (internalising stigma, worrying about impact for training, voicing the unspoken). - Features of disclosure (being selective, 'spilling	limited richness of data to an extent (although participants reported feeling comfortable with this medium). The findings are not inherently generalisable or transferable due to the nature of the methodology – it provides a limited understanding of

Author(s)	Location	Aims	Sample	Research Design and Method	Key Findings	Limitations
					out' vs 'controlled disclosure', 'testing the waters'). - Responses (listening vs. 'jumping to fix', exploring vs. lack of curiosity). - Impact (making it 'easier' to be open, growing connections, integrating different parts of self, 'finding the right	how the variables interact.

Author(s)	Location	Aims	Sample	Research Design and Method	Key Findings	Limitations
					support', clarifying positions). The model that emerged was largely consistent with research on disclosure in healthcare professionals and has implications for training programmes, supervisors and trainees when engaging in conversations about lived experience.	
Woods and Springham (2011)	United Kingdom	To explore one person's journey (as an art therapist who	One case study, who is also the first author of the paper. The two	A repeating interview cycle approach was	AW found that, in attempting to articulate her experiences through self-	The intricacies of their methodological approach was

Author(s)	Location	Aims	Sample	Research Design and Method	Key Findings	Limitations
		became a service user on a mental health inpatient ward). The authors described the paper as an examination of the experience of one individual when faced with the prospect of using art therapy. 'AW' (the case study) has suffered from anxiety and depression while	authors had encountered each other by chance – the second author (the 'interviewer') had been working at the service where the first author ('AW') was being treated, but was not involved in her treatment in any capacity. The authors credited 'a sequence of coincidences' as leading to the writing of	adopted to interview the art therapist with lived experience of a mental health inpatient ward. The interview was conducted by an art therapist. The authors recorded their conversations about what could e learned from the	reflection, she habitually 'found herself stranded' with only a professional language to describe 'what she went through'. The researchers found the following central themes: Concrete minds: It was difficult for AW to reflect on her experiences as an inpatient, as her inner world experience at the time was	unclear, as was the approach that the second author took towards the conversation. The means by which they reached their themes was not elucidated. The study's limitations were not discussed as part of the report. Bias may have been introduced due to the

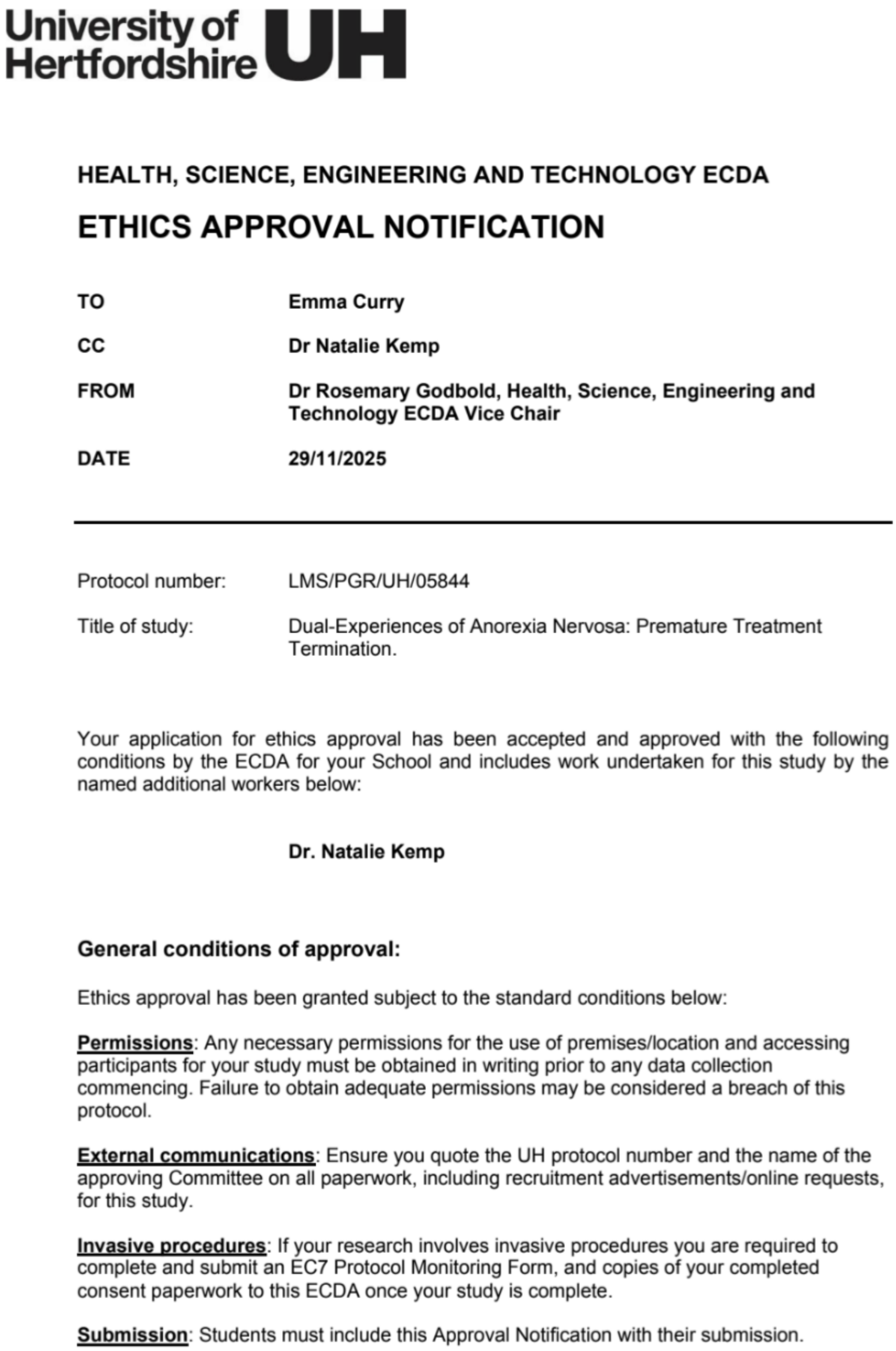
Author(s)	Location	Aims	Sample	Research Design and Method	Key Findings	Limitations
		working as an art therapist for adults with intellectual disability, and had required two informal inpatient admissions. The authors also noted that they had an additional motivation when writing the paper: to attempt to break the silence about talking about holding this	the paper. The interviewer proposed the study to AW, who agreed to it proceeding.	connections between AW's lived experience and her practice as an art therapist. Their methodology was heuristic, comprising of immersion, incubation and illumination stages.	more concrete and black and white. Concrete care for concrete minds: the comfort and difficulties encountered due to the concreteness of staff's care approaches. The waiting art therapist: the familiarity of art therapy felt anxiety provoking and unsafe as a patient.	researchers' rationale for the project.

Author(s)	Location	Aims	Sample	Research Design and Method	Key Findings	Limitations
		dual relationship with mental health difficulties.		Each central theme that they identified was organised into key experiences and learning outcomes. The researchers found that AW’s experiences did not unfold in a structured form, and that they therefore	The waiting art materials: the painful irony of encountering one’s own profession as an inpatient by feeling unable to use the materials that are part of your own professional battery. Genuinely seeking to understand: Encountering a genuine, caring nurse.	

Author(s)	Location	Aims	Sample	Research Design and Method	Key Findings	Limitations
				conducted multiple rounds of recorded conversation to facilitate AW in speaking about her experiences.	Hope: Reflections on the power dynamic between staff and patients.	

Appendix F

UH Ethical Approval



University of Hertfordshire UH

HEALTH, SCIENCE, ENGINEERING AND TECHNOLOGY ECDA

ETHICS APPROVAL NOTIFICATION

TO	**Emma Curry**
CC	**Dr Natalie Kemp**
FROM	**Dr Rosemary Godbold, Health, Science, Engineering and Technology ECDA Vice Chair**
DATE	**29/11/2025**

Protocol number:	LMS/PGR/UH/05844
Title of study:	Dual-Experiences of Anorexia Nervosa: Premature Treatment Termination.

