Examining Service Users' views on their experiences of recovery from borderline personality disorder across settings: A systematic review, and Borderline Personality Disorder; Secure inpatient Service Users' perspectives on what recovery means, its facilitators and barriers.

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Preface

The current thesis explores the experiences and views of recovery of individuals with a diagnosis of Borderline Personality Disorder (BPD), alongside any facilitators and barriers they have identified. BPD is characterised by extreme emotions, significant difficulties with relationships and a need to connect to others but struggling to trust them. The systematic review focused on a range of service settings, and the empirical study focuses on forensic settings.

Qualitative research approaches provide an opportunity to investigate lived recovery experiences and understandings of people with BPD. This systematic review aimed to use thematic synthesis to integrate findings from selected studies relating to recovery from BPD in a range of service settings, predominantly community. A systematic review protocol was developed and searches were run on five databases to identify qualitative peer-reviewed studies relating to the experiences and views of service users with BPD. PRISMA guidance was followed and nine articles were selected for inclusion. The quality of each article was evaluated using the CASP qualitative quality measure. Thematic synthesis was completed to develop themes. Two superordinate themes emerged: ‘Change, not ‘recovery’’, with two subthemes; and ‘Change is complicated’ with five subthemes. These reflect participants view that change is non-linear, and a combination of a variety key elements supporting change are needed for SUs to improve their wellbeing. A model is proposed to illustrate SUs views of recovery and wellbeing. Chaotic environments and traumatic experiences lead to disrupted early development, contributing to the intense relational and emotional challenges experienced by people with BPD. For individuals with BPD, this can make engaging with services overwhelming and challenging in the long-term. The SU meaning of recovery is broader than symptom reduction alone and it is important to incorporate this into current understandings of recovery with BPD. Staff would benefit from appropriate training to work with people with BPD. Possible areas for further research are discussed. This thematic synthesis contributes to the literature by highlighting that participants understandings of recovery are broader than symptom reduction alone, incorporating wider life factors and the knowledge that life will always present challenges, despite learning to cope better and maintaining wellbeing for longer. Participants point out recovery is non-linear and better described as living well despite their mental health challenges. Staff knowledge and training, a non-judgemental environment, trusting relationships, SU’s learning new skills and having ongoing meaningful activities are key in the process of positive change.

The second part of this thesis, the empirical study, focused on SUs experiences and conceptions of BPD recovery and the facilitators and barriers to it in forensic settings. The SU voice is under-represented in the research literature. Male service user views are also under-represented, and this study aimed to ensure this population was included. An Interpretive Phenomenological Analysis (IPA) approach was used to explore the experiences of seven participants; three female and four male. Participants were inpatients receiving treatment in medium secure mental health services. Interviews focussed primarily on experiences and understandings of recovery and its facilitators and barriers. Themes were developed for each interview transcript, followed by a process of drawing out group experiential themes. Analysis resulted in four group experiential themes. The first, ‘Developing BPD, instability early in life’ relates how negative early life experiences

impacted participants’ mental health and development. The second, ‘Developing awareness and taking the first steps to recovery’ is concerned with beginning the recovery process and what participants need. The third, ‘Anticipating and living the reality of recovery’ outlines participants understanding of recovery. The fourth, ‘Overwhelmed by the power of a problematic system’ identifies participants challenging experiences whilst in medium secure treatment settings. This study contributes a SU perspective on recovery in forensic health settings, which has wide overlaps with previous research on recovery in a range of health settings. Participants understandings of recovery are that it is a non-linear process with periods of wellbeing and mental health challenges, or ‘*yellow brick road’* as one participant described it. Living well with BPD using new strategies and good relational connection, supported by knowledgeable and compassionate care environments, seemed more realistic to SUs. However, in the forensic setting, epistemic injustice and iatrogenic harm are more strongly emphasised as barriers to recovery. Psychologists with experience in this field could offer training to staff, family and significant others.

Examining service users' views on their experiences of recovery from borderline personality disorder across settings: A systematic review.

To be submitted to Clinical Psychology Review (please see appendix A for author guidelines)

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Abstract

Introduction: Borderline Personality Disorder (BPD) is characterised by extreme emotions, significant difficulties with relationships and a need to connect to others but struggling to trust them. Qualitative approaches provide an opportunity to investigate lived recovery experiences and understandings of people with BPD. This systematic review aims to use thematic synthesis to integrate findings from selected studies relating to recovery from BPD.

Method: Searches were run on five databases to identify qualitative peer-reviewed studies relating to the experiences and views of service users (SUs) with BPD in the community. PRISMA guidance was followed and nine articles were selected for inclusion. The quality of each article was evaluated using the CASP qualitative quality measure. Thematic synthesis was completed to develop themes.

Results: Two superordinate themes emerged: ‘Change, not ‘recovery’’, with two subthemes; and ‘Change is complicated’ with five subthemes. These reflect that change is non-linear, and a combination of key elements supporting change are needed for SUs to increase wellbeing. A model is proposed to illustrate SUs views of recovery and wellbeing.

Conclusion: Chaotic environments and traumatic experiences lead to disrupted early development, contributing to the intense relational and emotional challenges experienced by people with BPD. This can make engaging with services overwhelming and challenging. The SU meaning of recovery is broader than simple symptom reduction and it is important to incorporate this into current understandings of recovery with BPD. Staff should receive appropriate training to work with people with BPD. Possible areas for further research are discussed.

Keywords

Borderline personality disorder, BPD, emotionally unstable personality disorder, EUPD, recovery, service user perspectives, views, qualitative,

Highlights

- A thematic synthesis of nine papers focusing on the experiences and meaning of recovery with BPD.
- SU understandings of recovery are broader than symptom reduction, incorporating wider life factors and acknowledgement that life will always have challenges for them, despite having learned to cope better and can maintain wellbeing for longer periods.
- Recovery is non-linear and better characterised as living well with occasional challenges.
- Staff knowledge and training, a non-judgemental environment, trusting relationships, SU's learning new skills and having ongoing meaningful activities are key in the process of positive change.

Introduction

Individuals diagnosed with Borderline Personality Disorder (BPD) experience a range of symptoms, including emotional instability (affective dysregulation), disturbed patterns of perception (perceptual distortions) and thinking (cognitive distortions), impulsive behaviour and intense, volatile relationships (NHS, 2022). The Diagnostic and Statistical Manual of Mental Disorders (DSM-5; American Psychiatric Association, 2013) criteria for BPD specifies "*a pervasive pattern of instability of interpersonal relationships, self-image, and affects, and marked impulsivity beginning by early adulthood and present in a variety of contexts*…" (p. 663), with nine distinct patterns of behaviour or experience, any five of which are required for diagnosis.

Worldwide prevalence of all personality disorders is approximately 7.8%, with higher rates in high income countries (Winsper et al., 2019). However, studies looking at western community and inpatient populations estimate prevalence rates between 1.6% to 21.5% (Black et al., 2007; Chapman et al., 2022a; Quirk et al., 2016). Prevalence of BPD is estimated to be approximately 1.6% in the general population and 20% in the inpatient population (Chapman et al., 2022b). Within these populations it is estimated that that 75% of those diagnosed are female (Skodol & Bender, 2003). Much of the BPD literature focuses on the female and inpatient populations, meaning male and community populations are underrepresented in the literature.

McKenzie et al. (2022), highlight that mental health professionals' views towards individuals with BPD tend to be more negative compared to other diagnoses like depression.

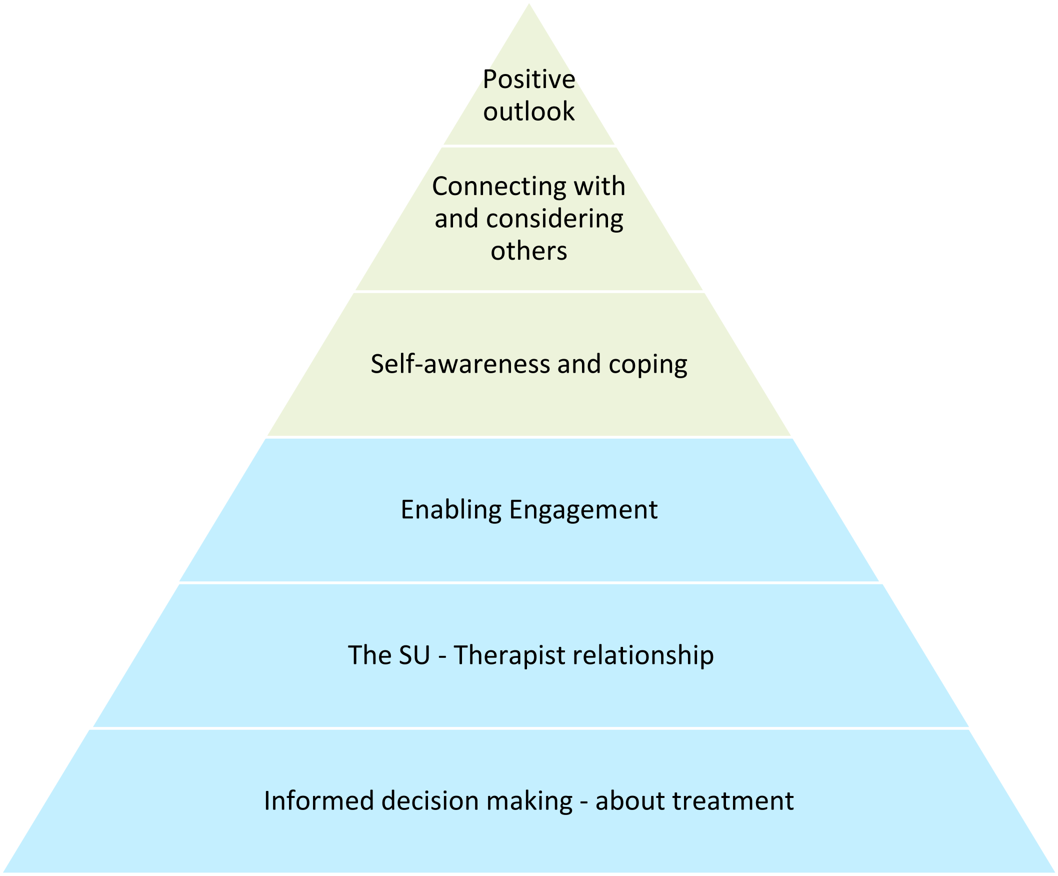
Emerging themes regarding attitudes of mental health professionals include: Service Users (SUs) can be a waste of time, manipulative, and are unlikely to recover (Bodner et al., 2011, 2015; McKenzie et al., 2022; Woollaston & Hixenbaugh, 2008). It has been consistently shown that negative views of SUs with a diagnosis of BPD are prevalent across community and inpatient settings (Aviram et al., 2006; Barr et al., 2020; Day et al., 2018; Ring & Lawn, 2019). Studies found nursing staff often perceived people with a BPD diagnosis as 'destructive whirlwinds' (p. 705) (Woollaston & Hixenbaugh, 2008), and Bodner et al. (2015) found that nurses and psychiatrists tended to have less empathy for individuals with BPD than psychologists and social workers. Previous research has suggested negative staff attitudes may negatively impact care quality and recovery (Henderson et al., 2013). It is important to acknowledge these views on BPD presentation and recovery, and compare them with those of SU's.

Theoretical definitions of recovery can help contextualise stakeholders' perspectives and provide a comparison against which theory can be critically scrutinised. 'Recovery' is a widely used term with varying definitions. The 'recovery model', a US Substance Abuse and Mental Health Services Administration (SAMHSA) approach, defines recovery as *'…a process of change through which individuals improve their health and wellness, live a self-directed life and strive to reach their full potential'* (SAMHSA, 2023). While this definition seems a good general approach to defining recovery, it is broad and relates to health and mental health generally. Clinicians' views on likelihood of recovery, if taking the above definition, suggest they think it is unlikely for SUs with BPD, which has been observed in previous research (Nehls, 2000). This may have a negative impact on SU treatment and recovery; therefore, it is important to understand the implications of this from the SU perspective. SU views are needed to explore themes salient to recovery as they relate to BPD. Compared to professionals' views, SU views of recovery from BPD appear to be under-represented in the literature. However, the range of research across community, inpatient and forensic settings is growing. Studies reflect how individuals with BPD, over time, by increasing knowledge of themselves and BPD alongside relational and environmental safety, can achieve recovery through a non-linear trajectory (Holm & Severinsson, 2011; Horn et al., 2007; Hussain et al., 2020).

A recent meta-ethnography reviewed studies focusing on engagement in psychological interventions in forensic populations, which observed themes relating to engagement and empowerment in psychological interventions, and belief in recovery. These were arranged into a hierarchy of stages **(Figure. 1)** salient to psychological intervention planning for forensic SUs, supporting their engagement and recovery. Stages do not have to be sequential, however it can be helpful to achieve one before the next, similar to Maslow's hierarchy of needs (Maslow, 1943). Cartwright et al. (2021) asked why studies are finding psychological interventions ineffective when SUs report a range of improvements. It is unclear whether a sufficiently comprehensive range of factors is currently being measured, e.g., reduction of symptoms, as commonly used clinically and in effectiveness studies. Elements of change in SU experience are similar across modalities, e.g., the therapeutic relationship (Cartwright et al., 2021a). Trusting relationships with peers and professionals, developing insight, self-worth and hope also emerged as themes and appear related to perspectives in previous studies (Holm & Severinsson, 2011b; Horn et al., 2007; Hussain et al., 2020b). The Cartwright (2021) review is a useful contribution to the literature; however, it is oriented towards conditions and requirements for engagement in interventions.

Exploring a wider question of what recovery means to individuals may endorse existing insights and reveal additional themes, whilst increasing the SU voice in the literature.

Figure. 1: *Cartwright et al. (2021 'Hierarchy of treatment'. The bottom three stages are within a category of 'treatment foundations'. The top three stages are within a category of 'Treatment benefits'*



Relatively few papers directly seek BPD SU views on what 'recovery' means to them, or BPD recovery in a range of health settings. Whether they see recovery as more than the outcome of a psychological intervention as measured by clinical tools is a pertinent question as differences here may have implications for clinical practice. Further insight into this may clarify what facilitates elements of the Cartwright et al.(2021) hierarchy such as the bottom tier- 'informed decision-making', and any relational and environmental requirements for recovery. Significant differences between SU understandings of recovery and clinical or theoretical understandings e.g., the Cartwright et al.(2021) model, have implications for quantifying meaningful and positive change. Additionally, SU views may help clinicians to approach SU difficulties with greater expertise and sensitivity (Black et al.,2014), facilitating the delivery of interventions and services. Therefore, the present review aims to systematically review the literature investigating BPD recovery from the perspective of the SU. A secondary aim is to clarify differences between SU and clinical recovery concepts. This review will synthesise these into a focused perspective on the process and character of recovery.

Method

The systematic review method was based upon the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidance (PRISMA) and Methods for the thematic synthesis of qualitative research in systematic reviews (Noyes et al., 2022; Page et al., 2021; Thomas & Harden, 2008). The study protocol was registered with the international database of prospectively registered systematic reviews in health and social care (PROSPERO – registration number CRD42022365543) (**Appendix D**).

Search Strategy

The PICo (Population, Phenomenon of Interest, Context) (Stern et al., 2014)**(Table 1)** framework was used to formulate the research question and inform search term development for identifying relevant studies (Stern et al., 2014).

Table 1. *PICo framework used to refine the review question* (Stern et al., 2014).

Elements of PICo	**PICo elements of the review question**
Population	Individuals with Borderline personality disorder
Phenomenon of Interest	Recovery
Context	All contexts (e.g. inpatient, community)

Five databases relevant to the subject area were searched without date restriction or filtering up to October 2022: APA PsycINFO, Embase, Medline, ProQuest and PubMed. To reduce the impact of publication bias, grey literature was searched for related theses through ProQuest, and one thesis was included in the review. The reference lists of all included studies and other relevant reviews were screened for further papers. No limits were placed on the date of publication.

Main search terms used included 'borderline personality disorder', 'emotionally unstable personality disorder' and 'perspectives' within database search engines – see **Appendix E.** for a comprehensive list of databases and search terms.

Eligibility Criteria

Study selection focused on the experiences, processes and meaning of recovery from the SU perspective. Table 2. specifies the inclusion and exclusion criteria used to select studies for the review.

Table 2. *A table describing the inclusion and exclusion criteria used to select appropriate studies for the review.*

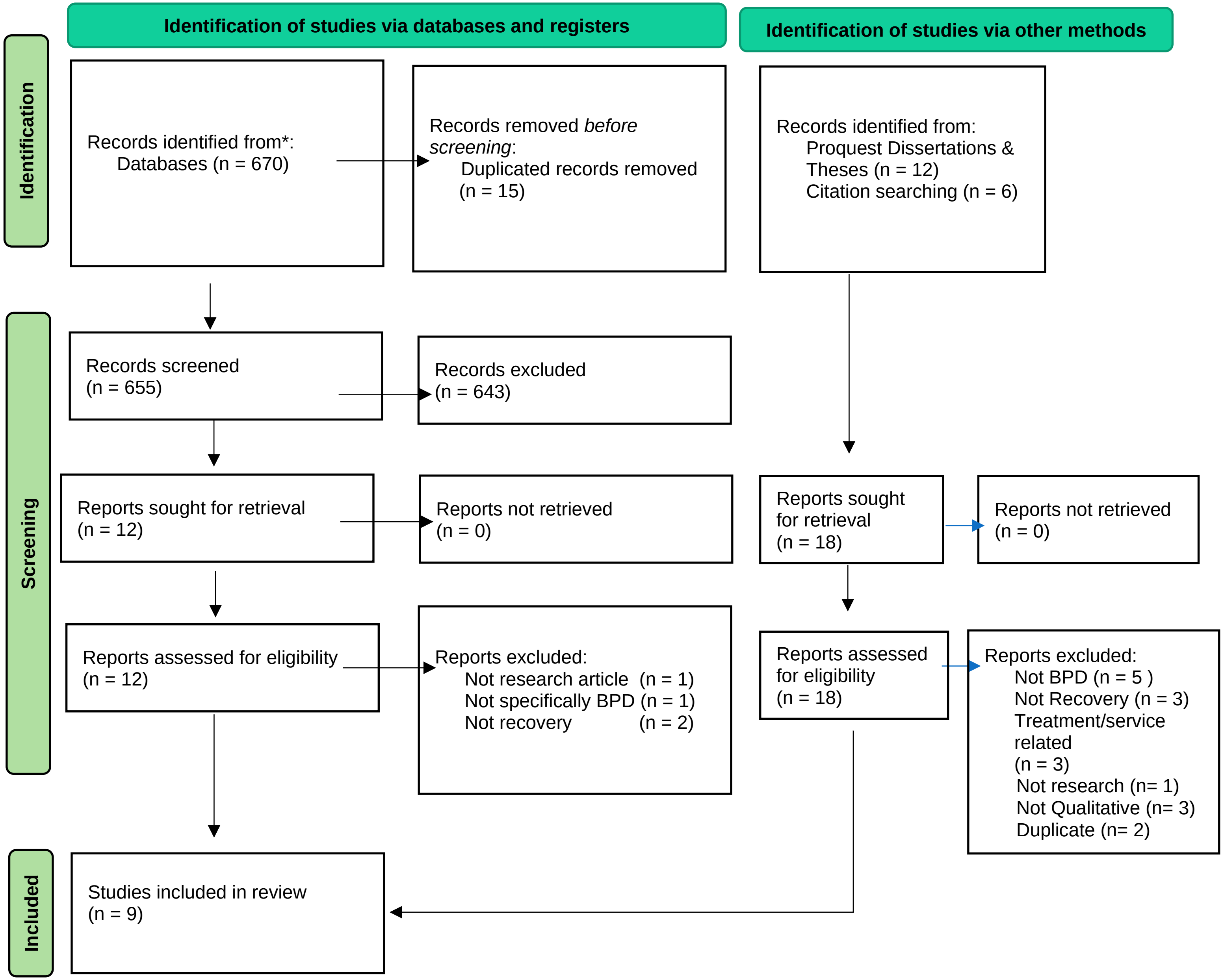
Inclusion & Exclusion Criteria	
Inclusion	• Qualitative (or mixed design that included qualitative reflections on recovery) • Borderline Personality Disorder/Emotionally unstable Personality Disorder – as defined by DSM/ICD – is the primary diagnosis, identified by clinician or a validated measure. • Any healthcare setting e.g: Forensic / secure / inpatient / community • Adults; 18 + • SU's perspectives, experiences, thoughts, feelings, attitudes, conceptualisations on recovery
Exclusion	• Quantitative designs; unless mixed and some qualitative SU reflection on recovery. • Children/adolescents, so that developmental processes are less likely to be involved. • Other Personality Disorders (PDs) – unless BPD is the primary/dominant diagnosis/experience. • Other mental health difficulties where there is a focus on recovery experiences. • Clinicians/family perspectives/views etc; unless there is SU reflection on their as well that can be clearly identified.

Inclusion & Exclusion Criteria
• Experience of diagnosis or treatment (as primary focus)

Paper Selection

Identified papers were exported to Rayyan (Rayyan, 2023) and duplicates removed. Titles and abstracts were then screened and studies not meeting the inclusion criteria were removed. All full text papers meeting the inclusion criteria were then screened by JB and 10% of these were also screened by an independent reviewer. Inter-rater reliability was measured using Cohen's kappa (κ=0.83). Four initial differences regarding ratings were resolved through discussion until 100% agreement was reached. This resulted in nine papers included within the final review. A PRISMA diagram summarising the selection process can be found in **Figure 2** below.

Figure 2. *A PRISMA flowchart detailing the search process for this systematic review.*



Study Characteristics

Six hundred and seventy studies were initially identified, and nine studies met inclusion criteria. The studies were undertaken in the following countries: Australia (n = 3), UK (n = 4), Norway (n = 1), Canada (n = 1). Eight studies were conducted within the last decade between 2015 and 2022, and the remaining study was conducted in 2012.

Data Extraction and Synthesis

All extracted data was collated within a key characteristics table in a Microsoft Excel document. Data extracted from the full texts are itemised in **Table 3**:

Table 3: *Data extracted from the full texts*

Study ID
Authors
Year
Quality Score (CASP)
Location
Main focus
Method/Design
Care setting
Participants & Sample size
Ethnicity
Gender
Age of participants

Main themes

Sub themes

Method of Quality Assessment

The Critical Appraisal Skills Programme (CASP) qualitative studies checklist was selected for this review (CASP, 2022). The CASP tool is designed to assess common quality issues that arise within qualitative studies. The measure consists of a ten-question checklist in which ‘yes’, ‘no’ or ‘can’t tell’ responses are possible. Greater numbers of items endorsed on this checklist indicates higher quality or more complete reporting within the paper. The CASP tool does not offer a scoring process, however, it does state that the more ‘Yes’ responses to questions indicates higher quality. National Institute for Clinical Excellence (NICE) guidelines for reviewing evidence were used with CASP to score studies on a three-point scale of ++, + and -. The ++ rating, + and – represent good, moderate and poor quality respectively.

JB quality assessed all included studies and 30% of included papers were randomly selected for quality assessment by an independent reviewer. One disagreement was discussed until there was 100% agreement.

A reflexive statement (**Appendix F**) was prepared after reflection with supervisors on possible influences JB may be subject to.

Data Analytic Method

Thematic synthesis was chosen to analyse the findings from the studies as it facilitates the development of themes reaching further than the primary studies (Thomas & Harden, 2008).

The complete results and discussions sections of each study were systematically coded using line-by-line coding. Line-by-line coding was completed in NVivo 12 software (QSR International Pty Ltd, 2018) (**Appendix G**). Coding the first study resulted in a bank of codes which were used for subsequent papers. New codes were created in each paper when required. This resulted in 263 initial codes which were assimilated into a hierarchical structure, resulting in 56 descriptive themes (**Appendix G**). Finally, analytical themes emerged through the author's interpretations and discussion with the research team.

Results

Table 4: Data extraction table

STUDy ID	Authors	Year	Quality Score (CASP)	Location	Main focus	Method/Design	Care setting	Participants & Sample size	Ethnicity	Gender	Age of participants	Main themes	Sub themes
1	Grenyer, Townsend, Lewis and Day	2022	+	Australia	Features contributing to response or non-response for individuals at different stages of recovery from BPD	Mixed methods	Community mental health	Individuals with BPD diagnosis by trained professional using standardised protocol receiving treatment at local mental health service (N = 48). (at follow up for thematic analysis)	Not available	M (N = 11), F (N = 41)	Mean Age 31.63 yrs.	(1) Love of self and others; (2) Making a contribution through work and study; (3) Stability in daily life.	
2	Katsakou, Marougka, Barnicot, Savill, White, Lockwood and Priebe	2012	++	UK	To explore what service users with BPD view as recovery	Qualitative. Draws on Grounded theory/thematic analysis.	Secondary mental health services. Including two specialist services for BPD.	Diagnosis of BPD and history of self-harming. (N = 48)	White (N = 33); Black (N = 5); Asian (N = 10).	F (N = 39), M (N = 9)	Mean age 36.5 yrs.	(1) Personal goals and/or achievements during recovery. (2) Balancing personal goals of recovery versus service targets. (3) How recovered do people feel?	

STUDy ID	Authors	Year	Quality Score (CASP)	Location	Main focus	Method/Design	Care setting	Participants & Sample size	Ethnicity	Gender	Age of participants	Main themes	Sub themes
3	Sheperd, Sanders, and Shaw	2017	++	UK	Map out pertinent themes relating to recovery process described by individuals accessing care in either community or forensic settings.	Qualitative. Interviews and thematic analysis.	Community and forensic mental health settings.	Diagnosis of BPD and who can speak English well enough to participate in interviews. (N = 41)	Not available.	F (N = 23), M (N = 18)	Range 18 - 60 yrs.	(1) Understanding early lived experience as informing sense of self. (2) Developing emotional control (3) Diagnosis as linking understanding and hope for change. (4) The role of mental health services.	
4	Donald, Duff, Broadbear, Rao and Lawrence.	2017	++	Australia	Explore meanings of and conditions for recovery from consumer perspective.	Qualitative. Grounded theory, semi structured interviews,	Community specialist BPD outpatient mental health service.	Diagnosis of BPD. Receiving treatment. (N = 17)	Not available.	F (N =15), M (N = 2).	Range 19 - 59 yrs.	(1) Understanding recovery. (2) Conditions of change.	(1) - Positive change is risky but possible; Positive change is difficult but possible through constant hard work. (2) Support from others; Acceptance of need for change; Work on past trauma without blaming oneself; Curiosity about oneself; Reflection on one's behaviour.
5	McCusker, Turner, Pike and Startup	2018	++	UK	Explore SU's views on commonly used outcome measures and definition of meaningful change in recovery from BPD.	Qualitative. Focus groups (N = 3). Thematic analysis.	Community Specialist Personality Disorder service.	Diagnosis of BPD. Screened on entry to service to check meeting criteria for BPD. (N = 15)	93% White British; 6.7% English /East Indian;	F (N = 12); M (N = 3).	Not available.	(1) Recovery to what? How do you rewrite who you are? (2) Conditions for change.	(1) Fluctuating changes: ' it's ongoing, it's a journey'; The dilemma of change: 'Would I still be me…'; Masking difficulties. (2) Maintaining self-care; Feeling safe and wanting to explore; Relationships and trust.

STUDy ID	Authors	Year	Quality Score (CASP)	Location	Main focus	Method/Design	Care setting	Participants & Sample size	Ethnicity	Gender	Age of participants	Main themes	Sub themes
6	Ng, Townsend, Miller, Jewell and Grenyer.	2019	++	Australia	To understand experience and conceptualisations of recovery in individuals with BPD at varied stages of recovery.	Qualitative. Semi structured interviews (Telephone). Interpretive Phenomenological analysis (IPA).	Community. Online social media and mental health organisations. Not specialist services.	McLean Screening Instrument for BPD (MSI-BPD) used. Both individuals meeting and not meeting criteria included. Matched on age, gender and treatment history. (N = 14)	Not available.	F (N = 14)	Mean = 33.36 yrs.	Stages of recovery - (1) Being stuck. (2) Diagnosis. (3) Improving experience.	Developing greater awareness of emotions and thoughts; Strengthening sense of self; Understanding the perspectives of others; Processes of recovery in BPD-: Active engagement in the recovery process; Hope; Treatment; Meaningful activities and relationships.
7	Lariviere, Couture, Blackburn, Carbonneau, Lacombe, Schnick, David and Tribble	2015	++	Canada	To qualitatively capture the experience of recovery in women with BPD.	Qualitative. Narrative research. Picture collage. Semi-structured interview. Second telephone interview. Medical record review. Thematic Analysis.	Community.	Diagnosis of BPD. Completed two continuous years of treatment in specialised PD program.	Not available.	F (N = 12)	Range 18 - 65 yrs. Mean = 37.2 yrs.	Dimensions of Recovery -: (1) Person. (2) Environment. (3) Occupation. (4) Facilitators.	(1) Better emotional management; Assertiveness; Definition of self; Letting go of the past; Hope; Exploring other ways of seeing life; Biting into life again; having confidence in self and others. (2) Having healthy relationships. (3) Taking care of oneself; Being involved in a meaningful role and/or activities; Having and maintaining a job; Carrying out a project; Taking responsibilities. (4) Person: Taking time for self-reflection; Knowing about BPD; Environment -: Appropriate and useful help from health services and community organisations, particularly the BPD program; Support from friends and family; Occupation -: Being involved in meaningful; roles and activities; Planning daily routine.

STUDy ID	Authors	Year	Quality Score (CASP)	Location	Main focus	Method/Design	Care setting	Participants & Sample size	Ethnicity	Gender	Age of participants	Main themes	Sub themes
8	Kverne, Natvik, Veseth and Moltu.	2019	++	Norway	(1) How do people with BPD experience the process of getting better? (2) How do they experience treatment interventions in their effort to ease suffering?	Qualitative. In-depth interviews. Team based, step-wise reflective approach to analyse participants experiences using thematic analysis.	Community. Treatment location.	Recent diagnosis of BPD (6 to 18 months before inclusion). Currently in contact with a treatment provider. (N = 12).	Not available.	Female (N = 12)	Range 21- 36 yrs.	Moving toward connectedness.	(1) Learning to hold one's own. (2) Needing honesty and genuine mutuality. (3) Daring to belong. (4) Making room for recovery.
9	Canacott	2019	++	UK	(1) Detained women with BPD perceptions of recovery (2) The recovery needs of women diagnosed with BPD in secure settings	Qualitative, Grounded Theory	Secure services	Diagnosis of BPD	Not available	Female (n = 7)	18 - 65yrs	(1) Attachment as empowering (2) Attachment & connectedness (3) Identity (4) Identity & self-Discovery	N/a

Thematic Synthesis

The thematic synthesis of nine studies resulted in two superordinate themes: 1) ‘Change’ not ‘recovery’ and 2) ‘Because change is complicated!’. Six subthemes emerged across the two main themes. Theme 1 sub themes included: 1.1) Working towards stability and 1.2) My symptoms are a part of me. Theme 2 included: 2.1) The nature of change; 2.2) Context and conditions; 2.3) The process of change; 2.4) Stages of change. Fourteen areas of focus are distributed across subthemes, and are detailed in **Table 5**.

In the description of themes, first order accounts (participants’ direct quotes) are presented in quotation marks and italics; second order accounts (original author interpretations) are presented in quotation marks without italics. Themes do not represent an exhaustive list of participants’ experiences. Rather, they summarise the prevalent themes described across the data.

Table 5. Illustration of themes and sub-themes across papers

Authors:	**Grenyer, Townsend, Lewis and Day 2022**	**Katsakou, Marougka, Barnicot, Savill, White, Lockwood and Priebe 2012**	**Sheperd, Sanders, and Shaw 2017**	**Donald, Duff, Broadbear, Rao and Lawrence. 2017**	**McCusker, Turner, Pike and Startup 2018**	**Ng, Townsend, Miller, Jewell and Grenyer. 2019**	**Lariviere, Couture, Blackburn, Carbonneau, Lacombe, Schnick, David and Tribble 2015**	**Kverne, Natvik, Veseth and Moltu. 2019**	**Cannacot 2018**
Themes									
<u>1. ‘Change’ not ‘recovery’</u>	X	X	X	X	X	X	X	X	X
1.1 Working towards stability	X		X		X	X	X		X
1.2 My symptoms are a part of me	X		X		X	X	X	X	X
<u>2. Because change is complicated</u>	X	X	X	X	X	X	X	X	X
2. 1 Diagnosis and the nature of change	X	X	X	X	X	X	X	X	X
2.2 Context and conditions	X	X	X	X	X	X	X	X	X
• *2.2.1 Trusting relationships*	*X*	*X*	*X*	*X*	*X*	*X*	*X*	*X*	*X*
• *2.2.2 Hope*	*X*	*X*	*X*		*X*	*X*	*X*	*X*	*X*
• *2.2.3 Basic needs*	*X*					*X*			*X*
• *2.2.4 Shame, blame, guilt and judgement*		*X*		*X*		*X*		*X*	*X*
2.3 The process of change	X	X	X	X	X	X	X	X	X

• *2.3.1 Development of knowledge*						X	X	X	X
• *2.3.2 Self-compassion, acceptance and the need for change*	X	X		X			X	X	X
• *2.3.3 Motivation, engagement and growth*	X	X		X		X	X	X	X
• *2.3.4 Ongoing meaningful experiences*	X	X		X	X	X	X	X	X
• *2.3.5 A broad range of skills needed*	X	X	X	X	X	X	X	X	X
2.4 Stages of change	X	X	X	X	X	X	X	X	X
• *2.4.1 Initial inertia*						X			
• *2.4.2 Maladaptive coping strategies*		X	X		X	X	X	X	X
• *2.4.3 Developing awareness*		X		X		X		X	X
• *2.4.4 Personal identity and self-belief*	X	X	X		X	X	X	X	X
• *2.4.5 Agency and independence*	X	X				X	X	X	X

Superordinate theme 1: 'Change' not 'recovery'

This theme reflects participants characterisations of recovery, and how the language used to describe it is important to them due to the long-term implications. Many participants feel they will always face some emotional challenges, and this is part of who they are but would like to manage these experiences more effectively. As such, '*recovery*' did not seem to fit participants' expectations, wishes or experiences at different points in their journey. Participants '*recovery*' was not very accurate, and potentially dangerous, presenting a dichotomous position between 'ill' and 'better'.