Your application for ethics approval has been accepted and approved with the following conditions by the ECDA for your School and includes work undertaken for this study by the named additional workers below:

Dr. Natalie Kemp

General conditions of approval:

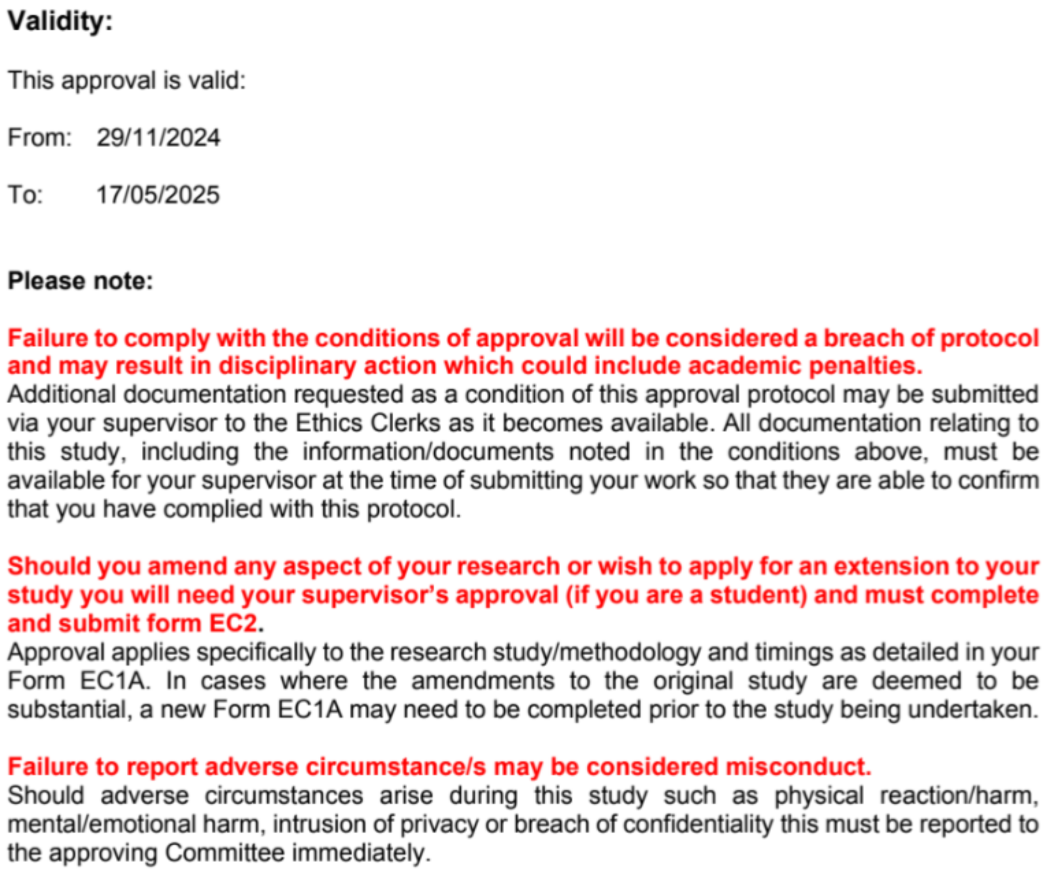
Ethics approval has been granted subject to the standard conditions below:

Permissions: Any necessary permissions for the use of premises/location and accessing participants for your study must be obtained in writing prior to any data collection commencing. Failure to obtain adequate permissions may be considered a breach of this protocol.

External communications: Ensure you quote the UH protocol number and the name of the approving Committee on all paperwork, including recruitment advertisements/online requests, for this study.

Invasive procedures: If your research involves invasive procedures you are required to complete and submit an EC7 Protocol Monitoring Form, and copies of your completed consent paperwork to this ECDA once your study is complete.

Submission: Students must include this Approval Notification with their submission.



Validity:

This approval is valid:

From: 29/11/2024

To: 17/05/2025

Please note:

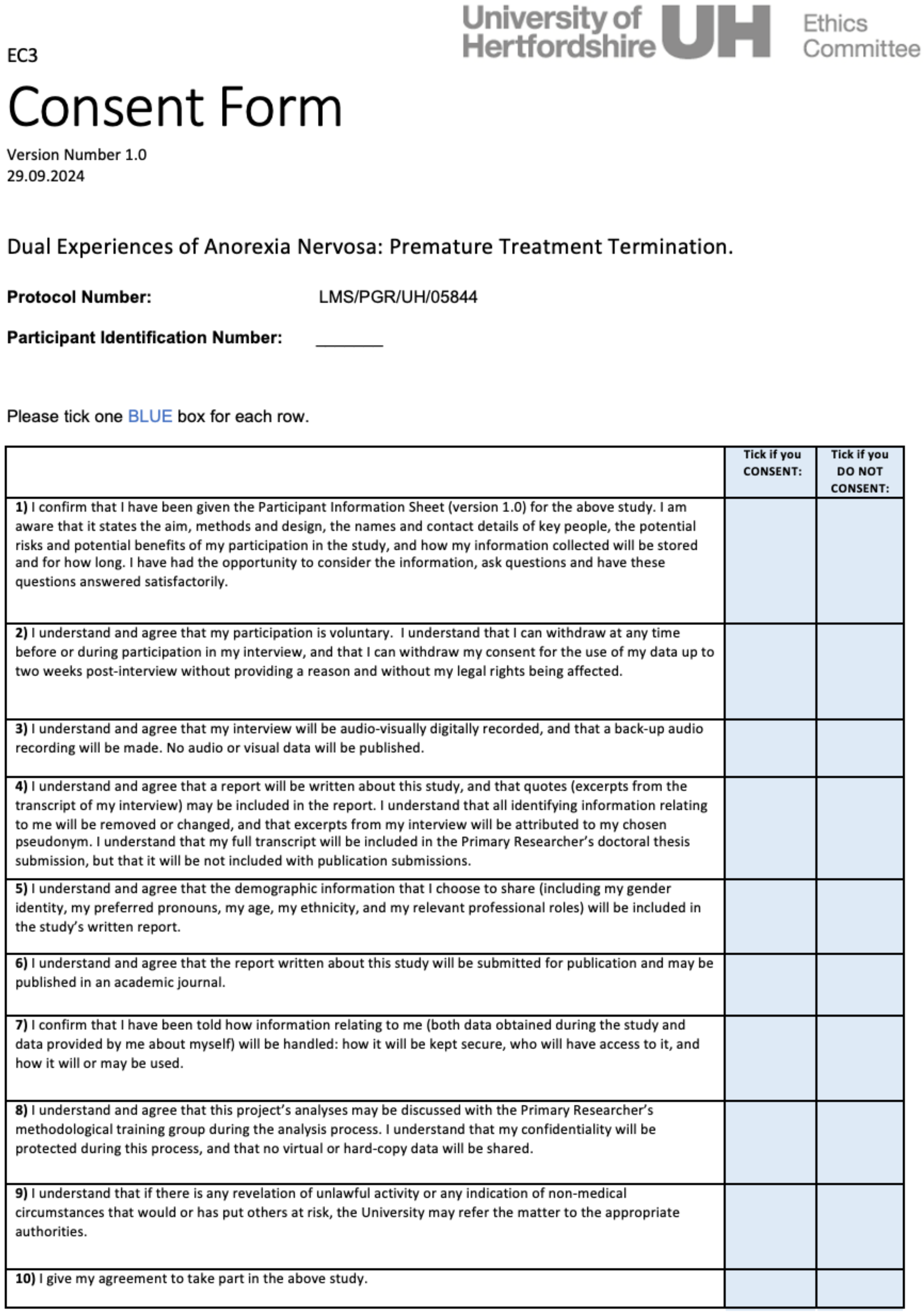
Failure to comply with the conditions of approval will be considered a breach of protocol and may result in disciplinary action which could include academic penalties.
Additional documentation requested as a condition of this approval protocol may be submitted via your supervisor to the Ethics Clerks as it becomes available. All documentation relating to this study, including the information/documents noted in the conditions above, must be available for your supervisor at the time of submitting your work so that they are able to confirm that you have complied with this protocol.

Should you amend any aspect of your research or wish to apply for an extension to your study you will need your supervisor's approval (if you are a student) and must complete and submit form EC2.
Approval applies specifically to the research study/methodology and timings as detailed in your Form EC1A. In cases where the amendments to the original study are deemed to be substantial, a new Form EC1A may need to be completed prior to the study being undertaken.

Failure to report adverse circumstance/s may be considered misconduct.
Should adverse circumstances arise during this study such as physical reaction/harm, mental/emotional harm, intrusion of privacy or breach of confidentiality this must be reported to the approving Committee immediately.

Appendix G

Consent Form



University of Hertfordshire UH Ethics Committee

EC3

Consent Form

Version Number 1.0
29.09.2024

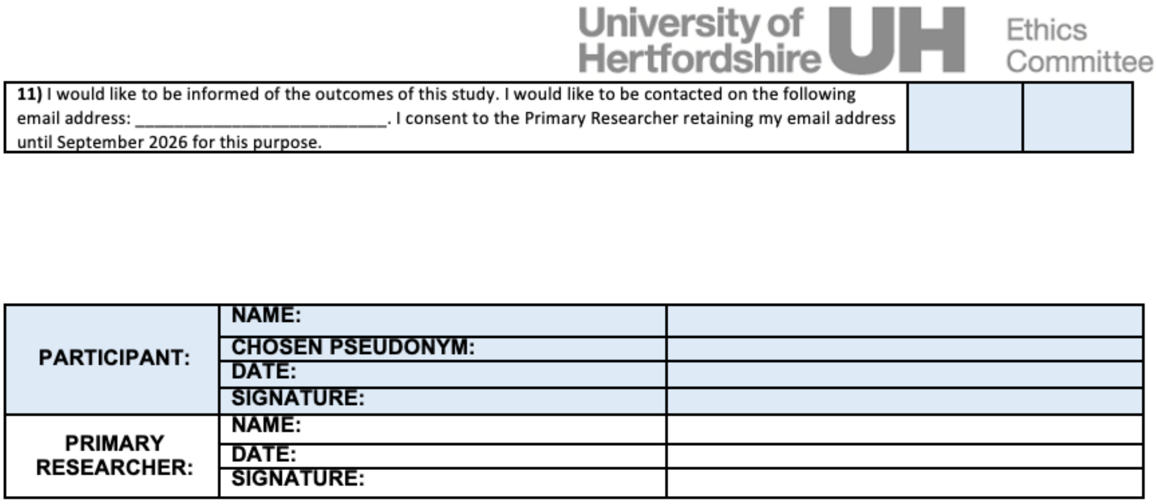
Dual Experiences of Anorexia Nervosa: Premature Treatment Termination.

Protocol Number: LMS/PGR/UH/05844

Participant Identification Number: _______

Please tick one BLUE box for each row.

	Tick if you CONSENT:	**Tick if you DO NOT CONSENT:**
1) I confirm that I have been given the Participant Information Sheet (version 1.0) for the above study. I am aware that it states the aim, methods and design, the names and contact details of key people, the potential risks and potential benefits of my participation in the study, and how my information collected will be stored and for how long. I have had the opportunity to consider the information, ask questions and have these questions answered satisfactorily.		
2) I understand and agree that my participation is voluntary. I understand that I can withdraw at any time before or during participation in my interview, and that I can withdraw my consent for the use of my data up to two weeks post-interview without providing a reason and without my legal rights being affected.		
3) I understand and agree that my interview will be audio-visually digitally recorded, and that a back-up audio recording will be made. No audio or visual data will be published.		
4) I understand and agree that a report will be written about this study, and that quotes (excerpts from the transcript of my interview) may be included in the report. I understand that all identifying information relating to me will be removed or changed, and that excerpts from my interview will be attributed to my chosen pseudonym. I understand that my full transcript will be included in the Primary Researcher's doctoral thesis submission, but that it will be not included with publication submissions.		
5) I understand and agree that the demographic information that I choose to share (including my gender identity, my preferred pronouns, my age, my ethnicity, and my relevant professional roles) will be included in the study's written report.		
6) I understand and agree that the report written about this study will be submitted for publication and may be published in an academic journal.		
7) I confirm that I have been told how information relating to me (both data obtained during the study and data provided by me about myself) will be handled: how it will be kept secure, who will have access to it, and how it will or may be used.		
8) I understand and agree that this project's analyses may be discussed with the Primary Researcher's methodological training group during the analysis process. I understand that my confidentiality will be protected during this process, and that no virtual or hard-copy data will be shared.		
9) I understand that if there is any revelation of unlawful activity or any indication of non-medical circumstances that would or has put others at risk, the University may refer the matter to the appropriate authorities.		
10) I give my agreement to take part in the above study.		



University of Hertfordshire UH Ethics Committee

11) I would like to be informed of the outcomes of this study. I would like to be contacted on the following email address: ___________________________. I consent to the Primary Researcher retaining my email address until September 2026 for this purpose.		

PARTICIPANT:	**NAME:**	
	CHOSEN PSEUDONYM:	
	DATE:	
	SIGNATURE:	
PRIMARY RESEARCHER:	**NAME:**	
	DATE:	
	SIGNATURE:	

Appendix H

Participant Information Sheet

University of Hertfordshire UH Ethics Committee

Protocol Number: LMS/PGR/UH/05844

EC6

Participant Information Sheet

Version Number 1.0 (27.09.2024)

An invitation to take part in research:

Dual Experiences of Anorexia Nervosa:

Premature Treatment Termination

Invitation to the research project

Thank you for showing interest in my research project. My name is Emma Curry and I am a Trainee Clinical Psychologist at the University of Hertfordshire. I am an eating disorder professional with lived experience of anorexia nervosa.

I am the Primary Researcher for this project, under the Lead Supervision of Dr. Natalie Kemp (Clinical Psychologist, Founder of in2gr8mentalhealth CIC, Principal Lecturer at the University of Hertfordshire) and the Secondary Supervision of Dr. Jenny Nicholson (Consultant Clinical Psychologist, Specialist Eating Disorder Unit, South Yorkshire Provider Collaborative). We also have an Expert by Experience Consultant on our research team, who has informed the development of this project. This project is in partial fulfilment of my Doctorate in Clinical Psychology. The University's regulation, UPR RE01, 'Studies

Involving the Use of Human Participants' can be accessed via the following link: https://www.herts.ac.uk/about-us/governance/university-policies-and-regulations-uprs/uprs.

What are the aims of this research?

The aim of this research project is to explore in depth how individuals with dual experience (in this case, the lived or living experience of anorexia nervosa or an anorexia-like presentation who have also held a role providing treatment or care for individuals with anorexia nervosa or anorexia-like presentations) make sense of their experiences of premature treatment termination. It is anticipated that the findings from this project may help to inform current discourses around this subject.

What would this involve?

Should you decide that you would like to go ahead and participate in this project, I would liaise with you via email to arrange a date and time for your interview. This would be held remotely via Microsoft Teams (please see the disclaimer at the end of this document). As the Primary Researcher, I will conduct your interview, and it will utilise a semi-structured format (I will have some pre-prepared questions but our conversation will be predominantly led by your experiences). Our Teams meeting will last for approximately 90 minutes, allowing us time for discussing the project, confirming your consent for participation, the interview itself, and any follow-up questions you may have. Should you wish to have a ten-minute break at any point during our meeting for any reason, we will pause accordingly. I will digitally audio-visually record our interview using the inbuilt Microsoft Teams recording feature. A backup audio recording will be made using a password-protected digital voice recorder. A transcript of your interview will be made by Microsoft Teams' inbuilt transcription feature.

What will you do with the information I give you?

All information collected is strictly confidential. Your data will be collected via your consent form, our email correspondences, and your individual semi-structured interview conducted by myself. I will ask you for personal data including your name, age, gender identity, preferred pronouns, ethnicity, and job roles relating to the care and/or treatment of individuals with anorexia or anorexia-like presentations, to provide demographic context to the experiences you share during your interview. You are at liberty to decline to share this information with me.

For this project, you will be asked to document your consent via a digital Word document. I will also audio and visually record your interview digitally using the Microsoft Teams inbuilt recording software in conjunction with a backup digital voice recording device. Your interview will be transcribed via Microsoft Teams' inbuilt transcription software. All of your data will be stored securely and separately on a university OneDrive, encrypted within separate password protected folders.

Immediately after your interview (once we have ended our Teams call), I will review Teams' transcription of your interview for accuracy by comparing the digital audio-visual recording of our conversation with the Microsoft Teams-produced transcript. Once this process is complete, I will destroy the audio-visual and backup audio recordings of your interview using multi-pass wiping technology to ensure that the files are not recoverable. Two-weeks after your interview, your interview transcript will be analysed. Sections of your interview transcript will be included in the project's written report under your chosen pseudonym, with all identifiable information pseudonymised or redacted. The full pseudoanonymised and appropriately redacted transcript of your interview will be included in the appendix of the written report that I submit in partial fulfilment of my Doctorate in Clinical Psychology at the University of Hertfordshire, in addition to any personal demographic information that you consent to sharing. I also intend to submit this project for publication in an academic journal. The version of the report submitted for this purpose will not include your full pseudoanonymised and appropriately redacted transcript, but will include pseudoanonymised and appropriately redacted excerpts and the demographic details that you consent to sharing. The transcript of your interview will not be made available to other researchers and will be used solely for the purpose of this project. It is of the utmost importance to me that your generous involvement in this project remains confidential.

All of the data you provide will be accessed by myself, my Lead Supervisor, and my Secondary Supervisor. Access to your information is also required by the University of Hertfordshire's Health, Science, Engineering and Technology Ethics Committee with Delegated Authority for the purpose of monitoring.

My analyses of data collected during this project may be discussed with my methodological training group, but all discussed data will have been previously pseudoanonymised.

Your data (excluding that which will have already been destroyed as previously mentioned during the research process) will be retained and stored safely, securely, and separately, until completion of the project (expected completion date is 25th September 2025). If you choose to be appraised of outcomes from the project (including publication), you will be asked to consent to your email address being retained for a further year in order to honour this request.

For further information about use of your personal data and your data protection rights, please contact the university's Data Protection Team: dataprotection@herts.ac.uk.

How will you use this information?

The results of this project will be written in a report in partial fulfilment of my Doctorate in Clinical Psychology. The research will also be written up for submission to peer-reviewed academic journals and conferences so that others can learn from your experiences. Both will contain pseudoanonymised excerpts from your interview and any personal demographic information you consent to being shared.

Are there any situations whereby something I tell you will be shared outside the context of this project?

Disclosure of any personal information from the interview would only occur in exceptional circumstances, such as if you shared information that indicated you may be a risk to yourself or others.

What are your choices about how your information is used?

- **You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.**
- **We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.**

Are there any potential benefits in taking part?

There are no direct benefits for taking part, but I hope to provide a space in which you can share your experiences of premature treatment termination and have your voice heard.

Are there any potential risks in taking part?

Although I hope you will have a positive experience of your interview, the sensitive subject matters we explore relating to your personal experiences may evoke difficult feelings or leave you feeling distressed. I will do my very best to ensure that you feel as heard and comfortable as possible during your interview, and that I conduct your interview with the utmost sensitivity. Aspects of your interview that are included in my final report will be attributed to your chosen pseudonym, and any parts of the interview that might enable you to be identified will either be pseudonymised or will not be included. If you meet this project's inclusion criteria but find this topic deeply distressing, I would kindly ask that you prioritise your own wellbeing and not participate.

Should your participation in this project evoke difficult feelings for you or leave you feeling distressed, I would strongly encourage you to contact one of the UK-based services detailed below:

BEAT Eating Disorders Charity

Access: 365 days access, Weekdays: 9am-8pm, Weekends and Bank Holidays: 4pm-8pm

Call: 0808 801 0677

Email: help@beateatingdisorders.org.uk

NHS 111

Access: 24 hours a day, 7 days a week

Call: 111

Email: 111.nhs.uk

Samaritans

Access: 24 Hour

Call: 116 123

Email: jo@samaritans.org

What happens after the interview?