1.1 Working towards stability

Studies reflect a consistent pattern in participants' views about a sense of stable functioning being at the core of what they hoped for in terms of a goal for change. "Stability in daily life" was a theme drawn out in Grenyer et al.(2022), which highlighted that when participants were functioning well, they desired stability and this was achieved and sustained through wider factors:

Table 6.

"Many did report that overall, their lives were more stable and this supported their independence and self-esteem. One individual shared: '*I've got a roof over my head. I am working, I am studying.*" (Grenyer et al., 2022).

Grenyer et al.(2022) also commented:

Table 7.

> "Lived experience perspectives have significantly advanced the field in understanding recovery from BPD (Gillard et al., 2015; Lariviere et al., 2015), highlighting the need for a therapeutic focus on fostering agency, occupational functioning, improving relationships and sense of self (Ng, Townsend, et al., 2019)." (Grenyer et al., 2022).

Shepherd et al.(2017) observed a theme of emotional skill, control or self-management being woven through this idea of stability:

Table 8.

> "Many participants, when discussing hoped for change, described their wish for greater control over their emotional life, as a process of developing a more coherent understanding of their experience. This then became an intimate part of the 'recovery process' – a greater sense of stability, or 'self-control':

Participant views on what life looks like when they are unwell or stuck appear to inversely reflect themes mentioned, Grenyer et al.(2022) observed:

Table 9.

> "… the doing poorly group showed qualitative themes of isolation and relationship breakup, and being insecure in housing and finances. Leximancer maps for this group plotted relationships between mental health challenges and problems in daily living, and

quantitative findings showed more enduring self-reported emptiness, distrust and mental health symptoms over the 12-month period…"

These definitions of positive change vs being unwell appear to support each other, endorsing the theme's consistency. McCusker et al.(2018) advise the importance of acknowledging the dynamic nature of change and why it is important to define it appropriately:

Table 10.

"… change is a dynamic process for individuals with BPD and helping individuals put voice to this process is critical in instilling hope." (Mccusker et al., 2018).

Some participants felt "recovery" implied a return to "normality" and they questioned this in the light of their own experiences (McCusker et al., 2018). However, despite familiarity with and acceptance of their experiences, some participants point out it is simultaneously possible to derive satisfaction from life during their journey:

Table 11.

"… satisfaction with that aspect of their lives; for example, '*we have just celebrated our sixth wedding anniversary on the weekend, so that—that part of my life is really—really good'*. Another participant stated: '*We've been together 11 years and they's sort of stuck through me … they's been to my psychologist a couple of times and my psychiatrist with me. And they knows how to calm me down.*", "Although several people in this group

> expressed satisfaction and content in their work or study (e.g., '*work is going quite nicely'*, and '*I've got a great job'*)" (Grenyer et al., 2022).

A phrase Grenyer et al.(2022) use is "…engagement in a life worth living". This illustrates that within the process of change there are opportunities for individuals to experience satisfaction and achieve a meaningful life, and sources of hope

1.2 My symptoms are part of me

Seven studies drew out themes relating to how participants described feeling like their identity is built on their experience of BPD and acceptance of the diagnosis is needed to progress. However, over-identification with BPD can impede change (McCusker et al., 2018; Ng, Townsend, et al., 2019). Ng et al. (2019) observed themes relating to the experience of identity:

Table 12.

> "Individual narratives discussed the lack of identity stemming from first experiences of BPD and their sense of self being constructed upon symptom experience and identification with the BPD diagnosis.

alongside the idea of a BPD illness identity and the dangers of becoming too attached to it:

Table 13.

“…acceptance of the illness is required to a degree to progress in recovery in BPD. Over-identification however, can lead to stagnation in recovery.”.

This tension between the need for change and safety in a familiar identity is further highlighted by participants in McCusker et al. (2018):

Table 14.

“The dilemma of change: ‘Would I still be me without them?’ (Lucy 1:10). …a sense of uncertainty expressed by participants regarding who they would be without their symptoms …participants described change as being ‘scary’ and difficult to imagine coupled with a loss of identity if they did change”.

Perhaps hesitancy around change is more relatable, as for many, the devil you know is better than the one you don’t.

Superordinate theme 2: Change is complicated

Results indicate that change is a multifaceted set of non-linear processes that require a supportive understanding environment and positive peer, family and staff relationships. Throughout the process new skills are learned and used to improve and maintain wellbeing, albeit with setbacks. Broad stages of change emerge from participant accounts of their experiences.

2.1 Diagnosis and the nature of change

Diagnosis was often not well received by participants and had a negative impact initially, even if it is seen as useful by others, and by many later in their journey:

Table 19.

> “3.3.1.1. Self-concept. Participants reflected on the way in which they viewed themselves early in their recovery journey. Receiving their diagnosis had profound impacts on the way in which they viewed themselves. Most participants had received their diagnosis at the point of admission, although [name] had received hers in their teenage years. Some participants reflected the sense that the diagnosis implied something fundamentally flawed in their being and way of life and struggled to accept the diagnosis as they believed it constituted an attack on their identity…”

Some participants reflected a belief that the diagnosis was a moral diagnosis, imposed upon them due to their behaviours. For participants who had committed an offence, the diagnosis was seen as a direct response to the offence (Canacott, 2019). This appears to be followed by a process of acceptance of the diagnosis (Donald et al., 2017). Other participants found it useful:

Table 20.

““it’s a relief, to be diagnosed. It’s a relief to know that, you know, I’m not a fucking imbecile, I’m not a freak of nature, I’m not a weirdo. I do fit into this world just in a unique minority of the world with mental health issues”- Michelle” (Canacott, 2019).

Participants found it important to accept and appreciate their diagnosis to begin the process of change (Shepherd et al., 2017). It is interesting to note that diagnosis was one way of generating hope, and hope is reflected as an important condition for change (Shepherd et al., 2017).

The process of change from diagnosis is experienced as an ongoing journey of wellbeing development and maintenance. Participants viewed this as a more realistic goal compared to a simplified static clinical goal of symptom reduction. The ‘process’ and its elements are central to the experience and meaning of wellbeing. This main theme illustrates the varied factors in the process of change. It is broadly recognised across included studies that change is complex:

Table 15.

“The picture that emerges from our participants’ observations is that recovery from BPD entails a complex set of processes revolving around the self, which are supported and reinforced through dialogue or relationships with other(s). Each of the five conditions of change identified in this study (support of others; acceptance of the need for change; work on trauma; curiosity about oneself; and reflection about one’s behaviour) may need to be present simultaneously for recovery from BPD to be optimized… ” (Donald et al., 2017).

Participants in Lariviere et al.(2015), characterised change similarly as a dynamic process that happens within the context of the waxing and waning of wellness and satisfaction:

Table 16.

> “In the present study, despite the different words used to talk about their experience, all were linked to the perspective of recovery in relation to wellness, talking about a positive process related to well-being or a satisfying life. Similarly to [15], these women with BPD described their recovery as a process, characterized by highs and lows. “(Larivière et al., 2015).

Participants indicate they expect to always experience difficulties and what varies is their ability to cope. This change is seen as dynamic and can involve set-backs and achievements. Sustainable wellbeing may be achieved through the consistent use of new skills and maintaining the right conditions. This weakens the idea of “recovery” as a being complete, discrete cure. This was reflected across all nine included studies, (Canacott, 2019; Donald et al., 2017; Grenyer et al., 2022; Katsakou et al., 2012; Kverme et al., 2019; Larivière et al., 2015; Mccusker et al., 2018; Ng, et al., 2019; Shepherd et al., 2017).

Similarly, Ng et al. (2019) observed that participants were mindful of the ongoing nature of the process, even after reaching periods of wellbeing:

Table 17.

> “Recovery was considered an ongoing journey with elements of survival, resilience and self-management. For example, ‘*it can be managed… I don’t think the symptoms will ever 100% disappear forever. They’ll always be there to some degree in the background. I hope I get to a point where it doesn’t impact on your life in a negative way*’ (JTR051 – NR).”.

Katsakou et al. (2012) reflected that the experience of the process can be arduous but is seen as natural:

Table 18.

> “Recovery was experienced as a dynamic process with various stages. Participants described how their recovery fluctuated, with periods with marked improvements followed by times when things were particularly hard to manage. This made them feel exhausted and disheartened, although it was often seen as a natural process in their recovery journey.”,

2.2 Context and Conditions

All nine studies contribute ideas about necessary conditions before skills development is likely to occur, (Canacott, 2019; Donald et al., 2017; Grenyer et al., 2022; Katsakou et al., 2012; Kverme et al., 2019; Larivière et al., 2015; Mccusker et al., 2018; Ng, Townsend, et al., 2019; Shepherd et al., 2017). These appear to relate to safety, trust and the quality of their relational world, with friends, family or clinicians.

2.2.1 Trusting relationships

This is a strongly represented subtheme in all studies, appearing to be one of the early prerequisite conditions for SUs to engage in the process of change. However, it is recognised that this is often not without difficulties:

Table 21.

> “3.2.1. Trust: The development of trusting relationships with staff was seen as both a facilitator and indicator of recovery. During the early stages of the recovery process, the nature of trust represented a significant barrier for participants. It was often reflected that past experiences which had violated participant trust (in professional or personal domains) impacted on their sense of confidence to place trust in others. In light of these experiences, the nature of trust taking time was reflected upon by many…” (Canacott, 2019).

This appears to be a necessity for change to begin, but also in consistently maintaining change. McCusker et al. (2018) observed that change requires safety and trust:

Table 22.

> “The second superordinate theme focused on how change is contingent on basic living conditions (e.g. self-care), sense of safety and security and trust in others.”.

Kverme et al. (2019) expressed how participants had a sense of being connected and in the world as a person and that this was part of having relationships; feeling connected to a trusted person helped them to hold on and tolerate emotional difficulties:

Table 23.

> “Across participants, connectedness implied feeling “I am like others and others are like me,” feeling human amongst other humans. Being connected seemed to help the participants standing steadier in raging emotional storms, reaching for and clinging on to support from friends and family and to the support found within themselves.”.

Interferences with relationships seemed more prevalent in secure forensic wards, and was deemed difficult by participants:

Table 24.

> “The transitory nature of inpatient relationships was reflected upon by participants. It was recognised that service-users are detained under various mental health sections, resulting in discharge or relocation to other services or wards: … In this sense, overcoming the challenges to establish positive peer relationships was accompanied by recognition of the inevitable loss of these relationships.” (Canacott, 2019).

2.2.2 Hope

Hope emerged as important in the process of change in eight studies, (Canacott, 2019; Grenyer et al., 2022; Katsakou et al., 2012; Kverme et al., 2019a; Larivière et al., 2015; Mccusker et al., 2018; Ng, Townsend, et al., 2019; Shepherd et al., 2017). SUs in early stages of change often do not experience or express hope strongly or at all:

Table 25.

> “States of hopelessness particularly observed during the early stages was prevalent in all individuals, such that ‘I didn’t have any kind of hope. I didn’t have anything to hold onto…’ (JTR239 – R).” (Ng, Townsend, et al., 2019).

However, it was acknowledged that hope could be generated in different ways:

Table 26.

> Seven women talked about hope in a similar way than [4], which is ‘‘the impression that what’s desired can be realized’’. Participant 4 expressed: «*In my perspective, I can work it out. There is little blue sky but I can make it…Don’t look back…don’t give up*». Three of them noted that hope emerged from receiving the diagnosis. Several participants discussed that through therapy, sometimes referring to mentalization, they became more positive and optimistic and had more realistic expectations.” (Larivière et al., 2015).

These comments seem to draw together a number of skills and conditions for change, suggesting that hope is needed for sustained change:

Table 27.

"Hope played a role in the maintenance of motivation, as it contributed to gains in self-belief and the reduction of self-doubt. '*That sense of just knowing the emotions will end, this isn't a permanent thing... I used to feel like it was just never going to end*' (JTR239 – R)." (Ng, Townsend, et al., 2019).

Some participants who believed they can change benefitted from the support of vocally supportive therapists who were an external locus of hope when they did not believe in themselves (Kverme et al., 2019a).

Progress through the process of change seemed to be connected to hope in numerous ways through becoming unstuck, acceptance, relationships and support, developing skills; these elements generate further opportunities for hope which help maintain engagement and progress (Kverme et al., 2019a).

McCusker et al. (2018) noted that hope is influenced by factors such as how change is constructed, understood and measured, suggesting that inappropriate measures can lead to hopelessness:

Table 28.

"A further issue described by participants was the way in which simplistic symptom measures may contribute to individuals feeling misunderstood and may lead to greater hopelessness within a group already high in hopelessness (Soloff et al., 2000)."\.

2.2.3 Basic needs

This emerged as an area of importance in three studies, (Canacott, 2019; Grenyer et al., 2022; Ng, Townsend, et al., 2019). Grenyer et al. (2022) observed how housing and finance affected participants who were struggling:

Table 29.

"Difficulties in housing and finance were also evident in other narratives of this group; for example, '*Everything is going pretty bad. We're trying to find a place to move, and I cannot seem to find a place, because no-one wants to rent this place and all that. And just all the finances are really stressing me out.*".

Given one of the central problems of BPD is emotional intensity, it is unlikely that the stresses induced by the lack of basic needs like a secure home and an adequate income will be helpful in creating conditions conducive to change. Particularly since stability is seen as a goal and is hoped for as part of wellbeing. A participant from Canacott (2018) was able to specify one way that these elements can combine to increase difficulties and likely slow down change and progress:

Table 30.

"…if I'm having trouble getting a job and because I'm having trouble getting a job I can't pay my bills then I'll get really stressed out then it's a possibility that I will revert back to

self-harm, not sleeping properly, maybe drinking cos of being back in the community that’s something I can do”- Amy”.

This illustrates a source of destabilisation for many participants’ ongoing efforts to meet basic needs in the process of change. However, links with other factors such as relationships, indicates the complexity of how conditions for change interact to create a supportive environment for its maintenance.

2.2.4 Shame, blame, guilt and judgement and their influence

Shame, blame, guilt and judgement were represented in five studies, (Canacott, 2019; Donald et al., 2017; Katsakou et al., 2012; Kverme et al., 2019a; Ng, Townsend, et al., 2019). A participant in Canacott (2019) highlighted how these experiences were difficult but opportunities for learning with the right support:

Table 31.

“Many learning experiences occurred in the relationship between participant and psychologist: “*I really struggle sitting with shame, guilt, acknowledgement. But my, my…my therapist makes me sit with a lot of these. It’s hard because I’ve never sat with them before. And I feel a lot of guilt for things that have happened in my life; I feel a lot of shame for things that have happened in my life*”- Michelle”.

A participant in another study reflected their experience and what helped them with it:

Table 32.

"One participant disclosed that they felt a lot of shame over their illness. Within the group they experienced that they could talk about their life without being embarrassed or judged, giving them a feeling of being understood and accepted. Within the group, they were part of a community, part of a whole." (Kverme et al., 2019a).

Shame, guilt and the effect of blame are directed to the self by themselves or others. It appears from above quotes that both vectors have a significant impact on the self and potentially, identity, which is reinforced by Cannacot (2019).

As participants progressed in the change process this internal sense of shame, blame and guilt seemed to ease:

Table 33.

"People expressed that they progressively felt more confident within themselves and less self-blaming. They wanted to let go of guilt and shame, develop a view of themselves as worthy individuals and the capacity to like themselves and feel compassion for their problems.′′ (Katsakou et al., 2012).

As such, a sense of non-judgement and understanding, and reductions in shame and guilt from both the self and others seems to be an important condition to create, but likely starts with understanding and acceptance from friends, family and staff/clinicians.

2.3 The process of change

Narratives illustrate a process of change is reflected in four areas: Development of knowledge; Self-compassion, acceptance and the need for change; Motivation, engagement and growth; Ongoing meaningful experiences.

2.3.1 Development of knowledge

This emerged in four studies as an ongoing activity for many, helping to initiate and maintain change (Canacott, 2019; Kverme et al., 2019a; Larivière et al., 2015; Ng, Townsend, et al., 2019). "Knowledge" appeared to relate to what can be known about themselves and BPD, and was consistent across studies. Kverme et al. (2019) observed:

Table 34.

“The participants who believed they could, experienced that they had learned something through therapy; they had gathered knowledge about their emotions, their thoughts, their behavior, and how thoughts influenced emotions and behavior and vice versa.” … “By having and using their knowledge and capacity to act, by taking a walk or cuddle up

by the TV with a comedy, the participants experienced that they could turn away from destructiveness, altering the thoughts and emotions accompanying this darkened state.

Receiving a diagnosis of BPD can be a difficult experience, though it is useful for many, and ensuring SUs receive good information about BPD early may help many with coming to terms with it:

Table 35.

“Some participants highlighted the immediate need for information about BPD to contextualise the diagnosis, as ‘*the worst thing is when people are not given any information when they are diagnosed with BPD.*’ (JTR280 – R).”.

These quotes also hint at a nascent sense of self-compassion that can come with diagnosis and knowledge, and this may support acceptance.