Following the interview, you will have no further involvement in the study. You will be given a debrief form that outlines next steps and shares the contact details for relevant support networks should you wish to access support.

What happens if I agree to take part but then later change my mind?

You can withdraw from the interview at any time point, including during the interview and up to 14 days after the interview. You can withdraw for any reason and you do not have to share your reason with me. Withdrawal from the project would have no impact on your legal rights.

Who is in the research team?

Name	**Role**	**Email**
Emma Curry	Primary Researcher Trainee Clinical Psychologist The University of Hertfordshire	ec22abq@herts.ac.uk
Dr. Natalie Kemp	Primary Supervisor Clinical Psychologist Principal Lecturer The University of Hertfordshire	n.kemp4@herts.ac.uk
Dr. Jenny Nicholson	Secondary Supervisor Consultant Clinical Psychologist South Yorkshire Provider Collaborative	jenny.nicholson@nhs.net

Our research team also contains an Expert by Experience Consultant, who would like to remain anonymous.

What do I do if I am interested in taking part?

1. Participation is entirely voluntary, so I would first encourage you to **take some time and space to think about whether you would like to take part**. If you have any questions, or would like more information, please email me (address below).

2. If you decide you would like to take part, please contact Emma: ec22abq@herts.ac.uk

Please be aware that I sadly cannot guarantee that all those who apply to take part will be interviewed.

This research is being conducted as part of my Doctorate in Clinical Psychology, sponsored by the University of Hertfordshire. The Research Team work in accordance with the British Psychological Society's professional code of conduct including ethical practice.

Although we hope it is not the case, if you have any complaints or concerns about any aspect of the way you have been approached or treated during the course of this study, please write to the University's Secretary and Registrar at the following address:

Secretary and Registrar
University of Hertfordshire
College Lane
Hatfield
Hertfordshire
AL10 9AB.

Microsoft Teams Disclaimer:

Our interview will be conducted via Microsoft Teams, which operates as a processor for any personal data exchanged. In common with other ‘free’ web services, it will be your responsibility to review their Privacy Policy and Terms and Conditions. You will be under no obligation to accept them. Please note, however, that the acceptance of the terms and conditions of Microsoft Teams (or similar online service) forms a contract between you and that company, independent of the University of Hertfordshire. Because you will be transacting with your personal information, please familiarise yourself with Microsoft Teams’ Privacy Policy and only proceed with arranging an interview if you are comfortable with the information that Microsoft Teams captures and what their company can do with it.

I will utilise my university Microsoft Teams account for our meeting. Our meeting will be password protected and I will share the password with you by email. The audio-visual recording of our interview along with the transcript will initially be stored on the Microsoft Teams Server. At the end of our meeting, once the recording and transcript have been finalised, both will be downloaded from Microsoft Teams into separate, secure folders on the university OneDrive. The recording and transcript will then be deleted from Microsoft Teams.

THANK YOU FOR CONSIDERING PARTICIPATING IN THIS PROJECT.

Appendix I

Debrief Sheet

Ethics Committee

Protocol Number: LMS/PGR/UH/05844

Debrief Sheet

Version Number 1.0 (27.09.2024)

Dual Experiences of Anorexia Nervosa:

Premature Treatment Termination.

A huge thank you!

Thank you so very much for taking part in this study and for sharing your experiences with me. This study is focused on the dual experiences of individuals such as yourself: individuals with lived/living experience of anorexia nervosa or an anorexia-like presentation and premature treatment termination who have provided treatment or care for individuals with anorexia nervosa or anorexia-like presentations. It is hoped that the findings from this study will inform narratives around this phenomenon and add the voice of dual experience to discourses around this subject.

What happens now?

Your digital interview recordings were pseudonymised at the point of data collection (our interview). Your interview transcription will now be reviewed in conjunction with your interview recording in order to ensure that the transcription is accurate, and it will be redacted to ensure your confidentiality is upheld. In the two weeks following your interview, you may still choose to withdraw your consent for the use of your data. If this is the case, please contact me via the email address **'ec22abq@herts.ac.uk'**. After this two-week period, your data will be analysed and can no longer be withdrawn.

What if I need to speak with someone following interview?

I hope you found the interview to be a positive experience. If, however, the experience has brought up difficult feelings or has left you feeling distressed, I would encourage you to contact one of the services listed below:

BEAT Eating Disorders Charity

Access: 365 days access, Weekdays: 9am-8pm, Weekends and Bank Holidays: 4pm-8pm

Call: 0808 801 0677

Email: help@beateatingdisorders.org.uk

NHS 111

Access: 24 hours a day, 7 days a week

Call: 111

Email: 111.nhs.uk

Samaritans

Access: 24 Hour

Call: 116 123

Email: jo@samaritans.org

What do I do if I have any questions?

Please do not hesitate to contact me via the email address **‘ec22abq@herts.ac.uk’** should you have any questions pertaining to the study or your involvement with it.

Thank you again for your time and for sharing your experiences; your input has been invaluable.

Appendix J

Research Distress Protocol

Developed based upon Whitney and Evered (2022)

Version Number 1.0 (29.09.2024)

Distress

A participant informs the researcher that they are experiencing stress or distress during their interview. Alternatively, a participant exhibits behaviours that may be suggestive of experiencing stress of distress during the interview.

Researcher responds by offering to pause the interview. If the participant feels their distress is manageable and wishes to continue, the interview may proceed. If not, see first line response.

First Line Response

The researcher will:

1. Pause the interview.
2. Ask after the participant's well-being and provide space for them to verbalise their distress if they would like to/feel able to.
3. Compassionately ask whether the participant would like to continue with their interview of prefer to stop.

Review

If the participant feels able and would like to continue with their interview, the researcher may resume the interview.

If the participant does not feel able to continue or does not wish to continue or feels their distress continuing to grow, follow second line response.

Second Line Response

The researcher will stop the interview and offer to provide contact details for services that can offer them support (service details are also listed on the Participant information Sheet). Where appropriate, the participant will be encouraged to contact their GP or their local A&E department.

The researcher will inform their Principal Supervisor of the participant's distress immediately following the Teams Meeting with the participant (in accordance with the participant's signed consent form).

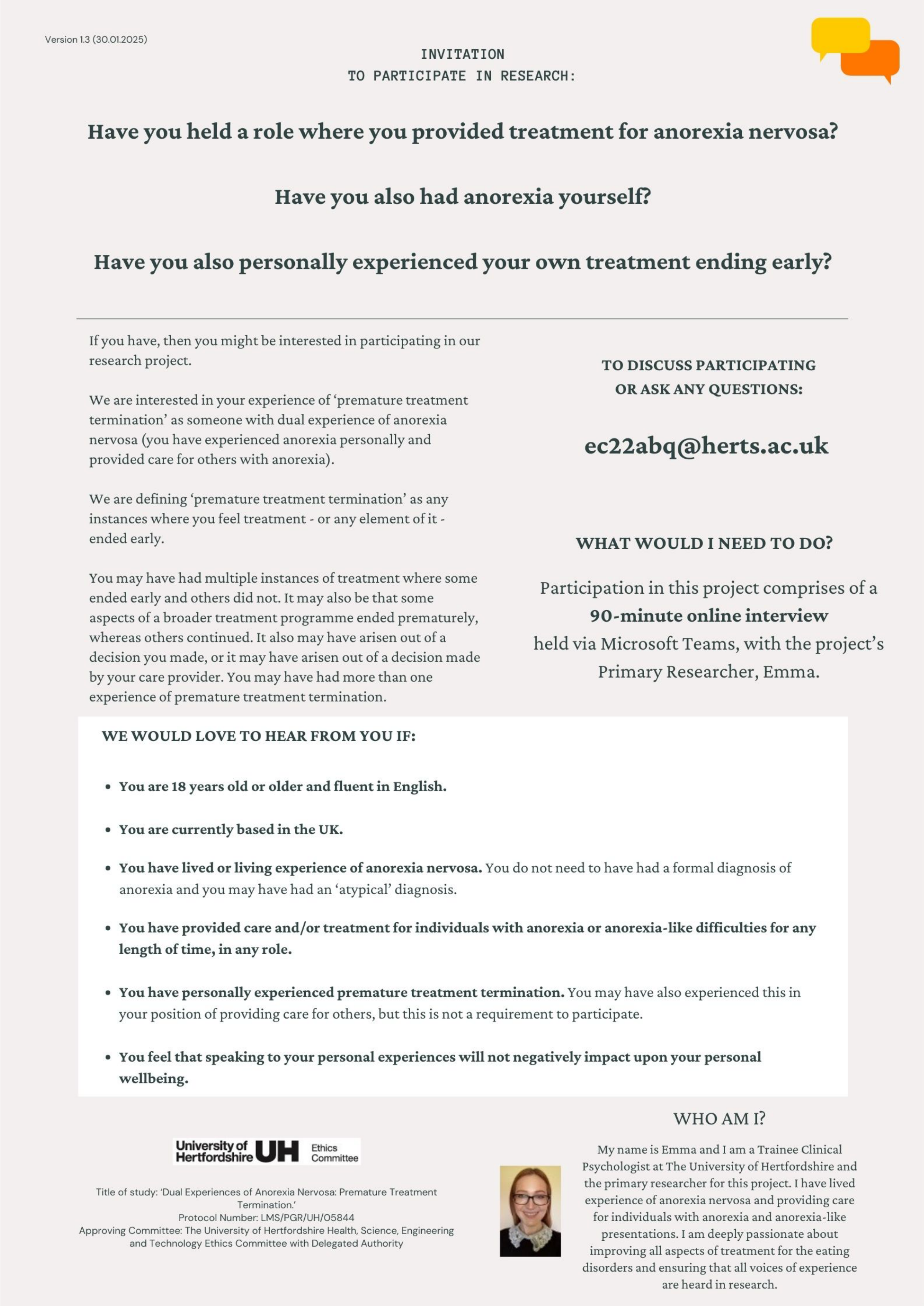
Follow-up

The researcher will provide a follow-up phone call (with the participant's consent to check-in and see how the participant is feeling now that the interview is completed.

If appropriate and if requested by the participant, the researcher can offer to reschedule the interview for another time.

Appendix K

Recruitment Poster



Version 1.3 (30.01.2025)

INVITATION
TO PARTICIPATE IN RESEARCH:

Have you held a role where you provided treatment for anorexia nervosa?

Have you also had anorexia yourself?

Have you also personally experienced your own treatment ending early?

If you have, then you might be interested in participating in our research project.

We are interested in your experience of 'premature treatment termination' as someone with dual experience of anorexia nervosa (you have experienced anorexia personally and provided care for others with anorexia).

We are defining 'premature treatment termination' as any instances where you feel treatment - or any element of it - ended early.

You may have had multiple instances of treatment where some ended early and others did not. It may also be that some aspects of a broader treatment programme ended prematurely, whereas others continued. It also may have arisen out of a decision you made, or it may have arisen out of a decision made by your care provider. You may have had more than one experience of premature treatment termination.

TO DISCUSS PARTICIPATING OR ASK ANY QUESTIONS:

ec22abq@herts.ac.uk

WHAT WOULD I NEED TO DO?

Participation in this project comprises of a **90-minute online interview** held via Microsoft Teams, with the project's Primary Researcher, Emma.

WE WOULD LOVE TO HEAR FROM YOU IF:

- **You are 18 years old or older and fluent in English.**
- **You are currently based in the UK.**
- **You have lived or living experience of anorexia nervosa.** You do not need to have had a formal diagnosis of anorexia and you may have had an 'atypical' diagnosis.
- **You have provided care and/or treatment for individuals with anorexia or anorexia-like difficulties for any length of time, in any role.**
- **You have personally experienced premature treatment termination.** You may have also experienced this in your position of providing care for others, but this is not a requirement to participate.
- **You feel that speaking to your personal experiences will not negatively impact upon your personal wellbeing.**

Title of study: 'Dual Experiences of Anorexia Nervosa: Premature Treatment Termination.'
Protocol Number: LMS/PGR/UH/05844
Approving Committee: The University of Hertfordshire Health, Science, Engineering and Technology Ethics Committee with Delegated Authority

WHO AM I?

My name is Emma and I am a Trainee Clinical Psychologist at The University of Hertfordshire and the primary researcher for this project. I have lived experience of anorexia nervosa and providing care for individuals with anorexia and anorexia-like presentations. I am deeply passionate about improving all aspects of treatment for the eating disorders and ensuring that all voices of experience are heard in research.

Appendix L

Interview Schedule

Version Number 1.1(15.11.2024)

1. **Start of Interview**

- Initial connections
  - Thank you for joining me today.
  - Are you in a safe and private space?
- Speak to the purpose of the interview and the Primary Researcher's role.
  - Today is about your experiences, and I'm truly honoured to be in the position to learn from you.
  - I appreciate I am a stranger in this privileged position of getting to learn about your experiences. To let you know a little about who you are giving this privilege to, I am Trainee Clinical Psychologist who is passionate about the care of individuals experiencing an eating disorder as well as mental health and lived experience advocacy. I also consider myself dual-experienced: I have both had anorexia and provided care for others with anorexia. My Principal Supervisor is Dr. Natalie Kemp, the founder of in2gr8mentalhealth CIC, and advocate for destigmatising and supporting the lived and living experiences of mental health difficulties in mental health professionals, a clinician with her own lived experience and Principal Lecturer at the University of Hertfordshire. My Secondary Supervisor is Dr. Jenny Nicholson,

a Consultant Clinical Psychologist who specialises in eating disorder treatment. Our team also has the privilege of an Expert by Experience Consultant – they have chosen to remain anonymous.

- Connect
  - My preferred pronouns are they/them. Do you have preferred pronouns?
  - If you feel comfortable to do so, I'd love for you to tell me about yourself.
  - What interested you in this project?
  - Which terminology would you prefer we use today to refer to anorexia/anorexia-like presentations and the people who experience them?
  - Touch upon working language for the study.

2. INVITING IN THE PARTICIPANT'S CONTEXT:

Lived Experience of Anorexia/Anorexia-like presentation and being a professional with lived experience

- To begin with, would you mind telling me a little about your eating disorder/eating difficulties?
  - What is/was your experience of your AN/AN-like presentation like?
    - What do/did these experiences mean to you?
  - What is/was your relationship with your AN/AN-like presentation?
    - Why do you think that is?
  - What kind of treatments/professionals did you experience?
    - What sense do you make of those experiences?

        - How do you feel about those experiences?

- Please could you tell me a little about your role in caring/treating individuals with AN/an AN-like presentation?
    - What do you feel led you to this/these role(s)?
    - Why do you think that is?
    - What does this feel like?

3. INVITING IN THE RESEARCH PHENOMENON:

Lived Experience of Premature Treatment Termination?

- Would you mind telling me a little about your experiences of premature treatment termination?
    - What kind of treatment are/were you having?
    - What kind of setting are/were you receiving treatment in?
    - What thought process do/did you have?
    - Which factors contributed to this decision?
    - How does/did this feel?
    - What was the impact of this?
    - How does it feel looking back upon those experiences?
    - Why do you think that is?
    - What effect do you think that/these experience(s) had for you?

4. **Professional Experience of Premature Treatment Termination?**
    - Would you mind telling me a little about your professional experiences of premature treatment termination for anorexia nervosa/AN-like presentations?
        - What did that feel like?
        - Why do you think that was?
        - What sense do you make of those experiences? /What do you feel that meant?

5. **ENDINGS:**
    - Is there anything you'd like to tell me that I haven't asked you about in our interview today?
    - How did sharing your experiences feel?
    - Thank you for your time.
    - Share Debrief Form.
    - Review of next steps.

Appendix M

Example of Initial Coding during IPA Analysis

Exploratory Notes Coding Key:
Descriptive
Linguistic
Conceptual

Initial Experiential Statements	**Interview Transcript**	**Exploratory Notes**
Anorexia sneaking up on her and her family. (p.14) Anorexia being unknown and difficult to recognise. (p.14) Anorexia interrupting her life. (p.14)	**Participant** Yeah, of course. Erm, so I was first… I first started struggling with anorexia… unbeknownst to me and my family, when I was…16? So it was my… final year of high school and it was literally coming towards the end, erm… And… long story short, I didn't finish the year because I was too unwell with the eating disorder. And it wasn't recognised as such until it got to the point where I was not eating anything and… the GP	'struggling with anorexia'. 'unbeknownst' – languaging as though from an epic tale. Formal. As though anorexia crept up on Serena and her loved ones. It was an anonymous presence – as yet without a name. Anorexia as a 'long story'. Emphasis, 'literally'. Anorexia interrupted her education. Anorexia was unrecognised until she stopped eating altogether.

Anorexia being unrecognisable until you stop eating altogether. (p.14) Not being underweight enough for professionals to intervene. (p.14) Her parents fighting for inpatient treatment. (p.14) The severity of her struggles going unseen and unheard. (p.14) Failing to be unwell enough for specialist eating disorder treatment. (p.14) Being categorised by her weight. (p.14)	recognised the way I was deteriorating, but I wasn't quite at the point where I was *severely* underweight. I'd lost significant weight in a very quick period of time, but I wasn't severely underweight. But my mum and dad - particularly my dad - fought for me… to go into an inpatient treatment because I already have low blood pressure. So the fact that I wasn't eating wasn't going to be doing my body any favours and I was prone to fainting very quickly on… when I started restricting. But where I'm located it there was no eating disordered service specifically, erm… And I think also because of my criteria at the time, I didn't meet the threshold for an eating disorder… eating disorder service. Erm, because I wasn't… *(gestures to indicate air quotes)* 'appropriate' weight category. So I went into a adolescence mental health inpatient service, so that looked at *every* mental	Her GP noticed she was rapidly deteriorating but her weight loss was not severe enough to trigger onward referral to a specialist service. This is now a criteria for the diagnosis of anorexia, but may not have been at the time for Serena. Parents 'fought' – the battle had begun with people fighting on her behalf. The battle began with recognition of the illness. Existing medical complications adding to increased risk – still not considered to meet clinical threshold for onward referral. 'not doing my body any favours' – sounds like what an impressed parent might say to a child. Who is Serena potentially berating here? No local specialist service. 'meet threshold' – clinical language. Threshold also the entry to a house – she wasn't welcome? 'appropriate' for anorexia – a paradoxical sentiment. 'Appropriate' – as though there's a right and a wrong. Serena sees the fault in this sentiment. Like failing to gain entry into an exclusive club. Also, you aren't ill enough to need/deserve this. Admission to a general CAMHS inpatient facility. Other young people with