2.3.2 Self-compassion, acceptance and the need for change

Self-compassion, acceptance and feeling the need for change also appear to be a part of ongoing change reflected in six studies, (Canacott, 2019; Donald et al., 2017; Grenyer et al., 2022; Katsakou et al., 2012; Kverme et al., 2019a; Larivière et al., 2015). Donald et al. (2017) observed “acceptance” is an early necessity for many alongside motivation:

Table 36.

> “Acceptance of the need for change for some participants (10/15), the first step toward change was acceptance of the need for it, along with developing a belief that change was possible. …

Acceptance is seen by others to include self-acceptance as well as acceptance of the diagnosis:

Table 37.

> “Participants described that they have managed or want to understand themselves more and make sense of their problems, their actions and thinking patterns, as well as the reasons underlying why they behave in certain ways. Understanding themselves and their history was seen as a step towards accepting themselves more, being less self-critical and coming to terms with who they are.” (Katsakou et al., 2012).

2.3.3 Motivation, engagement and growth

Motivation, engagement and growth emerged across seven studies, (Canacott, 2019; Donald et al., 2017; Grenyer et al., 2022; Katsakou et al., 2012; Kverme et al., 2019a; Larivière et al., 2015; Ng, Townsend, et al., 2019). In early stages of recovery participants are often less likely to feel motivated to change:

Table 38.

"For example… '*basically I just hide in my house, on my computer, watching TV … I just do not want to go out anywhere out there. I just want to stay home.' Similarly, another individual speaks of a similar experience: 'I just sit around a lot of the time just being upset.*" (Grenyer et al., 2022).

Others highlight the importance of engagement:

Table 39.

"The desire and willingness to engage in the recovery process was crucial for progress in recovery to be made. (Ng, Townsend, et al., 2019).

Hope was thought to help motivation and engagement by some participants:

Table 40."Seeking treatment was identified by all individuals as a key component in the recovery process, where effective treatment aligned with individual goals provided a sense of hope and the development of skills. Whilst these provided individuals a sense that 'this could be working. Maybe things will be ok' (JTR061 – NR)," (Ng, Townsend, et al., 2019).

2.3.4 Ongoing meaningful experiences

Ongoing meaningful experiences were important to participants throughout change and for long-term wellbeing, a robust theme across eight studies, (Canacott, 2019; Donald et al., 2017; Grenyer et al., 2022; Katsakou et al., 2012; Kverme et al., 2019; Larivière et al., 2015; Mccusker et al., 2018; Ng, Townsend, et al., 2019).

Meaningful experiences were mainly relational and occupational in nature:

> Table 41.“Engaging in meaningful activities and relationships was described as providing a sense of belonging and connectedness, the opportunity to practice new skills, reflect upon one’s emotional reactions and sense of self. … these commonly included employment, education, and relationships with friends, family, significant others and clinicians. Benefits such as the independence gained from being employed and the sense of ‘affirmation and sense of purpose’ (JTR011-R) was discussed.” (Ng, Townsend, et al., 2019).

Katsakou et al. (2012) also detected this and provided some examples:

> Table 42.“Participants believed that having more meaningful activities in their lives is particularly important. Achieving practical things that they used to find hard, like paying their bills, managing their household, going on a holiday, using public transport and so forth made them feel more confident.

2.3.5 A broad range of skills needed

This area of focus highlights a range of skills needed to facilitate change. This focus is evidenced in all nine studies, (Canacott, 2019; Donald et al., 2017; Grenyer et al., 2022; Katsakou et al., 2012; Kverme et al., 2019a; Larivière et al., 2015; Mccusker et al., 2018; Ng, Carter, et al., 2019; Shepherd et al., 2017). These skills relate mainly to self and emotion management and coping skills. However, reflection skills, awareness and life skills are also represented, all of which being an influential part of change. The following observation from Kverme et al. (2019) illustrate how skills are developed and used:

Table 43.

“They had gathered keys they could use to unlock doors opening up various possibilities of change. Importantly, these keys were about doing; making conscious choices, being curious about their inner world and practicing how to use their keys. ...

The development of skills appeared to be related to the development of a sense of agency which was related to belief in change, one-self and acting positively:

Table 44.

“Learning to Hold One’s Own, to be agents in the processes of change was pivotal. Agency implied being able to believe that change could come about by acting, by changing old patterns and habits. In the context of treatment, this seemed sparked by the experience

> of being seen as one “who could” be one’s therapist, and by daring to embrace the faith that the therapist had in them.”

Wider skills included curiosity about oneself and flexibility as observed by Donald et al. (2017) and Canacott (2019) respectively:

Table 45.

> “Our analysis also suggests that cultivating curiosity about oneself may be another specific skill that supports work on the self and that may lead to greater self-acceptance. The goal of greater self-acceptance may require the specific skill of having curiosity about oneself. It is notable that the conditions of change that our participants identified as important to their recovery were actually concrete or specific skills rather than more general goals.”

And:

Table 46.

> “…they increased their ability to tolerate the difficult emotions which depleted their coping resources in earlier stages. Participants described a shift in their ability to cope which became largely internally regulated. Managing difficult emotions and challenging interpersonal situations independently became an indicator of recovery. Asking for support represented a new skill for many participants who, in earlier stages, felt blocked

by caution and lack of trust with the team to seek support: "*I've learned to get help sooner, so I don't get myself in situations like that again*"- Amy".

Further skill areas emerged as having marked influence in the process of change and the development of sustained wellbeing.

Leading from curiosity, reflection skills emerged as an important part of the process of change, intimately linked with the process of increasing awareness, and appears across five studies, (Canacott, 2019; Donald et al., 2017; Kverme et al., 2019a; Larivière et al., 2015; Ng, Townsend, et al., 2019). Two clear areas of reflective skill appeared to focus on curiosity about one's inner self, and reflection on one's behaviour. Donald et al.(2017) observed narratives relating to this:

Table 47.

"Curiosity about oneself: Some of our participants (9/15) suggested that thinking about oneself or having curiosity about oneself was a key step toward positive change. This enquiry into the self was variously expressed as curiosity about the self or as self-discovery or increased self-awareness. For instance, some participants associated the benefits of therapy specifically with a focus on the self and understanding the self-better.

This indicates a general curiosity about the self and a will to think about how one thinks, both of which lead to increasing self-awareness over time. Reflection on behaviour, and how this affected others was also considered by participants in the same study:

Table 48

“Reflection on their role in past difficulties and the impact of past behaviour on other people were also key parts of change for a number of our participants (6/15).

A cautionary observation, however, suggests that this level of reflection and development may be too overwhelming or skilled for people in the early stages of change, and clinicians and others may need to remember to hold their expectations lightly since the process of change is not linear (Canacott, 2019).

Life skills related ideas were represented across six studies, (Donald et al., 2017; Grenyer et al., 2022; Larivière et al., 2015; McCusker et al., 2018; Ng, Townsend, et al., 2019; Shepherd et al., 2017). A range of life skills and wellbeing strategies seemed to be part of the toolkit participants develop as they change:

Table 49.

“Participants described some aspects of their living conditions or lifestyle that they perceived as central to their wellbeing. These were summarized by one participant as self-care and encompassed living in a tidy environment, sleeping and eating in a healthy way, maintaining physical care and being organized.” (McCusker et al., 2018).

Participants in this study also specified that finishing tasks of different kinds was an important skill:

Table 50.

> “Half of the women talked about the ability to continue a project until the end, including daily tasks and long-term projects like studies or the therapy program.’ (Larivière et al., 2015).

The importance of life skills and the views of participants seem to indicate that skills are not only needed for creating the environment for change but the environment for change is needed for skills development. This theme around the conditions for change is reflected across all studies include in this review.

Coping skills development in the context of relational stability seemed to be important along with ‘awareness’ and ‘responsibility-taking’ in the development of empowerment:

Table 51.

> “Thus, empowerment through attachment enabled participants to engage in learning processes which provided further opportunities for empowerment through increased self-awareness and skills acquisition, enabling responsibility, agency and self-management.” (Canacott, 2019).

Katsakou et al. (2012) reported that participants centralise skills around emotions, mood and thinking:

Table 52.

“Participants described that an important part of recovery is gaining more control over their emotions, moods and negative thoughts. They want to have more control over negative emotions such as anger, sadness, grief, emptiness, fear.

Canacott (2019) used Siegel’s (1999) Window of Tolerance model to indicate what SUs might aim to move towards in terms of emotional tolerance, where SUs aim for optimal arousal between hyper and hypo arousal where they are better able to tolerate intense emotions or can think and feel more effectively.

2.4 Stages of change

There appear to be a number of stages reflected in the process of change relating to the self. These are around: Initial inertia, Maladaptive coping strategies and behaviours, awareness, and personal identity and self-belief.

2.4.1 Initial inertia

This relates mainly to times early in SU treatment experiences before they were actively engaged in their process of change. Participants described “being stuck’:

Table 53.

‘*floundering, getting bounced in and out of hospital… I was lacking in therapy and not really engaging in services*’ (JTR191-R). (Ng, Townsend, et al., 2019).

Linked to this was the experience of emotional intensity impacting on daily activities:

Table 54.

> “An individual’s emotional intensity was identified to impact upon daily living and was noted to extend beyond the realms of normal experience, where ‘*emotions are so raw and powerful, they drove everything. I had no insight whatsoever into what I was doing. I didn’t know who I was, what I was doing or why. I reacted to everything in an unhealthy way’* (JTR280-R).” (Ng et al., 2019).

This study also reflected that this was a stage where maladaptive coping strategies such as self-harm or suicide attempts are common, and that early trauma experiences often affect how people in this stage relate to and view others and themselves (Ng et al., 2019).

2.4.2 Maladaptive coping strategies

Seven studies included experiences of relying on old maladaptive coping strategies (Canacott, 2019; Katsakou et al., 2012; Kverme et al., 2019a; Larivière et al., 2015; McCusker et al., 2018; Ng, Townsend, et al., 2019; Shepherd et al., 2017). These were largely forms of self-harm and substance abuse engaged as coping strategies to manage emotional experiences. Cannacott (2019) asserted that:

Table 55.

> “Participants described the difficulty in accessing internal resources to regulate emotion, recognising that past strategies were often reliant on external resources such as self-harm or the use of drugs and/or alcohol. In the early stages, with the absence of internal resources, participants drew upon what was available to them: the use of self-harm and

the secure environment. Those who self-harmed reflected that in the existing stage, this was their most accessed source of coping.

It was acknowledged in this study that participants want to reduce suicidality, self-harming and other symptoms (Katsakou et al., 2012). Kverne et al. (2019) observed that at some point in this early stage of recovery SUs begin to feel able to engage with the process of change:

Table 56.

“Some participants had started feeling that “*they could*,” and were actively engaged in helping themselves to make moment-to-moment decisions that could help them deal with their emotions without needing to self-harm, moving them forward in their personal recovery.”

However, Cannacott (2019) and their participants highlighted that it is a fragile stage of recovery and can be impacted by old coping mechanisms at times, playing into the dynamic non-linear nature of change:

Table 57.

“Participants described that the development of newly established coping skills could be challenged by the availability of old coping strategies in the community such as alcohol or substances.’

It appears that while stabilising and starting to develop alternative strategies in these early stages there may be a process of awareness development, such that Sus become more aware of when to use new coping strategies. This, in combination with new strategies, offer some initial feelings of stability and hope in the face of setbacks.

2.4.3 Developing awareness

Awareness, and reflection on the role awareness plays, as a stage in the change process appears across five studies (Canacott, 2019; Donald et al., 2017; Katsakou et al., 2012; Kverme et al., 2019a; Ng, Townsend, et al., 2019). On one level some participants talked about coming to terms with the past through understanding:

Table 58.

"…themselves, their behaviour and exploring and understanding their offence. In many cases, this involved coming to terms with past experiences: "*I've suffered quite a lot, and... very traumatic things happened in my life that I never dealt with historically, but I'm dealing with them now*"- Michelle" (Canacott, 2019).

Ng et al. (2019) drew out ideas relating to awareness in a different light:

Table 59.

"Developing greater awareness of emotions and of self and others was described as a core stage and influencer of recovery."

The genesis of the motivation to become aware of is suggested by Donald et al. (2017), where they state:

Table 60.

"…our data suggest that processes of self-inquiry including the specific skill of curiosity about the self may be the key. Curiosity about the self, particularly if guided by a supportive other, may lend itself to a more balanced appraisal of the self (which is often problematic for individuals with BPD), and accordingly lead to greater self-awareness and self-acceptance."

Curiosity about oneself might often be facilitated initially by others, indicating a nascent level of concurrent trust and relationship building, an idea endorsed by Canacott (2019). This hints at skills and elements of the recovery process described in previous themes, however, more immediately links to ideas about personal identity and self-belief.

2.4.4 Personal identity and self-belief

This appear to be important as a developmental stage of recovery represented across eight studies, (Canacott, 2019; Grenyer et al., 2022; Katsakou et al., 2012; Kverme et al., 2019a; Larivière et al., 2015; McCusker et al., 2018; Ng, Townsend, et al., 2019; Shepherd et al., 2017). Awareness appears to be a necessary step in terms of identity and self-belief as it is a precursor to acceptance:

Table 61.

> “Acceptance in terms of past behaviour was described not only in terms of offending but in the context of self-harming too. Kelly, who had no offence history, described the shift in their identity, whereby acceptance of difficulties and past coping behaviours facilitated their sense of worthiness for life without struggling:” (Canacott, 2019). “.

However, awareness can also have an initial or concurrent negative impact, particularly in the form of diagnosis (Canacott, 2019), indicating the centrality of both identity and self-worth or worthiness of wellbeing even at early stages of the process of change, and that acceptance in terms of the past, and difficulties and behaviours, seems influential in the process of self-worth development and a stable basis for a developing identity. However, fragility of self is well conveyed by Cannacot (2019), who acknowledges the importance of language, particularly in early stages of the change process. This is endorsed by observations by Shepherd et al. (2017), who stated:

Table 62

> “For all participants, the process involved a process of ‘fitting’ the diagnosis alongside their sense of themselves in their personal identity. For those who were, or had been, classified as offenders however this process could be seen as being still more complex, as they contended with feelings of ‘double’ stigmatisation – making sense of being an ‘offender’, ‘mentally ill’ or ‘personality disordered’ [35]. Concepts of mental disorder

> therefore became incorporated into other understandings of self, for example ideas of rehabilitation [36], or ‘redemption’ [37, 38]; for some the idea of ‘personality disorder’ was helpful for this process, for others it was not – and was rejected.”.

This quote also gives a sense of the assimilation of diverse factors into identity as a part of the process of developing awareness and acceptance, although this seems more visible and problematic in secure forensic settings. A facilitator of identity development seems to be psychological work; Lariviere et al. (2015) identified this with their participants:

Table 63.

> “Participant 4 described this: ‘‘*Now, with the therapy, I feel that… I exist. So if I exist interiorly, I can exist exteriorly, with the others. That I have my place*.’’…‘‘*To assert myself in what I am, what I think*.’’”.

These quotes highlight the complexity of identity by itself regardless of the complexity of the wider process of change.

Lariviere et al. (2015), endorse the importance of strengthening a sense of self in the process of change:

Table 64.

> “All individuals acknowledged that developing one’s sense of self was a central component of the recovery journey. Individuals who identified with being recovered provided greater details of the nuances of developing a stronger sense of self. This was conceptualised as a process of reframing how one understands or perceives oneself. This process was noted to commence in conjunction with developing skills to recognise and tolerate emotions.”.

This quote re-emphasises the importance of awareness and acceptance in terms of recognition and tolerance of aspects of self and concomitant response whilst also indicating that this requires the development of skills.

2.4.5 Agency and independence

Agency and independence appear in six papers, (Canacott, 2019; Grenyer et al., 2022; Katsakou et al., 2012; Kverme et al., 2019a; Larivière et al., 2015; Ng, Townsend, et al., 2019). Participants spoke of feeling motivated to achieve independence:

Table 65.

> “They wanted to be more competent in dealing with their problems and their lives, more independent, and gradually reduce the support they receive form mental health services.” (Katsakou et al., 2012).

Participants reported a sense of motion towards autonomy through increasing ability:

Table 66.

"One participant described how they felt themselves growing stronger by witnessing their own journey from powerlessness to emergent control. Experiencing themselves as one "who could" and seeing the changes they were making in their own life gave rise to feelings of pride, achievement and mastery.

Kverme et al. (2019) observed the importance of the SU being engaged and that that relied on belief and hope:

Table 67.

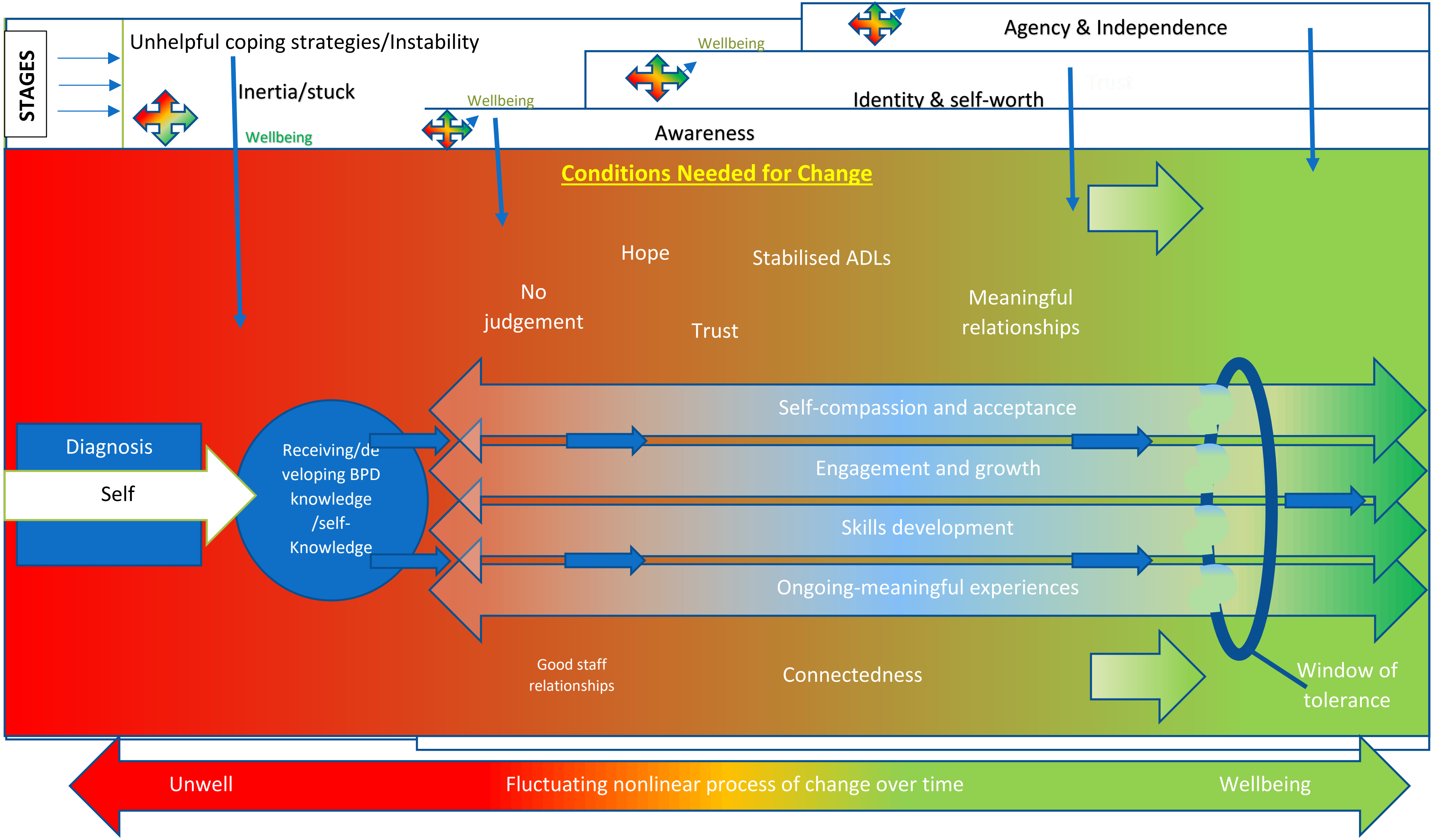
"To be agents in the processes of change was pivotal. Agency implied being able to believe that change could come about by acting, by changing old patterns and habits. In the context of treatment, this seemed sparked by the experience of being seen as one "who could" by one's therapist, and by daring to embrace the faith that the therapist had in them. Some participants had started feeling that "they could," and were actively engaged in helping themselves to make moment-to-moment decisions that could help them deal with their emotions without needing to self-harm, moving them forward in their personal recovery.".

Discussion

The purpose of the current thematic synthesis was to identify, appraise and integrate the available (N=9) qualitative studies regarding the experiences of recovery of individuals with BPD. A secondary aim was to identify the differences, if any, between SU definitions of recovery and those held by clinical services, such as symptom reduction or elimination. The current study found two superordinate themes represented participants' experiences of recovery: '<u>Change' not 'recovery''</u>, and '<u>Because change is complicated</u>'.

Studies provided in depth service user perspectives on the experience of 'recovery' from varying settings and positions in the change process. Participants characterised 'recovery' as a process of change, or a 'journey' due to the varied internal and external factors involved in change. The process from diagnosis through to developing BPD knowledge, self-awareness, self-compassion, engaging, starting meaningful activities and developing new coping skills, is dynamic and variable according to the individual and context. Environmental conditions SUs seek from services and treatment include meaningful relationships with staff, trust, feeling connected, stability in daily life, not feeling judged and hope. Participants clearly assert this process is non-linear and complex. The elements involved in change can interact in different ways at different times for individuals; the data suggests that however they aggregate for an individual at a specific time, the more they cluster together, the more progress the SU tends to experience. Progress can engender hope, empowering further development and growth. This is a process that, for many and over time, leads to self-management of sufficient degree to maintain wellbeing within a personal window of tolerance. This state is characterised by stability with agency, supported by a more positive identity, improved self-worth and improved awareness. **Figure 3.** illustrates this model of change.

Figure 3. A model of dynamic BPD change, wellbeing and development



This model aims to aggregate the elements needed for change and wellbeing to occur; however, it is simplified for the purposes of illustration. In reality, these elements are more dynamic, relating to individuals and their experiences variably. When comparing this model of individuals’ experience of change and wellbeing to the description of ‘recovery’ discussed in the introduction by (SAMHSA) ‘*…a process of change through which individuals improve their health and wellness, live a self-directed life and strive to reach their full potential’* (Lyon, 2022), there is significant overlap. This illustrates significant similarities between the concept of BPD recovery and recovery from other mental health difficulties, speaking to the consistency of human needs. However, change for individuals with BPD appears to have additional nuances, such as the importance of awareness, identity, sensitivity to language and meanings, the conditions needed to support change, and a specific skillset to achieve a stable and functional life.

These results complement the Cartwright et al. (2021) model. Their model describes factors conducive to engagement in psychological interventions and a suggested sequential hierarchy. This review developed a different model to encompass elements relatively with the dimension of time but significant similarities appear throughout the two models, particularly around knowledge, awareness, coping skills, relationships and hope. A potential limitation of the Cartwright et al. (2021) model is that it provides less emphasis on context and environment and the dynamic process of recovery over time. This is due to their focus on establishing facilitators and barriers to engaging in interventions. Nevertheless, the similarities appear sufficiently convergent to see how elements Cartwright et al. (2021) highlight are needed for engagement with treatment, fit within a wider supportive and informed context providing many of the same elements. Trusting relationships with peers and professionals, developing insight, self-worth and hope were themes in previous studies (Holm & Severinsson, 2011b; Horn et al., 2007; Hussain et al., 2020b) and appear to be consistently related to recovery across a range of mental health care settings. They were also reflected in this review; triangulation against other studies and reviews, theories and modalities suggest this review's results offer complimentary insights to current understanding, and highlights the importance of relational and life stability. This review emphasises understanding recovery as a non-linear process of wellbeing management.

The development of recovery 'nested' within family, service and treatment and wider social systems over time, one amongst the other, in this review's model appears consistent with how development is modelled in Bronfenbrenner's (1977) Ecological Systems Theory. Bronfenbrenner suggested human development occurs in the context of five systems: Microsystem (systems immediately around the person, e.g., family etc.), mesosystem (where microsystem systems interact and influence the person), exosystem (Extended family, etc.), Macrosystem (Ideas and ideologies of culture), and the chronosystem (changes that occur over time/life) (Bronfenbrenner, 1977). This resonates with this review which suggests change occurs over time within a context of differing systems which need to be conducive to positive change. Particularly, the importance of trusting relationships with friends, family and clinicians. It also reflects the idea that these elements have influence on the individual and how they develop. Bronfenbrenner criticised the one-way nature of other developmental theories such as Erikson's (1951), asserting that bi-directional influences within systems was more ecologically valid; this review supports the idea of bi-directional and indirect influences. This is seen in how SUs report change is a non-linear journey and they can have achievements and setbacks along the way. Indirect systemic influences can be seen in how the cultures and requirements of treatment settings can affect hope and engagement in treatment. The idea of non-linear, dynamic change presented in this review is reflected in Kelly and Coughlan's (2019) theory of youth mental health recovery synthesising elements of developmental and recovery theory (Kelly & Coughlan, 2019). Their model, although designed to illustrate facilitators and barriers to recovery, similarly shares convergent themes with this review. Many of the facilitators of recovery resonate with this review's themes around conditions and process of change, e.g., Understanding, reassurance, diagnosis, connection, acceptance and support (Kelly & Coughlan, 2019).

Similarities between developmental theory and the themes emerging in this review may indicate one way of characterising the process of change and wellbeing. Studies indicate many individuals experiencing BPD appear to have had disrupted developmental trajectories (Bradley et al., 2005; Paris & Zweig-Frank, 1992), raising the question of whether they may need to progress through developmental processes to facilitate positive change. From this perspective, individuals may potentially be seen as needing development opportunities and conditions as opposed to the negative views that are sometimes held of people with BPD (Bodner et al., 2011, 2015; McKenzie et al., 2022; Woollaston & Hixenbaugh, 2008). Often, this disruption is due to chaotic lives as children or adolescents and one or more traumas (Bradley et al., 2005; Paris & Zweig-Frank, 1992). Understanding this and SU needs for non-judgemental contexts for development and the opportunity to grow though developmental stages, as they might have had with more stable early experiences, appears to be important to individuals with BPD. This differs from seeing individuals as developed adults but ‘broken’, and who need ‘fixing’ by way of the reduction of symptoms, something SUs find unhelpful. This does not mean infantilising them; however, they do express a need for the containing context, compassion and support such as a child needs to develop. This may indicate that change is simultaneously a developmental process equipping individuals with resilience, a sense of themselves and autonomy.

Critique of included studies

All the studies included in this review were published between 2012 and 2022, as such, all participants’ accounts are relatively contemporaneous. Studies were conducted in a range of countries, and was difficult to appreciate the effects of culture and varying service provision. All nine studies met the ++ quality score suggested by NICE (2012), meeting most or all of the CASP checklist criteria and reflected good quality papers. However, even though papers often met checklist criteria, eight of them appeared to meet some criteria only superficially. Five of the studies met reflexivity criteria, while four did not, or it was unclear whether they had. The studies that did not, may be at increased risk of being influenced by researcher bias. Reflexivity is important for facilitating transparency and so researchers are aware of what may potentially influence them and how this might affect study design, data collection, interpretation and conclusions. A reflexive statement can be found in **Appendix F**. Although there appears to be some variability in study quality, findings across studies are broadly convergent, suggesting that results may not be significantly affected.

Limitations and future directions

All nine studies included were published in English, and there may be additional studies in other languages on individuals' experiences of change and wellbeing that have been overlooked. Additionally, all studies included were conducted in Western countries, therefore, it is unclear whether individuals in different cultures would report similar experiences of positive change and concept of recovery.

Further qualitative research may help develop approaches to monitoring and measuring change in BPD, particularly with reference to contextual, functional, relational and occupational areas of life. It may also support clinical guideline development in relation to treatment and staff training. There is potential for offering SUs the opportunity to co-produce the development of a specific outcome measure reflecting their view of wellbeing.

Deeper understandings of peoples' experiences of being in the early stages of change and how they started to feel open to it would enhance the literature. This may be used in the development of particular approaches to early treatment, potentially moderating the intensity of SU experiences. Further exploration of SUs views may also indicate particular strategies, techniques and approaches that may facilitate receptiveness to the idea of change.

Further research into the developmental nature of recovery from BPD and the model suggested by this review may help evaluate the robustness of this review's themes and develop understandings, enabling treatment and training refinements.

Clinical implications

The SU conceptualisation of change and wellbeing is broader than symptom reduction. This has implications in terms of what SUs' and clinicians' goals and expectations. Therefore, this review indicates that broader indicators of change should be routinely considered alongside clinical measures, focusing on areas such as occupation, maladaptive coping strategy monitoring and control, relationship quality, and life satisfaction (Canacott, 2019; Donald et al., 2017; Grenyer et al., 2022; Katsakou et al., 2012; Kverme et al., 2019a; Larivière et al., 2015; McCusker et al., 2018; Ng, Carter, et al., 2019; Shepherd et al., 2017). It is likely a specifically researched and validated measure may reflect change in BPD more comprehensively, particularly with specific provision for SU generation of goals. A related theme from this review concerns the language used to talk about BPD, change and wellbeing. This highlights a need for clinicians to be sensitive to how they talk about change throughout SU recovery journeys, due to sensitivity relating to belonging and self-worth, a will for realistic expectations and a need for vigilant internal self-awareness. SUs feel language and measurement can at the least be inaccurate and at worst damaging (McCusker et al., 2018). Were wider aspects of change and wellbeing more comprehensively measured alongside individuals' qualitative goals, change and measurement may feel less threatening to SUs and more accurately reflect wellbeing (Grenyer et al., 2022; McCusker et al., 2018). This may reflect a need for clinicians to be specifically trained to be aware of the conditions, process, and stages of change. It may also be important that clinicians be appropriately supervised to work with SUs with BPD. This appears to be important in individuals' acceptance of the need for change and ability to muster motivation.

Services users need to feel safe, not judged and to develop trusting connections with staff, friends, family, and peers alike (Canacott, 2019; Donald et al., 2017; Grenyer et al., 2022; Katsakou et al., 2012; Kverme et al., 2019; Larivière et al., 2015; McCusker et al., 2018; Ng, Townsend, et al., 2019; Shepherd et al., 2017). This social network should be encouraged and supported as it can generate hope and facilitates the development of new skills. Observing how hope and skills influence recovery, clinician skills and knowledge appear to be key.

Conclusion

BPD is a severely debilitating psychological presentation which can leave individuals experiencing intense and fluctuating emotions, challenges with sense of identity, disturbed patterns of perception and thinking, impulsive behaviour and intense, volatile relationships. Individuals describe recovery as a continuous and fluctuation process of change that is broader than clinical understanding. This usually begins with diagnosis when individuals are unwell, and through a process of awareness, skills development and growth supported by a context of understanding and positive relationships, can progress from being stuck to independence. Improved wellbeing may be achieved and sustained by many. Contexts that support positive change offer hope, positive and trusting relationships, a sense of connectedness or belonging without judgement. The findings of this review suggest BPD recovery could be viewed as a series of developmental stages such as individuals might have experienced with a more stable early life. The findings of this review appear to be complimentary to previous research and indicate potential areas for further investigation.

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Borderline Personality Disorder; Secure inpatient Service Users' perspectives on what recovery means, its facilitators and barriers.

Word count: 7578 (Main text)

James Baily

Abstract

Introduction: Borderline Personality Disorder (BPD) is a psychological condition characterised by intense emotional and relational experiences. There is a lack of representation of service users' personal experiences and conceptions of BPD recovery and the facilitators and barriers to it in forensic settings in the research literature. Male service user views are also under represented, and this study aimed to ensure these were included.

Method: An Interpretive Phenomenological Analysis (IPA) approach was used to explore the experiences of seven participants: Female (n = 3), Male (n = 4). Participants were all inpatients within medium secure mental health services. Interviews focussed on experiences and understandings of recovery and its facilitators and barriers. Themes were developed for each interview transcript, followed by group experiential themes.

Results: Analysis resulted in four group experiential themes. The first, 'Developing BPD, instability early in life' relates how negative early life experiences impacted participants' mental health and development. The second, 'Developing awareness and taking the first steps to recovery' is concerned with beginning the recovery process and what participants need. The third, 'Anticipating and living the reality of recovery' outlines participants understanding of recovery. The fourth, 'Overwhelmed by the power of a problematic system' identifies participants challenging experiences whilst in medium secure treatment settings.

Conclusion: Participants understandings of recovery from BPD in forensic settings are broader than symptom reduction alone. Recovery is seen as a non-linear journey, and that living well with BPD using new skills and good relational connection, supported by knowledgeable and compassionate care environments, is more realistic. Individuals with BPD in forensic mental health service settings can feel shame related to past experiences and behaviour, and therefore need staff to be understanding and non-judgemental. Epistemic injustice and iatrogenic harm are emphasised as barriers to recovery. Psychologists with experience in this field could offer training to staff, family and significant others.

Keywords: Borderline personality disorder (BPD), emotionally unstable personality disorder (EUPD), recovery, facilitators and barriers.

Highlights

- Service user understandings of recovery are broader than symptom reduction.
- Recovery from BPD requires a compassionate, knowledgeable, non-judgemental care environment where trust, relationships, awareness, adaptive coping skills and hope can come together in varying ways for individuals.
- Recovery is characterised as a potentially life-long non-linear journey with achievements and setbacks, or ‘yellow brick road’. There will always be challenges, however, with new skills, good relational connection, occupational, educational and recreational purpose, wellbeing can be achieved and substantially maintained.
- Epistemic injustice and iatrogenic harm are significant barriers to recovery. Quality of treatment is variable across different care providers.