Others’ anorexia being noticeable to her. (p.15) Recognising others who were also facing battles against anorexia. (p.15) Battling anorexia without support despite being in treatment. (p.15) Treatment feeling like a physical location that she was placed in which lacked psychological and practical support. (p.15) Feeling uncared for by staff. (p.15) Treatment feeling procedural and impersonal. (p.15)	health disorder. So it wasn't specifically for eating disorders. There was a few other inpatients that had eating disorders, but it was never really talked about what they had, but it seemed quite apparent they had what I was struggling with, erm… But they were… more underweight than I was, erm… And so they must have faced similar battles. But… they… didn't give me any sort of… support. Psychologically. Practically. Really it was, I'm here. I'm away from my family and you need to start eating three meals a day. With the snacks. And… they would sit you there and wait until you'd eat them or not. They'd give you an ensure drink. So… they didn't really explain really what this meant, erm… and why… what… like obviously just completely battling against everything I was doing. So it just felt that this pure punishment that I've been taken	eating disorders there, but no shared eating disorder treatment. Eating disorders being unnamed, unspoken. Culture? Shame? Hesitation – perhaps out of recognition that what she said might be interpreted as an ‘anorexic’ thought? Or perhaps an intrusion of her past anorexic voice? ‘Battles’ again – repetition. She perceives others to be locked in battle, too. No practical or psychological support – just expectations. Emphasis – full stops, succinct. Switching voices – hers to the professionals’. A sense of uncaringness from staff – you could eat them or you could not. Procedural, disconnected. Dispassionate. The gate-keeping of knowledge. Why does Serena think this happens? A battle with staff. Fighting on all fronts, except, perhaps, anorexia at this stage? To Serena, the battle was obvious, clear.

Feeling deeply punished by being taken away from her family and her understanding of herself being withheld by staff. (p.15) Being discharged because her eating had somewhat improved. (p.15) Fighting her way out of hospital to protect herself through compliance by eating. (p.16) Feeling traumatised through witnessing the distress of other patients. (p.16) Being discharged from an inpatient setting with no further support. (p.16) Deteriorating due to a lack of support for two and a half years. (p.16) Professionals neglecting basic responsibilities. (p.16)	away from my family and now I've got to eat and there's no further, like, understanding of why I was doing what I was doing? So… I was there… for five and a half months? Erm… I had bouts where I could go out and spend time with my family, but I was discharged because… I was eating better. Kind of. Basically I fought my way out because it was a really unpleasant and somewhat… small 't' trauma because of what I witnessed in there as well, it was… not appropriate for somebody that had had an eating disorder of any sort to see somebody with psychosis and self-harm actively in front of you. When that's not something I was suffering with, erm… But then I came out with no additional support put in place, so from there for the next… two and a half years to three years? No, sorry. Yeah, two and a half years. I deteriorated more and more and more	'Pure punishment' – alliterative emphasis. 'Taken' – a sense of kidnapping, almost. Force. Lack of choice. A sense of hollowness – no understanding gained. Emptiness. 'Bouts' – like an illness, an episode. Discharged because she was eating better, but Serena was not feeling better. Discharged because 'kind of' eating 'better' – suggests Serena was unconvinced by this rationale. 'I fought my way out' – more fighting against staff. Protecting herself from further harm. Inpatient treatment was traumatic. Being a witness to the distress of others. Switching between 'I' and 'you' – needing distance from this experience. 'Came out' – echoes of imprisonment. No support was put in place for Serena post-discharge for another 2.5 years. Deterioration. Emphasis on the duration without support. The duration that her anorexia was allowed to deteriorate. Emphasis on how far she deteriorated without no one

Feeling disregarded by professionals. (p.16) Being told that she needed to lose more weight in order to access treatment. (p.17) Punishing herself by losing more weight. (p.17)	with no help, erm… Aside of… a… I don't even know what she was called, to be honest, but I would assume knowing what I know now… possibly like a community psychiatric nurse, *possibly*? Erm… never really explained her job title. We'd meet once a week towards the latter end before I was an inpatient again. Just checking in with me, seeing how I'm doing. Am I eating enough, doing a bit of colouring…. creativity work, just a bit of - tiny bit of emotional support. Erm… and one day I- she was *(laughs)*… she checked my weight and she said she showed me a graph and went, this is the BMI chart, erm… You're here at the moment *(points to a point on an imaginary graph)*, so I was underweight and she then said, but in order to go to inpatient treatment, you need to be here *(gestures to a point much lower down the imaginary graph)*. So she literally told	stepping in/stepping up? Serena's health deteriorated to anorexia due to the absence of meaningful help. She didn't direct class the CPN as 'help'. The CPN is an afterthought for Serena. The gate-keeping of information by professionals. Neglectful? Deliberately withholding? Dismissive, disregarding. Left with uncertainty. Stark contrast between Serena describing her traumatic experiences and the CPN's offering of colouring. Laughter – disbelief? Locating Serena through her weight – weight centric. Not unwell enough to receive intensive, specialist support. The CPN told Serena that she needed to lose more weight in order to get support. This became her goal.

Starving herself to death. (p.17) Wanting a painful death. (p.17) Her father fighting for her life. (p.17) Feeling unwanted and uncared for due to her weight (p.17) Her local MP taking over the fight to get her access to treatment. (p.17) Feeling threatened by sectioning to ensure compliance. (p.17)	me, in a nutshell, I needed to lose more weight. So that is exactly what I did. And I just pushed and pushed and pushed because I was… already punishing myself, so what was the point in staying where I am? I just kept going and I didn't see there was anywhere… I didn't realise what I was doing, but essentially I was starving myself to death and that's ultimately what I really wanted. I wanted a painful end. Erm… and all this time my - bless my dad. He fought for me. Even up to that point, to try and get me back in inpatient, but nobody would take me. Nobody would, because I wasn't meeting that criteria. He wrote to the local MP and the local MP got back to him because he had personal experience within his family, erm… and fought for me to get a place somewhere else in the county. It was a lo… it was further away, but it was a specialist eating	Very matter of fact, here. She received an instruction and acted upon it. Repetition for emphasis, 'pushed'. A sense of exhaustion, desperation. Anorexia as self-punishment. Hopelessness. Serena lacked insight at the time – gained with hindsight. 'I was starving myself to death and that's ultimately what I wanted. I wanted a painful end.' Repetition of 'wanted'. Hopelessness. Death became the ultimate goal. Her dad was continuing to fight to get her access to treatment. 'Nobody would take me' – rejection for failing to meet criteria. Unwanted, uncared for. Rejected. The local MP took up the fight to get Serena access to the treatment she needed. Everyone was having to fight for Serena's life when professionals weren't. She ended up going farther afield for specialist treatment.

Witnessing and feeling responsible for the suffering that anorexia caused her family. (p.18) Needing longer treatment due to how physically unwell she had become in the absence of meaningful support. (p.18) Feeling physically supported but psychologically neglected in inpatient treatment. (p.18) Only her body being cared for. (p.18)	disorder service, erm… And I was told that if I didn't come in now voluntary, it would be under section. So I said I will come and voluntarily because I didn't want to be sectioned at that point… And I kind of realised the suffering everybody had within the family, erm… And it was more set up for… eating disorders because it was an eating disordered specialist service. And I was there for 6 1/2 months, umm… Because I was more malnourished and more underweight, so I needed a lot longer to recover, umm… But again, I found it was very supportive physically in that, you know, they kept checking our observations on a regular basis, made sure we were having, you know, gentle refeeding and, you know, a bit kind of like group support, but there was no further psychological support when I got to a more, I suppose, a healthier place weight wise to maybe take	A rapid escalation from 'nobody would take me' to we will take you by law if you don't attend voluntarily. Threatening. Feeling responsible for her family's suffering? But 'the family' – a sense of separation, detachment. Serena had become increasingly malnourished and underweight in the time it took for all of those fighting for her to get her access to specialist treatment. The treatment protected her body but neglected her psychologically. The specialist inpatient setting was supportive physically but psychological support continued to be lacking. 'gentle', her body was cared for, prioritised. Still no psychological support even once she was physically well enough for it to be indicated. Nobody helped her to understand her experiences. No one helped Serena to understand what was happening to her and why she had become unwell. Can you battle

Feeling ill-equipped to battle anorexia due to not understanding its cause. (p.18) Clinicians discharging her once she reached a 'healthy weight range'. (p.18) Being discharged while still vulnerable without support again. (p.19) Feeling hopeless following discharge. (p.19) Being discharged from treatment without coping. (p.19)	things in more cognitively. Erm… which I thought potentially would start to happen is like nobody at any stage is kind of sat me down and talked me through a bit more as to why this was happening. Why had I, erm… turned in to restrictive eating? And why was it still prolonged? What was it that was going on underneath? Erm… so I was recovered – recovering, should I say? With my weight management and they got… I got to a point where it's within a healthy range was maintaining and they agreed discharge. But because I was… erm… discharged… erm… from part of the county that I wasn't living in to another part of the county, they had different, erm… treatments, because there was nothing where I was living.	something if you don't understand the enemy yourself? 'Turned in to' – turning towards. Needing anorexia to step in and help her cope. A relationship she allowed in? In the process of recovery – ongoing. Precarious, perhaps, and vulnerable? No post-discharge support because of falling between different regions. Back to nothing. Like how it started. A sense of hopelessness. She hadn't been equipped to manage her eating disorder independently. The inpatient unit had taken responsibility away from Serena but did not teach her how to take this back. Repetition of 'nothing' – emphasis of the care void. Abandonment?