Introduction

Individuals with a diagnosis of borderline personality disorder (BPD) commonly experience symptoms, including emotional instability (also known as affective dysregulation), disturbed patterns of perception (perceptual distortions) and thinking (cognitive distortions), impulsive behaviour and intense, volatile relationships (NHS, 2022). The Diagnostic and Statistical Manual of Mental Disorders – Fifth Edition (American Psychiatric Association, 2013), criteria for BPD specifies "*a pervasive pattern of instability of interpersonal relationships, self-image, and affects, and marked impulsivity beginning by early adulthood and present in a variety of contexts…" (p. 663),* with nine distinct patterns of behaviour or experience, five of which are required to make a diagnosis (American Psychiatric Association, 2022).

In Western community populations, BPD prevalence rates range from 4.4% to 21.5% (Quirk et al., 2016) with a prevalence of approximately 10 – 30% in outpatient settings, 15 – 20% in inpatient settings and 0.5–1.4% in the general population (D'Agostino et al., 2018). Research into BPD is less frequent compared to other common mental health conditions, possibly because of its complexity, heterogeneous clinical presentations and implications (D'Agostino et al., 2018). Much of the BPD literature focuses on female and inpatient populations, with male and community populations less well represented. Interest in BPD from the perspective of clinicians is reflected in the literature but the service user voice is under-represented (Horn et al., 2007).

A number of models have been developed to understand the aetiology and presentation of BPD, including, the Borderline Personality Organisation model (Kernberg, 1967); the Emotion Dysregulation Model (Linehan et al., 2007); Reflective (mentalisation) Dysfunction model (Fonagy &

Target, 1996); Interpersonal Hypersensitivity model (Gunderson & Lyons-Ruth, 2008); Hyperbolic Temperament model (Hopwood et al., 2012a; Yalch et al., 2015; Zanarini & Frankenburg, 1994) and Interpersonal Dysphoria model (Monti & D'Agostino, 2018). The Emotion Dysregulation model is the model that Dialectical Behaviour Therapy (DBT) is based on, and Mentalisation Based Therapy (MBT) is based on the Reflective (mentalisation) Dysfunction model (D'Agostino et al., 2018).

The Hyperbolic Temperament model and the Interpersonal Dysphoria model are the most recent and try to assimilate aspects of the previous theories. There is evidence to support all of these and may indicate elements in common or closely related concepts (D'Agostino et al., 2018). The hyperbolic temperament model (Hopwood et al., 2012a; Yalch et al., 2015; Zanarini & Frankenburg, 1994), characterises BPD with three main features: emotion dysregulation, interpersonal hypersensitivity and impulsivity. It also suggests there are acute and temperamental symptoms; the former include impulsive coping strategies (e.g., non-suicidal self-injury) and pervasive negative emotions and inappropriate interpersonal behaviours (e.g. behaving in a demanding or devaluing way). The temperamental symptoms are related to chronic dysphoria, interpersonal dependency and fear of abandonment. The Interpersonal Dysphoria model places dysphoria at the core of BPD. Dysphoria is described as negative, emotionally complicated and characterized by discontent, irritability, interpersonal resentment and surrender. It is thought to function as a 'psychopathological organiser' through giving meaning to manifestations of BPD. The model posits 'background dysphoria', is a persistent emotional state pervading the ongoing lived experience of BPD, and 'situational dysphoria', appearing in some stressful circumstances when background dysphoria and negative interpersonal style interact. This is an acute emotional state dominating the here-and-now experience of BPD. Symptoms of BPD are seen as surface presentations of situational dysphoria. Exploration of the course of BPD indicates reductions in symptoms over time, although functional recovery is less consistent, and further research related to improving functional outcomes is needed (Biskin, 2015). These elements may be reflected and augmented through the exploration of Service Users (SU's) perspectives on the aetiology, experience and recovery from BPD.

Recovery

One definition of recovery from the US Substance Abuse and Mental Health Services Administration (SAMHSA) is '…*a process of change through which individuals improve their health and wellness, live a self-directed life and strive to reach their full potential'* (SAMHSA, 2023). A New Zealand definition of the term was '…*living well in the presence or absence of one's mental illness*' (p. 57) (O'Hagan et al., 2012). These definitions are good general approaches to defining recovery, but they are broad and relate to mental health in general. One approach borne from a social movement, the recovery model of mental health (Warner, 2010), a holistic, person-centred approach to mental health care, does not prioritise full symptom removal but focusses on resilience and control over problems and life (Jacob, 2015). Building resilience within mental illness and supporting those in emotional distress is an emphasis of the model. Guiding principles include emphasising hope and a strong belief that regaining a meaningful life despite ongoing symptoms, is possible. Recovery is frequently seen as a process, or conceptual framework (Jacob, 2015). This model posits that the most effective recovery process is directed by the patient (Lyon, 2023). While there are likely many common elements shared between recovery from a broad range of mental health presentations and from BPD, particularly as they may be co-morbid, exploration of service user views may offer specific insights for consideration.

Research into recovery in BPD is limited and focused on staff perspectives. Several studies have found that staff hold more negative attitudes towards individuals with BPD than other diagnoses (Woolaston & Hixenbaugh, 2008; Bodner et al.,2015; McKenzie et al.,2021). These negative views are often consistent among some mental health staff (Shanks et al., 2012), and themes that emerged show that individuals with BPD are viewed as '*a waste of time*' and '*manipulative*' (McKenzie et al., 2021; Woollaston & Hixenbaugh, 2008). However, it is important to understand the service users' perspective on recovery, which has received less focus.

One such review of SU perspectives in a forensic setting, a meta ethnography by Cartwright et al.(2021), found many elements of recovery in the service users' experience are similar across therapeutic modalities, for example, the therapeutic relationship, trusting relationships with peers and professionals, developing insight, self-worth and hope emerged as themes consistent with previous studies (Holm & Severinsson, 2011b; Horn et al., 2007; Hussain et al., 2020b). Having little or no knowledge about interventions, alongside a lack of choice and agency in relation to these, appeared to interfere negatively with recovery (Cartwright et al.,2021). Epistemic injustice, where harm is done to someone by having their capacity as a 'knower' or 'transmitter' of knowledge (e.g., their experience and understanding of illness and recovery) is undervalued due to prejudice and appears to be a significant barrier to recovery in forensic settings (Cartwright et al., 2021b; Markham, 2022). Iatrogenic harm, where individuals are harmed by the process of treatment, also seems to be prevalent in this setting (Markham, 2021). This is useful for highlighting facilitators and barriers to engagement in recovery; however, exploring a wider question of what recovery is to individuals in forensic settings may reveal new themes and add to the SU voice in the literature.

Katsakou et al. (2017) explored a wider concept of recovery through synthesising findings from fourteen qualitative studies exploring SU's with BPD, experience of treatment within a community setting. Their synthesis highlighted ten themes, within three domains. These are shown in **Table 1**.

Table 1: Domains and themes relating to recovery (Katsakou & Pistrang, 2017).

Domains	***Areas of change***	***Helpful and unhelpful treatment characteristics***	***The nature of change***
Themes	*Developing self-acceptance and self-confidence*	*Safety and containment*	*Open-ended journey*
	Controlling difficult thoughts and emotions	*Being cared for and respected*	*Series of achievements and setbacks*
	Practising new ways of relating to others	*Not being an equal partner in treatment*	
	Implementing practical changes and developing hope	*Focusing on change*	

The review identifies recovery elements and processes experienced by individuals with BPD, and what they value in treatment. These are broadly consistent with descriptions of recovery already discussed, e.g., the recovery model (Warner, 2010). However, further insight is needed into understanding how recovery changes are made and maintained. The majority of participants in the studies reviewed were female and therefore further insight is needed into male perspectives and experiences. Participants were all receiving treatment in community settings, and exploring the views of individuals in forensic settings would extend the literature.

Another BPD recovery conceptualisation was highlighted by Kverne et al. (2019), who interviewed 12 female SUs recently diagnosed with BPD in community settings about their experiences with recovery and treatment. An overarching theme of '*working toward connectedness*', with four sub-themes emerged. These were "*Learning to hold one's own*," "*Needing honesty and genuine mutuality*," "*Daring to belong*," and "*Making room for recovery".* This conceptualisation of recovery emphasises a strongly expressed need for genuine mutual connection and a sense of belonging. This aim is achieved by learning skills, developing two-way relationships, fitting what needs to be done into everyday life and accepting belonging and connection instead of rejecting others due to mistrust, for example. This is a helpful description of recovery as it is specific and demonstrates common elements with non-BPD recovery models. This study also suggests ways recovery changes can take place over time, starting to address the Katsakou et al. (2017) question of how recovery happens. However, it does not include forensic settings or male participants, and thus may miss important reflections from these populations.

Aims

There is a need for specific research into the views of service users' in forensic settings about what recovery with BPD means to them. It is also important to understand what the barriers and facilitators of recovery are for them, alongside the process of recovery. This study aims to represent a balance of male and female participants so that male perspectives are better represented. The objective is to develop a rich understanding of SU perspectives on recovery, to explore whether there are significant differences between what services and service users are working towards and how services can best support individuals to achieve and maintain recovery.

Method

Design

Interpretive phenomenological analysis (IPA) was chosen for this study due to its explicit focus on understanding the lived experience of individuals, without the imposition of other theories or understandings (Smith & Osborn, 2015). The IPA process explores the detailed experiences of each participant iteratively, before assimilating them and developing overarching interpretive themes. IPA is a methodology well suited to exploring topics which are complex, ambiguous and emotionally laden (Smith & Osborn, 2015). IPA is similarly suited to homogenous samples (Hefferon & Gil-Rodriguez, 2011; Larkin et al., 2018), which individuals with BPD in secure inpatient settings may potentially be. Experiences of BPD, therefore, may be understood more comprehensively using this methodology. Grounded theory (Charmaz, 2014), was considered due to the possibility of developing a model of recovery processes. However, to develop an effective model required more interviews than were possible within the time available.

IPA requires rigor of analysis and this facilitates the reduction of researcher bias. This approach is appropriate for exploring understanding of recovery from and with BPD allowing for the complexity and subjectivity of perspectives.

Ethical considerations

This project received ethical approval from Research Ethics Committee 6 (Wales) in December 2022 (**Appendix J**) following review by Cardiff University School of Psychology Research Governance and Ethics team and the Ethics Committee (**Appendix K-L**), in addition to agreement from all participating Health Boards Research and Development departments (**Appendix R**).

Participants

Seven (3) participants in total were interviewed, including both male (n = 4) and female (n = 3) (3) SUs. One female participant interview was short and was excluded from the analysis. Five participants were between the ages of 30-39, two were in the 18-29 range and one was in the 50-59 range. Length of admission ranged between 1-2 years (n=1), 2-3 years (n=1), 3-4 years (n=1), 4-5 years (n=2), over five years (n=3). All participants were from the U.K. and English was their first language. Six participants had confirmed diagnoses of BPD. Some preferred not to say (n = 2), however clinicians confirmed their diagnosis. Some participants had co-morbid diagnoses cPTSD, depression, anxiety, paranoid schizophrenia, Attention Deficit Hyperactivity Disorder and BPD with antisocial PD traits.

Inclusion and Exclusion criteria

The following inclusion and exclusion criteria were used (**Table 2**).

Table 2. Inclusion and exclusion criteria

Inclusion	**Exclusion**
• Male and female. • Adults (18yrs +). • Receiving mental health care in NHS and private settings. • Service users who have formal diagnosis of BPD, and may have co-morbid diagnoses. • Service Users who have capacity to understand the process, given informed consent and are willing to participate.	• SUs whose primary diagnosis is not, BPD. • SUs who have disengaged from services/interventions. • SUs who are in crisis. • SUs who may pose a risk to researcher. • SUs who are unable to give informed consent.

Recruitment

Participants were recruited from NHS and independent services in the United Kingdom. Participants were provided with information about the study by a field link (a psychologist working in the participating settings). This included providing the study participant information sheet (**Appendix N**). Field links were available to answer potential participant's questions about the study. The researcher met with field links (Clinical & Forensic Psychologists) to discuss the research project and inclusion criteria. Field links approached people within their service who met the inclusion criteria that had formal diagnosis.

Materials

Participant and staff information sheets were disseminated to participating research sites in advance of interviews (**Appendix N-O**). The interview schedule was co-produced with a service user representative, and was used to guide each interview **(Appendix M**). Participants completed a demographic questionnaire (**Appendix Q**), then read and signed a consent form before commencing the interview (**Appendix P**). Interviews were recorded on an encrypted Dictaphone. Interview recordings were transcribed by the author and by a professional transcriber (**Appendix S**) for an example of the transcript).

Data collection and procedure

Rich qualitative data was gathered through semi-structured interviews. Participants choosing to participate were invited to interview in a private clinic room at each location, and were offered the choice of having a clinician present or available in the next room. Three participants were interviewed online using video conferencing software, all of whom had a clinician present. Before interviews began, participants were reminded that they could withdraw from the study at any time without consequences, their responses would be anonymised and were offered the opportunity to ask questions. Each participant was interviewed once in their care setting for between thirty and sixty minutes. A debrief consisting of checking in with participants about how they were feeling and asking if they needed anything. They were also reminded that if they needed support they could request it from the onsite researcher (field link) who was one of their clinicians.

Interviews were transcribed, coded and analysed allowing theme development grounded in the data. Following interviews, the researcher reflected on impressions from interviews in supervision alongside later impressions from listening to recordings and transcriptions.

Quality

A plan for maintaining quality was followed to strengthen reliability and validity of the study. Four quality indicators outlined by Nizza et al. (2021) were used measure and improve quality. These were: Constructing a compelling unfolding narrative, Developing a vigorous experiential and or existential account, Close analytic reading of participants' words, Attending to convergence and divergence. Additional checks included: Review of the interview schedule and participant information sheet by a SUC representative, the research team and field links. Transcripts, coding and theme development were reviewed by a member of the research team. A reflective journal and notes were kept throughout data collection, analysis and supervision processes. Reflections and reflexive observations were shared throughout with a member of the research team who has worked within inpatient mental health rehabilitation to check its face validity. A reflexive statement can be found in (**Appendix F**).

Analysis

Standard IPA guidelines (Larkin & Thompson, 2011; Pietkiewicz & Smith, 2014) were followed during data analysis. Each transcript was analysed one at a time, enabling the author to immerse themselves in the experiences of the participant. Starting with the first participant, their transcript was read and any thoughts, ideas, emotions and reflections on the interview and reading the transcript were noted. The purpose of this was to aid author awareness of biases and experiences of their own that may influence data interpretation. Free-coding then took place where exploratory ideas, quotes catching the author's attention, thoughts and emotions about the participant's experience were noted on the transcript (**Appendix S**). Line-by-line coding pertaining to experiences and meanings for participants was performed on the transcript (**Appendix S**). Emergent themes were organised in sequential tables in a spreadsheet with the supporting quotes (**Appendix T**). This process was repeated with all transcripts and the reflective journal was referred to regularly during the data-analysis and supervision.

IPA follows a circular process (Smith & Nizza, 2021), and as new themes emerged from subsequent transcripts, the researcher checked to ensure new themes resonated with quotes from other participants and updated the table of emerging themes.

Themes and subthemes were organised into a global structure to merge the data. Similarities and differences between participants' experiences were explored and themes were refined (**Appendix T**). Themes unrelated to the question were removed. They were then condensed by collapsing similar concepts into each other and applying psychological theory to create the final list of superordinate and subthemes (**Appendix T**).

Results

Four group experiential themes and eleven subthemes resulted from data analysis **(Table 3)**. Subcategories are identified throughout in italics. An account of the primary themes will be provided using direct quotes from interview transcript data. Redactions of identifiable information and clarification will be included within [brackets]. Omissions are indicated with the use of ellipses (…). Please see **Appendix S-T** for examples of transcript coding and theme development. All participant names are gender neutral pseudonyms.

Table 3. Distribution of themes across participants

Participant	**001 - Ashley**	**002 - Leslie**	**004 - Taylor**	**005 - Blair**	**006 -Alex**	**007 - Charlie**	**008 - Jamie**
Theme							
1. Developing BPD, instability early in life	x	x	x	x		x	x
1.1 BPD genesis in experiencing trauma and instability		x		x		x	x
1.2 Disconnecting and feelings of loneliness	x	x	x			x	
1.3 Experiencing intense emotions	x	x	x				
2. Developing awareness and taking the first steps to recovery	x	x	x	x	x	x	x
2.1 Developing awareness	x		x	x		x	
2.2 Starting the process, first steps	x			x			x
2.3 Seeking help, understanding and safe relationships	x	x	x	x	x	x	x
2.4 Compiling a toolkit for change	x		x		x	x	x
2.5 Context for recovery	x		x				x
3. Anticipating and living the reality of recovery	x	x	x	x	x	x	x
3.1 Envisaging the recovery journey	x	x	x	x	x	x	x
4. Overwhelmed by the power of a problematic system	x	x	x	x			x
4.1 Feeling the challenges of the system, and some positives	x	x	x	x			x

1. Developing BPD, instability early in life

This main theme was represented across six transcripts, illustrating early experiences of instability, trauma and challenging relational dynamics leading to mental ill health. This indicates the commonly observed situational and interpersonal experiences at play in the development of BPD for many.

1.1 BPD genesis in experiencing trauma and instability ideas emerge in four interviews illustrating early experiences that appear to be related to participants' everyday instability due to chaotic family life and poor coping strategies in response to concomitant mental ill health. For Charlie, these experiences were so bad, self-harm seemed like an option; "*When I was nine years old things were unstable at home with my biological parents...had to go into foster care...I tried harming myself...so my Gran took me out [of foster care] …,*".

This participant observed that the introduction of a stable, consistent home life made a significant difference, alongside positive relational connection. For Charlie, this meant a warmth and security not experienced often before; "*There was stability there...My grandmother didn't have addiction issues, they was working a proper job...so was their husband, there was stability... love and affection...consistent*,"

Similarly, another participant described instability and then explained how they responded to it. This participant asserted that the instability had meant that the environment was working against them, which angered them. Blair: "*it [instability]...controlled me as a child, it made me very angry...thinking the world was against me*," Trauma, survival and guilt emerged consistently, illustrating a range of traumas in early life. Participants described what they experienced whilst trying to get what they needed. The emotional and developmental influence is seen throughout quotes relating to trauma and survival. The following participant explained how they responded to their and their sister's traumatic experiences; Lesley: "*me and my sister got sexually abused...between the ages of [redacted]...went on for a long time...I blamed myself…*,"

Not all traumas were sexual in nature, as illustrated by quotes from Charlie, and could be one or more of a range of unpredictable and emotionally stressful circumstances, often requiring having to take responsibility for serious matters without support at a young age. This became normality for them at an early age, meaning their view of the world was that it was frightening and they were alone; "*I remember one incident where they [mother]… [Redacted. Traumatic experience/non-sexual] ... it was normality by then...; when I was 13 years old...my stepfather was...emotionally unavailable*,"

One participant illustrated how experiencing physical and psychological bullying, romantic rejection and sexual abuse led to anger and a sense of needing to take control to meet their needs as opposed to fostering romantic relationships appropriately. Bullying and rejection seemed to be a common experience early in life for Jamie; "*I was the punchbag … and I would just be the person that would have to deal with that; I... struggled...in…High School...to make … [romantic] relationships...my behaviour ... became ... sexually inappropriate ... I was sexually abused …; …and…behaviours came… out,"*

1.2 Disconnecting and feelings of loneliness appear as consistent experiences when participants reflected on their relational lives and histories. This often related to family relationships, particularly with parents. Charlie described how their mother recently confirmed that their stepfather rejected them as a child, confirming their understanding that they hadn't been wanted; "… '*Yes, he did treat you different.'... 'He only put up with me because I was with you.' ...she said; he was aggressive and very emotionally unavailable...I would...cuddle him to say goodnight...He would flinch...shoulders would come up...ask him a question and he'd...blank me...And just not respond. Carry on watching TV, wouldn't even look at me like that; I do get rejected...sense of dysphoria...,*"

Lesley spoke about the assumptions they made about themselves to understand why they were feeling consistently rejected by their father. The meaning to them appears to be that they were different in such a way as they wouldn't, or couldn't be wanted; "*I remember wanting to be with my dad and like feeling, okay, well, I must be different because he doesn't want to know,"*

Taylor described how their developing illness isolated them, led them to self-harm and hurt others, engendering feelings of guilt. Later when in the prison system, they explain the emotional impact of enforced isolation from family. This impact seems to be centred around a loss of hope for achieving what they need and loneliness; "*But years ago, I couldn't speak to anybody... [due to] my PD... I even hurt myself or hurt others…end up feeling guilty ...; ... locked behind a closed door with nothing … and even if my family did come and visit me in prison ... only for an hour ...; ... felt like nothing ... pointless seeing them ... heart breaking seeing them walk through that door*"

Ashley talked about the experience of being misunderstood, loneliness due to not maintaining friendships and a sense of being cut out of their family; *"I mean I don't even know what sexuality I am…. I think I'm gay...I'm not sure...but people don't understand me; I'm never keeping friendships going so nobody visits me...I find that I'm very lonely...every day going down [name of place] having a* *smoke, that's my life...; so they [family/siblings] shared [inheritance when father died] between them and they didn't give us [me] anything...I was on the streets...that money would have helped me get off the streets,"*

1.3 Experiencing intense emotions emerged as a subtheme across three interviews, describing how BPD affects them emotionally and the intensity and persistence of that experience. A sense of extremes and concomitant responses emerged and the idea that this is something they need to take control of. Ashley describes panicking and taking control by pushing people away, suggesting then that they are lonely due to having few connections. In a sense, to Ashley, safety requires loneliness; "*you basically go into panic mode … you're pushing away... when someone coming on to you basically go into panic mode…; I find that I'm very lonely... that's my life you know*,"

Taylor similarly describes emotional extremes and makes an explicit link to BPD, explaining the experience of being unaware when unwell, and then progression on to more significant symptoms and trying to end their own life. The intensity and consequences are such negative experiences that extreme solutions are deemed necessary, indicating a sense of there being no other way out; *"when I've gone high...and I've crashed, that's the EUPD [Emotionally Unstable Personality Disorder] …emotional...tie ligatures, or cut myself; that's EUPD...that's definite...a state where I'm not thinking... not seeing what I'm doing...not feeling what I'm doing; Then I hear voices...then...it has a ripple effect; ...seeing things...and trying to end my life; ...emotions were all over the place. I didn't mean to commit my offence...,"*

Lesley emphasises these symptoms as fast and extreme using a strong metaphor which seems to characterise a physical sense of volatility. They identified negative emotions and self-critical feelings being common and chronic, highlighting long-term low self-worth. Lesley also articulated that BPD is like a separate entity, and takes control assertively if it is taking over; *"constant emotional roller coasters…feelings of…unworthy, shame, all the bad stuff, it just affects you every day … so you take control, keep their [Personification of BPD] on a leash,"*

2. Developing awareness and taking the first steps

This main theme was represented across all participants, highlighting the beginnings of the process of recovery, starting with becoming aware, building relationships, taking steps to engage with support, building a repertoire of positive coping strategies and the contextual and relational requirements for these elements coming together.

2.1 Developing awareness ideas were prevalent in the accounts of four participants; becoming aware of internal experience, knowledge of own triggers and behaviours, coping tools and strategies alongside knowing what they need from supportive environments. Ashley indicates the importance of an awareness of their internal state and triggers, together with an appreciation that their past coping strategy is not acceptable, indicating better awareness of the wider social environment. This appears to indicate not only developing awareness, but a willingness to try something different; *"I find it doesn't help if you just sit there and let it build up...that's when it's gonna [sic] blow; you can't treat violence with violence...it doesn't work,"*

Taylor indicated having developed an awareness of an internal patterns of experience, and how they use a mental model to try to understand these better. This appears indicative of a process of understanding and externalising BPD experiences, potentially facilitating guilt reduction and awareness with insight rather than being consumed by the experience; *"when I've gone high...and I've* *crashed, that's the EUPD...emotional...then I'll go and tie ligatures, or cut myself…; ...It's separate things...they bounce off each other...like ten...different sections with one big circle in the middle…,"*

Blair articulated that being aware of when they are struggling, the help available and what they needed to do to understand themselves and alternatives to old coping strategies such as self-harming, is important. This appears to suggest a focusing in understanding of the self within context, awareness of alternative coping strategies, and perhaps a nascent sense of agency; *"if you kind of get involved with everything that's offered to you– you can go a long way...as long as you don't try too much at once...you need to be aware...when you're struggling, not to say, I'll get it done tomorrow...if you're feeling...bad...you don't want to put that off...you don't know what that could lead to...it's not worth...putting it off...doing something stupid...self-harming: ...if you manage it well and, you're aware of...what your triggers are...you'd be okay...; ...I've done a lot of work with my psychologist, [name]...to figure out why...behaviour happened...; ...you need to accept the help that is – is being offered...,"*

Charlie echoed the need to be aware of and make use of the help available alongside an observation that an insight into themselves and learning self-control were key to achieving a variety of other elements of recovery. This seems to be represented by a sense of experiencing a cohesive 'self' with self-determined direction within a social, leisure and occupational context; *"I think with a disorder like mine, it's about insight...to learn to control your emotions or become aware and manage your emotions; insight…has got to be the main catalyst for recovery...relationships, hobbies...gaining of self-worth, gaining a self-identity...education; be you and find yourself, use this now – there are people in the community who would pay thousands upon thousands for this treatment, use it to your advantage, learn…,"* Charlie also illustrated their awareness of different types of medication for different purposes, identifying the qualities they have and what they help them with. They demonstrated enough awareness of themselves and the tool, to know what to use it for and when; *"the Methadone… masks some of the emotional instability...suppress some of that trauma...benzodiazepines helped with anxiety and hyper-arousal...Methylphenidate...helped my concentration…,"*

Taylor shows they are aware of what kinds of environments are good for their, e.g., the work environment, which they felt eased isolation and poor mental health. They also demonstrate an awareness of an adaptive coping strategy (e.g., talking openly) they can use as an alternative to previous maladaptive strategies, alongside the availability of tools such as therapy and medication; *"very positive to have a job…it's really good for people, sufferers with mental health, because they're not stuck in one bubble; but now I've learned to talk, not to assault…; Talk to people...very important...get everything off your mind...fresh beginning... till the next hiccough. Then talk...scream about it...shout...swear...whichever way you want to do it, without hurting yourself or hurting others...I prefer therapy over medication...medication can be a blocker…,"*

2.2 Starting the process, first steps emerged as a subtheme across three participants; illustrating a combination of openness, engaging with therapy and staff, ability to compromise and flexibility as areas where change appeared to be important for recovery. Blair described their progression through becoming more open and engaging in therapy; *"it's always been difficult trying to speak to people...I'm a lot better these days, talking to people...especially...my psychologist...they managed to drag a lot out of me…; ...That has been a help quite a bit [EMDR]...I did CAT therapy, that … really worked…,"* Jamie also stressed the importance in engaging with services and indicated a need to develop the ability to compromise, highlighting it as an indicator of progress. In this case, a willingness to compromise appears to be part of a willingness to engage, and be open to change and flexibility; *"I spent ... time in hospital ... to work on my offending behaviour ... my behaviour in general; sometimes you do have to just compromise ... when you do ... it shows a progression ... understanding ... that you're working with and on the problems…,"*

2.3 Seeking help, understanding and safe relationships emerged as a subtheme across seven participants. A sense of sadness when connection isn't available, compared to the support gained when trusting relationships are made, illustrates the difference in outcome when participants started to reach out and connect with others. Participants, through reflection on processes such as developing relational skills, identified the importance of connection, a sense of belonging and the reality of their relational needs. An emphasis on good relational connection with friends, family and peers, as well as opportunities to meet new people was observed in participants' accounts.

Ashley reflected on not having friends, and that they did not engage with staff to begin with. They also remarked that this changed and they became able to connect to staff more as they made progress. This reflects a period of settling of chaotic emotional experiences making space for relational development; *"well no I always lose friends because when I make new friends, then I'm getting recalled...so I'm never keeping friendships going so nobody visits me …; … but recently ... I made relationships with staff ... I've settled down ... I do, I find staff very helpful ... because they help people …; I like just being around people chatting…,"*

Taylor highlighted how they constructed trust and connection with staff and how it can be lost, contingent on perceived mutual respect; *"we've done a lot of work, me and [Name/staff], and going* *through all care plans and things to get to know me ...To get to know my triggers and things; ...It's helpful because…when there's an incident…when I slam my door, to give me that ten minutes...Yes, they understand...It's called a PBS plan...it makes me respect them a lot more. They respect me, I respect them. They disobey me, then that's trust gone…,".*

Lesley identified that reaching out to others, both staff and friends, was important to maintain a support network to help cope in times of difficulty. They convey the experience of a balancing act requiring occasional steadying, like when learning to walk; *"I knew I needed help...I walked into [name of place] ... I managed to get a sponsor…; "[Name/staff] is amazing. I said to them when they first started therapy with me ... I will only work with [Name/staff} on a... psychological thing…; ... reaching out is a big thing ... like, I have a good support network ...– friends and staff, like my CPN ... a part of my way of coping ... I will text them on the weekends...that's one way of riding the emotion...,".* However, they also highlight the efforts they have made to connect, what they need from friendship and the importance of good relationships with staff. Lesley emphasises the importance of and their positive regard for their clinical staff, indicating the centrality of this in recovery; *"I've been visiting everybody...But I am going to pull back...I'm the one always reaching out …; ...Yeah. It has to be two-way…; ...You need good relationships with the team. As long as that's cool, don't worry about anything else…; I'm just grateful for the team I've had here the last couple of years. You know, [Name/staff] has been with me since day dot…,".*

Alex spoke about having the kind of relationship with staff where they could trust them to help them manage difficult emotions and alluding to a sense of containment from intense experiences and their consequences; *"like in a situation of ... can't cope ... they will ... if I ask them ... try and ... give me the time so I can speak to them ... Try and calm me down ... tell me to use my – like coping ...,"* Jamie was able to offer further detail about their relational needs, and the kind of relationships that are not helpful for them. They conveyed an experience of feeling safe to be open and sense of being acknowledged being important to them; *"team around me here that I can tell them anything, even if it's related to my offending behaviour and I know that I'm not going to be punished or judged for that. In fact, I'm probably going to be praised for coming forward and talking about the issue rather than hiding it or trying to keep it away from them...; ...I think those non-adaptive relationships are…soul-destroying really, because they say that they're here to help and then they're not helping…that has made me feel…if you're not going to help me, I can't expect the rest of the team around me to help me as well…; ...I've got some really strong relationships with my MDT and with a few staff on the ward. I've also got strong relationships with staff that work on other wards, like [Name/staff]. So, if I ever see them out and about in the grounds, they always comes over to say hello, which is quite nice. Because… it feels like that people are remembering you and that they're still showing a level of care, even though they are not directly involved with me...,"*

Blair enjoyed and valued meeting new people and hearing their stories, but also work acquaintances and staff were a support because they were a stable group to belong to. The power of good friend and family relationships is also illustrated, characterised by the experience being included and belonging; *"...meeting new people and chatting to people, and, you know, you'd hear everybody's like stories working in a pub; …in work were people who were quite sensible and, you know, were like level-headed…; ...the staff are pretty good. I tend to be a bit of a – a joker sometimes and we have quite a bit of banter...I talk to staff...; … There's nothing stopping me when I'm with friends and family...my Mum says, …they's always going to support me and…my brother says the same… I think, I feel pretty good when they say that...Just knowing that you're not on your own…,"* Illustrating the importance of fulfilling relationships, the need to hang on to them and skills that can be used to maintain relationships, Charlie described these needs alongside knowing that BPD often has an impact in this area, and how the ability to reflect on others' perspectives can help; *"I think people are important ...that's where things went wrong for me, I was lonely …; …having relationships is part of having a good life, or, a better life, I think a stable supportive relationship that have insight into the disorder ... who you are as a person, as well as you having insight, or being able to mentalise around other people's values,"*

2.4 Compiling a toolkit for change ideas appeared across five participants; characterising a variety of skills a from medication and psychological skills to more practical strategies. Both Ashley and Taylor spoke about using medication as one of their tools, however both also gave the sense that they would rather not use it, or only find it a limited help respectively. Both have developed other coping strategies including using distraction and long-term psychological support. Taylor: *"medication is a big one...But I don't...like taking medication. I'd rather therapy instead of medication,"* and Ashley: *"I like to listen to music...can take your mind away from...things...what I do...distraction...once you start going up there you gotta [sic] do something…; ...walking away from bad situations that's the best thing to do don't get yourself involved...; ...they can give you is this tablets...they [tablets] work for it now and again...,"*

Jamie identified building a range of strategies to choose from in times of need, but also knowing when they need help. They anticipated learning the skills they will need to manage daily life in the community; *"…built up...arsenal of coping strategies... Then...trying and deal with it at the time in a constructive manner...able to understand that sometimes things just don't go the way you want them; ...my skills are about...dealing with negativity...trying to find a solution to a problem; the focus now...learning to cook… for an independent life, learning to use local transport; To be open and* *honest...about what is going on in my head...about whether I can deal with it myself or...I need somebody to...help me through,".* Charlie echoes many of these skills and approaches on this aspect of recovery, demonstrating the range of abilities coming together to support ongoing positive change; *"I use mindfulness ... problem-solving skills… bought myself some DJ mix decks ... laptop ... as a hobby; ... therapies can help you gain insight ... doing something with my psychologist about my values and identity ... insight is the main catalyst for recovery ...; ... love yourself, be compassionate to yourself ...,".*

2.5 Context for recovery was a subtheme represented across three participants; this identified key elements needed in the environment to effectively promote and sustain recovery. These included having a supportive family, exercise and good health, love, occupations where colleagues understand their difficulties, having hobbies and worthwhile activities.

Jamie envisages all of these elements working together, much as they commonly do for people in the general population, perhaps aspiring to enjoying life as others do; "*... with the help of like my mum and dad ... home team to overcome, and … continue to live ...; if I … recovered ... I would have ... a job that I could be satisfied with that's not too stressful, that understands my condition ... having a social network ... through work or a ... hobby ... maybe ... a family ... an intimate relationship ... doing ... exercise ...,*".