Appendix N

Example of A Participant's Initial Experiential Statements

Feeling reduced to one word, 'anorexia'. (p.4)

Anorexia being linked with feminine identity. (p.4)

Clinicians not explaining anorexia to him. (p.4)

Anorexia feeling deeply embedded and in need of being uprooted. (p.4)

Services offering food and antidepressants as opposed to challenging anorexia. (p.4)

Feeling misaligned with anorexia. (p.5)

Recovery being still hearing anorexia but being able to ignore it. (p.8)

Feeling trusted by others with anorexia because of his lived experience. (p.14)

Understanding the living experiences of others with anorexia through his own experiences. (p.14)

Services failing to uproot his anorexia. (p.15)

Doing everything that services told him would lead to his recovery from anorexia but his anorexia remaining intact. (p.15)

Treatment feeling like a meaningless tick box exercise that paves the way for discharge. (p.15)

Discharge gifting Kevin's anorexia free rein once again. (p.15)

Believing he was recovered because he had been discharged from services. (p.15)

Treatment for anorexia focusing on a target weight rather than uprooting the anorexia. (p.15)

Suffering for many, many years as a result of the discharge. (p.16)

His life and time being stolen by anorexia. (p.16)

Feeling abandoned to anorexia. (p.16)

Trusting services entirely, only to be abandoned to his anorexia. (p.16)

Losing many years of his life due to clinicians' actions. (p.16)

Feeling gripped by anorexia. (p.16)

His trust being stolen by services. (p.16)

Discharge leaving him feeling unworthy of help. (p.16)

Anorexia denying its existence. (p.17)

Services' actions costing his trust in everyone. (p.17)

Becoming used to a painful life. (p.17)

Resigned to a life with anorexia. (p.17)

Feeling dominated by anorexia. (p.17)

Life passing him by. (p.17)

Being a little boy inside a female body. (p.18)

Wanting to be a boy but being unable to work out how to be. (p.18)

Over-exercising returning his male body to him. (p.19)

Over-exercising taking over his life. (p.19)

Restricting to find his male body again. (p.19)

Burning away his body’s femaleness. (p.20)

Anorexia almost costing his kidney. (p.20)

Living with anorexia without knowing. (p.20)

Anorexia feeling like a living death. (p.20)

Rationalising keeping anorexia. (p.20)

Being deceitful to protect anorexia. (p.20)

Being gripped by anorexia. (p.21)

Feeling isolated with anorexia. (p.21)

Anorexia fighting him back. (p.21)

Family intervening to try and fight his anorexia. (p.21)

Asking for help from the eating disorder service. (p.21)

Being open and honest with the eating disorder service. (p.21)

Desperately pleading services to allow him to keep his male body. (p.22)

Being unseen, unheard and dismissed by eating disorder services. (p.22)

Gender dysophia being dismissed by eating disorder services. (p.22)

Still trusting in services and wanting help. (p.22)

Desperately pleading to be a boy. (p.22)

Learning about weight loss rather than himself. (p.22)

Grieving the loss of himself. (p.22)

Clashing with his therapist. (p.23)

Being unheard by his therapist. (p.23)

Scales being in the way of treatment. (p.23)

Being divided into diagnoses that were not allowed to exist together. (p.23)

Living a life of referrals. (p.23)

Being gripped, trapped by anorexia while anorexia was free to roam. (p.23)

Left to a painful, unchanging daily routine. (p.23)

Anorexia going unchallenged in treatment. (p.24)

Just existing within the world. (p.24)

Feeling lonely, guilty and in pain. (p.24)

Anorexia being company and ‘becoming everything’. (p.24)

Believing in clinicians. (p.25)

Trusting clinicians to know how to support him. (p.25)

Fearing weight restoration and the return of femaleness. (p.25)

Anorexia being his only hope to be the man he was. (p.26)

Giving himself over to clinicians. (p.26)

Trusting clinicians. (p.26)

Hoping clinicians would understand and know how to help. (p.26)

Being held back from becoming the man he is by anorexia. (p.26)

Existing within a diagnostic binary. (p.26)

Feeling bitter, angry and let down. (p.26)

Not being allowed to struggle in the way he did. (p.27)

Locating the blame. (p.27)

Blaming society and the eating disorder service. (p.27)

Antidepressants being pushed onto him. (p.28)

Distressed at being silenced. (p.28)

Feeling like just a ‘job’ to staff. (p.28)

Being treated like a ticky box by staff. (p.28)

Eating disorder services' focus on weight playing into anorexia's hands. (p.28)

Staff trying their best within the limitations inherent to their roles within the service. (p.29)

Staff as doing what they are told. (p.29)

Weight gain in treatment for anorexia being a tick box for staff. (p.30)

Being reduced to what you ate. (p.30)

Feeling united with his fellow inpatients. (p.30)

Feeling disrespected by the superiority of staff. (p.31)

Us. Vs. them, patients vs. staff. (p.31)

Peers as keeping each other's identities alive. (p.31)

Treatment feeling like being regulated. (p.31)

Allowing himself to feel resentful and angry. (p.31)

Feeling unheard by his therapist. (p.31)

Fearing the return of anorexia while not recognising its ongoing presence. (p.32)

Staff's actions leaving him emotionally numb, empty. (p.32)

Failed by services. (p.32)

Horrific treatment in services. (p.32)

Looking back on his relationships with his inpatient peers with a profound fondness. (p.32)

Feeling neglected in the inpatient unit, and sad and angry about this. (p.32)

Feeling a deep sadness for his peers. (p.32)

Deeply damaged by his therapist. (p.32)

Being harmed for being the first patient of a newly qualified and inexperienced therapist. (p.32)

Feeling angry with the therapist. (p.32)

His difficulties being trivialised by the therapist. (p.32)

Losing a part of himself. (p.32)

Disbelief at the actions of his therapist. (p.32)

His body reflecting the harm caused by services physiologically. (p.32)

Being reduced to a physical manifestation of the harm caused by services. (p.32)

Being failed by specialist eating disorders services, along with the peers that they remember so dearly. (p.36)

Anorexia was not seen or understood correctly by the service. (p.36)

Treatment feeling like being re-fed and then having the door closed on you. (p.36)

Feeling deeply relieved when clinicians finally recognised him as a whole and allowed his difficulties to coexist. (p.37)

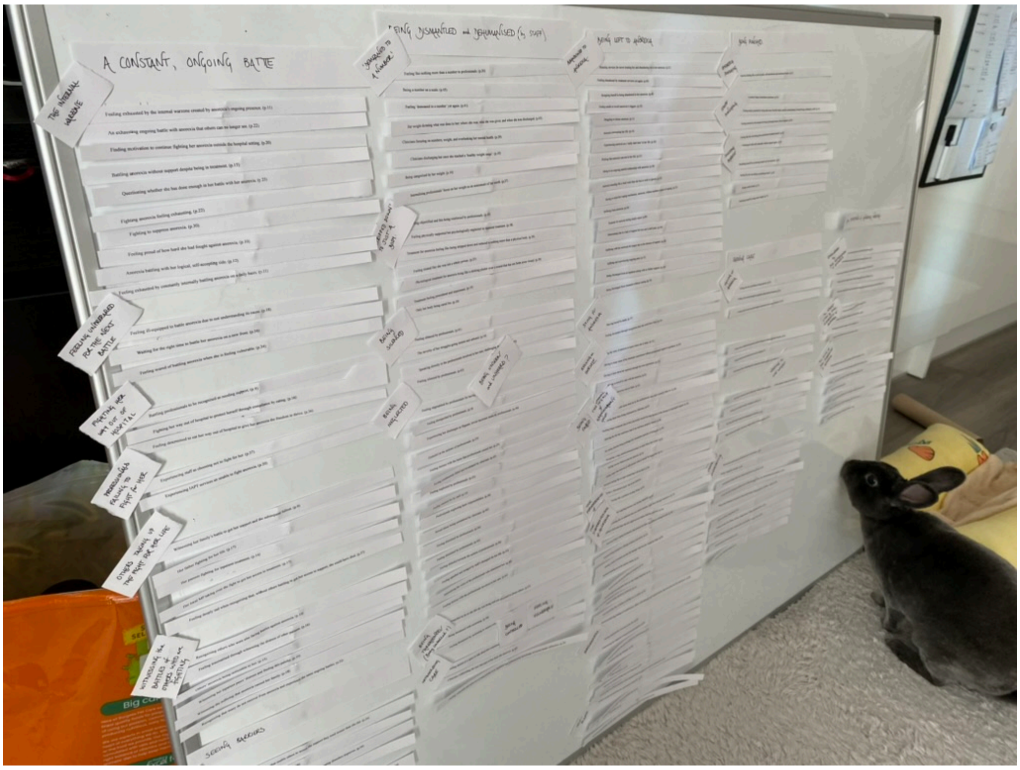
Finding trust in new clinicians when they allowed him to ‘come together’. (p.37)

Appendix O

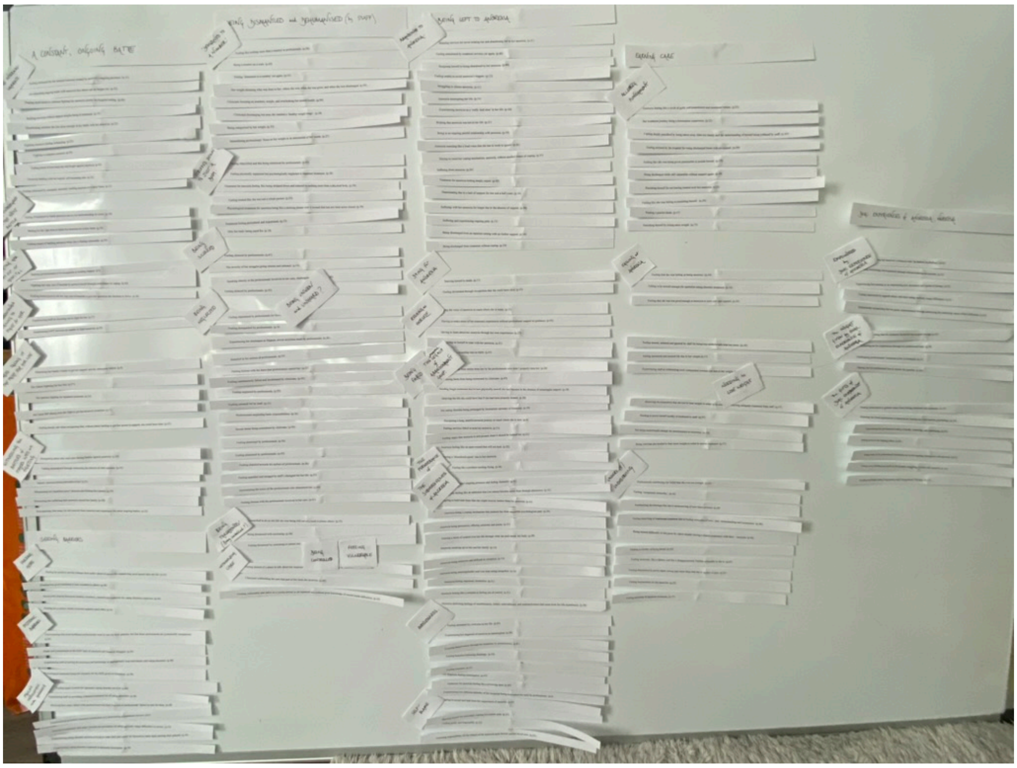
Examples of Two Participants' Initial Experiential Statement Clustering

Appendix P

Example of Stages of PETS Clustering



An Example of a Participant's PETS Clustering.



The Same Participant's PETS Clustering Following Some Final Changes After Revisiting their Original Transcript.

(A number of the initial PETS ended up being collapsed together).

Appendix Q

Participants' PETs Tables

'Rachel'

PET	Subtheme
Epistemic injustice going unheard.	The silencing of experiential knowledge.
	The privileging of misinformation held by professionals.
	The systemic absence of understanding.
	The gifts of dual experience of anorexia.
Locating responsibility.	Being blamed for anorexia.
	Providing care for peers.
	Professionals evading responsibility.
	Assuming clinical responsibility.
Being left to anorexia.	Fearing anorexia.
	The absence of support feeding anorexia.
	The lure of anorexia.
	Abandonment and hopelessness.
The polarity of professionals.	Being punished.
	Being dehumanised.
	Them vs. us: a power struggle.
	Losing trust.
	Feeling fortunate for incredible professionals.

'Serena'

PET	Subtheme
A constant, ongoing battle.	The exhaustion of the internal warzone.
	Battling professionals.
	Feeling ill-equipped to fight anorexia.
	Witnessing the battles of others.
Being abandoned to anorexia.	Dying for anorexia.
	Becoming lost between systems.
	The painful legacy of abandonment.
	Hopelessness.
Earning care.	Failing at anorexia: unworthy of care.
	Anger at the withholding of care.
	Accepting punishment.
Being dehumanised.	Reduced to a number.
	Being stripped down to a physical body.
	Being unseen and unheard.
	Being neglected.
Seeing the system.	Seeing the systemic barriers.
	Witnessing the system failing others with anorexia.
	The insight of dual experience.
	Holding hope.

‘Samantha’

PET	Subtheme
Becoming lost.	Falling into ‘diagnostic margins’. Becoming lost in the gaps between services. Being abandoned to anorexia. Acceptance of a life lost to anorexia.
Locating responsibility.	Internalising blame. A ‘hot potato’: avoided by professionals. Assuming responsibility for giving others hope.
The trials and strengths of dual experience.	Seeing systemic failures. Being feared. Being penalised. A new, strengthened skillset. A protected recovery.
Being lucky.	The luck of encountering a good therapist. The pure chance of having evaded death. ‘Falling into’ dual experience.
Being dehumanised.	Being just a number. Being punished. Being silenced. The withholding of care.

‘Louise’

PET	Subtheme
Falling into the gaps between services.	Conflicting messages: CAMHS vs. Adult services. No longer mattering. Feeling hopeless. Permission to disappear.
Being left to anorexia.	Getting to keep anorexia. An ongoing self-treatment. The anger of being abandoned to anorexia. Having strength and resilience.
The worthiness of weight.	Being stripped down to a number. Internalising the value of being a low weight. Learning that weight loss earns care.
Professionals’ thefts.	Stolen and manipulated narratives. A stolen chance at recovery.
The strength of dual experience.	Holding hope for the NHS. The insight of dual experience.

'Sarah'

PET	Subtheme
Feeling lucky.	The privilege of paying for care.
	The chance of a great therapist.
	The luck of survival.
Being abandoned to anorexia.	The systemic nourishment of anorexia.
	Permission to disappear.
	The lure of anorexia.
	Suffocated and lifeless.
The right time for ending treatment.	Fear of repercussions: the decision to close the door to treatment.
	Feeling the remission of anorexia.
	Ruptures in a strong therapeutic relationship.
Being stuck in the gaps between treatment systems.	Systemically closed doors.
	Being too well to access care.
	Not having 'the right' anorexia.
	Systemically imposed shame.
The offerings of dual experience.	Seeing the systemic barriers: de-internalising shame.
	Avoiding assumptions of sameness.
	Genuineness: Being with clients

'Kevin'

PET	Subtheme
Being reduced to femaleness by the system.	Reduced to a weight.
	Reduced to a ticky-box.
	Reduced to a rash.
	Reduced to a label.
Being abandoned to anorexia.	Services feeding anorexia.
	The closed doors of treatment.
	Resignation to a painful existence.
	Grieving lost years.
Identity: Being seen and heard.	The gifts of anorexia.
	Stolen through treatment: a denied existence.
	Protected by peers.
	A change of luck: a great professional.
A journey of trust.	Entrusting professionals with his experiences.
	Losing trust in the gaps between services.
	Dual experience: entrusted by others.

‘Rose’

PET	Subtheme
Ever waiting in the company of anorexia.	Abandoned to anorexia.
	The lure of anorexia.
	A deteriorating hope.
	Becoming lost.
Sudden departures, sudden losses.	The farce of therapists’ departures.
	Grieving lost relationships.
	Unceremonious eviction to the ‘real world’.
	Preparing for relapse.
	Systemic betrayals.
Harmful ‘helpers’.	Being infantilised.
	Being unseen and unheard.
	The need to self-protect from professionals.
	Gaps in professional knowledge.
The insight offered by dual experience.	The gift of retrospective sense-making.
	Seeing systemic barriers.
	The assimilation of knowledges: a gap filled.

‘Amy’

PET	Subtheme
Being trapped.	Performing compliance.
	‘Screaming and shouting’ to be heard.
	Desperately chasing a normal life: the price of escape.
	Being trapped in anorexia.
	Recovery being an empty promise.
Being deconstructed.	Autonomy being stolen.
	Becoming powerless within the treatment system.
	Grieving a ‘fizzling’ identity.
	Being a larger body.
	Dying for anorexia.
Being unwelcome.	Not being unwell enough.
	Being too unwell.
	Being too much.
	Systemic racism.
Encountering distance.	Cold and distant professionals.
	Being far from home.
	The gift of distance: a professional lens.
	Professional vs. experiential knowledges.

Appendix R

Recurrence of Themes Table

Themes		Participants							
GETS	Subthemes	‘Rachel’	‘Serena’	‘Samantha’	‘Louise’	‘Sarah’	‘Kevin’	‘Rose’	‘Amy’
Systemic Barriers: Becoming Lost	*“Too sick, not sick enough”*: Falling into diagnostic margins.	x	x	x	x	x			x
	“You’re no longer with us”: Being lost in the gaps between services.	x		x	x		x	x	
The Systemic Feeding of Anorexia	*“It was very much about weight. Which of course, anorexia* wants *it to be”*: Being reduced to a number.	x	x	x	x	x	x	x	x
	“Just left… to fend for ourselves”: Being abandoned to anorexia.	x	x	x	x	x	x	x	x
“Have you any idea…? The damage	*“Screaming, shouting”* to be heard: The silencing of experiential knowledge.	x	x	x	x	x	x	x	x

that you've caused?": Being hurt by the helpers	*"I don't have a single choice in the world"*: Powerlessness.	x	x	x	x	x	x	x	x
	"The Neglect*"*: Being met with a lack of compassion and understanding.	x	x	x	x	x	x	x	x
	"Had the wind just been blown in the other direction…": Being lucky.	x	x	x		x	x	x	x
"Dual identity… A privilege and an honour": The Gifts of Dual Experience of Anorexia	*"Professionally, the sense that I make of that is…"*: Consulting a professional lens.	x	x	x	x	x	x	x	x
	"I can see…": Seeing the system.	x	x	x	x	x	x	x	x
	"On the other side": A new knowledge.	x	x	x		x	x		