Taylor conceptualises elements they need such as relational connection, having a way forward and an aim in mind, in their '*yellow brick road'* analogy. They also make a more concrete link to opportunities available to them in hospital such as leave in the community; *"The easiest way of putting it, it was my yellow brick road, where Dorothy...the tin man...scarecrow...lion...eventually you reach the* *castle...that would be your house...So, you've got to follow this...so the scarecrow could be [Name/staff]; it could be one yellow brick road, it could be my emotions or PD or anxiety or my journey out of here, my recovery, whichever way I want to work it, I always end up with positivity because I stop and think. I think, right, Taylor you've got a ground, you've got to create, you've got escorted [leave], you've got group leaves, you've got all this going for you,".* Taylor also echoed other participants identification of having a worthwhile occupation, or way of earning money in the community. It appears to represent a vision of real life and an opportunity to be self-supporting and to make the most of life with a self-earned income; *"I'm going to be washing the clinic cars...Hoovering them and wiping them and so, that will give me a bit of a boost; it will give me a pinch of my proper life when I'm out there, getting a job …; I want a voluntary job ... So, I'll be working in charity shops or with animals or something ...; Not just sitting down, it's having money ... and doing something to get the money ... to enjoy your life,"*

3.0 Anticipating and living the reality of recovery.

This main theme was present across seven participants' interviews, indicating a breadth of consistent views. These were mainly characterised by the reality of everyday management of recovery as a journey, and the skills and tools they will use to reach relational, occupational, educational and other aims as they recover.

3.1 Envisaging the recovery journey involved both looking forward to a time when participants were functioning to the extent that they could have a more usual experience of life, whilst acknowledging that they may experience BPD challenges occasionally. Ashley highlighted they can live a '*normal*' life but there are no quick fixes, and they will need to use their strategies to manage; *"I mean I can live a* *normal life but you still struggle, it's really difficult avoiding bad situations ...; ... there's like no magic wand for anything …,".* Similarly, Blair thought that mental health difficulties will always be a risk in the future, and the emphasis is that recovery is an ongoing process of management; *"I don't think that mental health just goes away like that ...; ... I wouldn't say so much of a cure...I'd say it's more about...managing it correctly...it's...like...when someone has alcohol problems or ... there's always that risk of [relapse] ...,".*

Blair also paints a broader picture of what recovery means to them; "*I always wanted to just not be getting into trouble ... wanted to settle down … just be sensible…; ... recovery for me would mean being out on the community, knowing that I need my medication...keep taking my medication...if I'm struggling or feeling like self-harming, make sure that I talk to a member of my team...Having my connection with family and friends....I like to be outdoors...; ...go out into town whenever I want...; ...Just carry on going forward; ...I'd just like to be settled with family...just days out with the family, like, going to the beach...doing every day-to-day family stuff...,"*

Taylor used the analogy of the yellow brick road to visualise their recovery, and to characterise it as a journey with a goal and good connection to people to who can help along the way; *"Is to follow the yellow brick road ... That's when I'll have a job ... I'll have my daughter back ... getting supported housing and then working with the community team for a couple of years, and getting my own house, then I'll have my daughter to visit. It will be amazing; ... I'd probably go back to the farm. I'd have a nice job; ... I'd earn my own money ...,"*

Charlie outlined a comprehensive vison, with elements consistent with other participants, but which expanded the idea further, incorporating ideas around resilience, addiction, goals and purpose; "*... it's* *[recovery] the ability of building up a resilience towards some of the … trauma ... maintaining your goals and aspirations ... the drink and the drugs, staying clean ... managing ... your emotions … lifestyle outside of hospital ... supported accommodation ... nothing exciting or extravagant ... average life ... being reasonably content with the life you have ... Not being impatient; ... alongside education and hobbies people are important...; ... some voluntary work to begin with; ... working with occupational – therapy; I think addiction is always going to be primary – it's always going to be the biggest challenge for me; ...having my own one-bedroom flat in a community house...going out, semi-supported...The rest, on my own...driving licence in the future...get back into education...voluntary work or peer mentoring...,"*

Lesley described their reasonably recent progression to having a more stable life and recovery as they were experiencing it at that time; "*...Now, it's [Mental health] the stablest it's ever been; ...I haven't been bursting out in tears since Christmas as much ... getting better … is ... finding the right therapies and doing them... I will never be fully better; ... I'm in control of my life now. I never was before; I see the world in a different light now. I notice the colours and the trees and everything and I never used to notice that. You know, nature and stuff, ... But also, like giving back. I've worked in charity shops for year; ...having a life, having the skills,".* These reflections seem indicative of how negative emotions have made room for the influence of confidence in new skills, hope and agency in manifesting wellbeing and a life worth living.

4. Overwhelmed by the power of a problematic system

This main theme emerges across five participants, and is characterised by narratives of frustration around services not being there when needed, and when they are, they are oppressive and dealing with the system's requirements, rather than the needs of the SU.

4.1 Feeling the challenges of the system, and some positives*,* is a common theme in participants' experiences of prison and forensic mental health settings, the judicial system and community-based services. Charlie emphasises that it would be helpful if others had more in-depth knowledge of the condition, and could therefore understand their challenges better; "*I think personality disorder generally gets a bit of a bad rep … it's important for people to distinguish between the cluster B type personalities, the special borderline personality disorder, narcissistic and anti-social … [its important] people see that when your brain is formed as a child, if you're under constant threat, your brain is going to form differently ... you're going to grow up being an adult rather than being more focussed on learning, achieving and progressing. You're going to be more focussed on self-soothing and whether that be drink, drugs or whatnot…,".* The inference appears to be that people don't understand the complex reasons for the way they are, and that because BPD has a bad reputation, so do they.

Taylor describes how they feel their conviction is wrong due to their mental health presentation, but then in addition, that staff may sometimes be prejudiced against them due to that conviction; "… *but when I'm well enough, when I'm out … I'll be appealing my conviction ... that's caused a lot of distress on me because I didn't mean to …[offence]; ...– when you're on a sentence, or a conviction … the staff can – they shouldn't do but they can tell you – do against you...to make your life that bit harder...,*". This judgement of their character is keenly felt, experienced as unjust and is seen as a barrier to recovery.

Blair describes the sensory environment in prison and the impact of that when already trying to cope with mental health challenges. They also observe that there are limits to prison mental health teams' knowledge and treatment options, and this had a negative impact; "*But in gaol … it's really noisy, it's really busy and – especially when you have mental health problems…; I've always found the mental health teams in prison can only help so much…, when you have mental health problems and you ask for a bit – a bit of support and, sometimes, if they don't know what to do, it's usual for them to lock you in your cell, rather than deal with the problem; ...I was getting restrained all the time and, you know, I was kind of being left in a cell*...,". This conveys a sense of chaos and isolation built into the system due to a lack of knowledge and resources, that at best is not conducive to recovery and at worst can be damaging.

Lesley reflected on how they had sought help without success for a long time before accessing care, and more recently, the personal emotional impact of waiting for placements when they fall through. They describe a sense of being static or without purpose, leading to the return of intense emotional experiences; *"...but I was begging services for help all my life practically... it's hard out there…; I was only existing before I came into services… Lost my income completely…; I was supposed to go to my placement in the September, but that fell through and it was dragging on for months... like living in limbo, I can't do that... It makes me so emotional. I need structure*,". They seemed to indicate a sense of irony around there not being help when asked for, and when the system does kick in, it does it poorly.

Ashley explained their moral dilemma in relation to meeting the requirements of the system, and how this can result in their remaining stuck within it; "...*they want ... that I'm not going to have a drink ...* -

and I won't lie to them, but if I lied to them and said Oh no, I'm not touching it, I'd be out! ... Why lie to them I'm gonna [sic] do it anyway? so I've been truthful with them saying I'll drink when I get released, I will go out and drink, and because I'm saying that it's preventing it from moving forward; ... I'm getting dragged in all the time I get brought back not because I'm doing anything wrong but because I'm breaking one of the rules…,". This reflection indicates their struggle to reconcile the rules and what they see as right or wrong alongside the irony as they interpret it, of being honest and being punished for it. Unfortunately, they struggled with and found it difficult to meet the expectations of the service, highlighting that they did not have good relationships with staff or the service. This combination of experiences, perspectives and lack of functional, insightful relationships appears to have been a significant barrier to their recovery.

Taylor identified that there is significant variability in the care provided by different hospitals and services, but that currently their experience is positive. They highlights that this is due to the team around them; *"Yes, it's all been here [This hospital, skills] ... it's quite upsetting really because you'd think every hospital was the same, but it's certainly not; ...Catching up with … the team to let them know my triggers and my good points and my bad points and it's just good all round this hospital it, it's amazing,".* This indicates the importance of the right environment that this can have a significant impact on recovery. Jamie also describes a positive experience of a past care setting, where there the environment and context was more connected and stimulating; *"when I was in [Name] Healthcare, we had activity co-ordinators, technical support workers, OTs ... café was open seven days of the week ... art therapists, drama therapists, advanced movement therapists, creative art therapists. There was a lot more going on in the community...,".*

Discussion

This study focused on SU's in a forensic setting perspective on the meaning of recovery from BPD, and the facilitators and barriers to it. Participants experiences suggest recovery is a life-long on-going journey rather than a time after which there are no problems. This is consistent with the research, for example, the Katsakou & Pistrang, (2017) review themes, which highlight the nature of change as being 'an open-ended journey', and 'a series of achievements and setbacks'. They also expressed how good relationships with friends, family and staff are key to generating and maintaining wellbeing. In addition to this, participants identified a range of skills that were needed to cope with their BPD symptoms and start to build a life with a sense of purpose and belonging. Unfortunately, participants also highlighted areas of their experience relating to struggling with the power and requirements of the forensic mental health system. They report instances of both epistemic and iatrogenic harm which had a negative impact on their recovery journey. The four main themes were:

1. Developing BPD, instability early in life;
2. Developing awareness and taking the first steps to recovery;
3. Anticipating and living the reality of recovery;
4. Overwhelmed by the power of a problematic system.

The first main theme: Developing BPD, instability in early life, indicates there are many negative experiences the participants shared. These generally happened throughout early childhood and adolescent years, reducing their opportunities to develop secure, loving attachments, often leading to self-harm and long-term cycles of intense emotions and relational difficulties. These themes were reflected in the results of a systematic review investigating the aetiology of BPD, despite debate in understandings of BPD aetiology (Ahluwalia Cameron et al., 2018). These instabilities and traumas often lead to mistrust; despite this, participants were also seeking good connections with others. This was one of the first problems participants needed to overcome. This is reflected in the hyperbolic temperament model (Hopwood et al., 2012a; Yalch et al., 2015; Zanarini & Frankenburg, 1994), within the interpersonal hypersensitivity and temperamental symptoms domains, where interpersonal dependency and fear of abandonment can interact. Although the hyperbolic temperament model acknowledges the role of the environment, it also places emphasis on the genetic role in temperamental predisposition to intense emotional experiences (Hopwood et al., 2012b). This study emphasises the gravity and impact of SU's negative experiences, and is consistent with models of BPD (Bradley et al., 2005; Hopwood et al., 2012b; Monti & D'Agostino, 2018; Yalch et al., 2015; Zanarini & Frankenburg, 1994).

The second main theme: Developing awareness and taking the first steps to recovery, described the process of participants becoming aware of their internal state and their context, starting to engage with treatment, build relationships, and develop coping skills. Participants expressed that they first needed to seek and establish trusting relationships with staff, friends and family. There was a sense that, in order for these elements to work, a compassionate, knowledgeable and understanding environment was needed. These themes are substantially reflected in Katsakou et al. (2017) study of BPD recovery, particularly in relation to relationships, making practical changes, e.g., developing skills, and the need for a supportive environment. The Kverne et al. (2019) model, highlighted a strong need for genuine mutual connection and belonging, achieved by learning skills, developing two-way relationships, coping with activities of daily living (ADLs) and learning to accept relationships instead of rejecting them due to mistrust. Similar themes are substantially reflected in this study, particularly in the areas of connection and belonging. Additionally, this study highlights emphasis in the areas of skills development, learning to manage ADLs within a compassionate and knowledgeable treatment setting.

The third main theme: Anticipating and living the reality of recovery, gave a clear indication of participants' view that recovery is not a discreet event after which there are no more mental health challenges. Participants acknowledged that they will likely struggle with BPD related challenges indefinitely and what will change is their self-awareness, and ability to connect and cope, which are themes reflected in Cartwright et al. (2021). Participants in the current study characterised recovery as a journey, or a 'yellow brick road' with goals and companions, illustrating a non-linear process of recovery. Many of their goals centred around education, developing hobbies and occupations. Participants spoke of wanting to have a '*normal*' life and a sense of wanting to be connected to the wider world. These themes are complimentary to the concept of The Recovery model of mental health discussed in the introduction (Jacob, 2015); however, the results of this study appear to extend the definition, placing greater emphasis on relational skills and aspects of recovery, reflecting the nature and aetiology of BPD. These nuances endorse the argument that BPD treatment requires specific clinical knowledge and conditions.

The fourth main theme: Overwhelmed by the power of a problematic system appears to be an expression of frustration caused by systemic problems. This included lack of staff understanding and prejudice against them due to BPD, necessarily impacting negatively on environmental needs such as not feeling judged. Participants highlighted the requirements of the system did not sit well with what they needed for recovery, or to avoid a worsening of their mental health. This appeared to highlight they felt unheard or under-valued, resulting in epistemic injustice. Others had poor experiences in prison and hospital in terms of mental health support and treatment. This included being isolated due to staff not knowing what to do and waiting '*in limbo*' when placement arrangements fell through.

These experiences hindered recovery, leading for some to iatrogenic harm and epistemic injustice, which were also identified as a barrier by Cartwright et al., (2021), as discussed in the introduction. However, participants also acknowledged good experiences of treatment settings and compassionate, knowledgeable staff which was a significant facilitator of recovery. These themes were also reflected in Cartwright et al. (2021), alongside others such as: trusting relationships with peers and professionals, developing insight, and hope. Some participants in this study felt they were recovering well and ready for the outside world, and that was due to having had a capable environment where staff understood BPD and could establish trusting relationships with them. This in turn allowed them to access the development they needed to become better able to cope for the future.

In comparison to the recovery model (Jacob, 2015), the idea of recovery communicated by participants in this study bears significant similarities. Participants' idea of recovery characterises it as an on-going non-linear journey. They feel that a meaningful life is possible and that with new skills and the right support they can achieve it. This has parallels to the recovery model in terms of it being a journey, building resilience, and living life well enough in the presence of mental health challenges. This study's participants' accounts, however, appear to place notable additional emphasis on the development of positive, reciprocal relationships, skills, compassion, understanding and a need for a sense of belonging. They also indicate the importance of being respected and valued. These themes are substantially present in BPD recovery studies by Katsakou & Pistrang, (2017), and Kverme et al., (2019a), particularly recovery as a journey and the need for belonging. This may be an indicator of a need for positive relationships of the kind which were not available during earlier developmental stages. This appears to invite the question of whether the process of recovery in BPD has parallels to developmental models, e.g., Erikson's (1943) developmental stages, or the Kelly & Coughlan, (2019) theory of youth mental health recovery which synthesises elements of developmental and recovery theory.

The themes from this study resonate with theory, definitions of recovery and previous studies across a range of mental health service settings (Cartwright et al., 2021a; Hopwood et al., 2012a; Katsakou et al., 2012; Kverme et al., 2019a; Yalch et al., 2015; Zanarini & Frankenburg, 1994). Studies observe narratives around the importance of genuine, mutual connections and a sense of belonging. Kverme et al's (2019) participants also highlighted a needed to learn skills in order to achieve this and progress to having a more normative daily experience and goals. These themes have strong parallels in this study, which helps to strengthen the SU voice, and incorporates their perspectives into the literature on recovery with BPD. This study also bears similarities to the Cartwright (2021) review, where damage from both epistemic injustice and iatrogenic harm is highlighted as being a particular barrier to recovery. This study also highlighted perspectives from participants that had received treatment in multiple settings, observing that treatment quality can vary considerably between services and hospitals. This study's participants contribute additional insight into understanding the complex interaction of elements and variable, long-term nature of recovery.

Limitations and implications for future research

Due to challenges with successfully arranging interviews with SUs due to their treatment needs and circumstances, it was difficult to recruit more participants within the time available. Extended data may have validated and developed nuances further. These challenges also meant that SUs with comorbid conditions participated, potentially biasing results towards a conceptualisation more relevant to more general mental health recovery. However, participants were representative of this population, and as such comorbid mental health is likely to be challenging to exclude while representing the sample. Participants in this study did not have any routine mental health measure data available for inclusion. Insights may have been missed on the relationship between mental health, stages of recovery and how to encompass the breadth of BPD recovery in a single measure.

Although the research team discussed and adjusted themes through discussion, and themes were checked with practicing professional field links working with this population, further refining of themes may have yielded more sensitive results.

Further research is needed to augment the service user voice in the literature, as this is still under-represented. Future research could seek to confirm and develop themes already emerging in the literature and explore development of measures to encompass additional nuances of recovery highlighted by participants but not currently reflected in outcome measures. Further research into epistemic injustice and iatrogenic harm specifically in relation to how it interacts with the challenges individuals with BPD experience, would be a valuable contribution to the literature.

Clinical Implications

Participants accounts in themes 1. ‘Developing BPD, instability in early life’ and 2. ‘Developing awareness and taking the first steps to recovery’ highlight their need to feel safe, not abandoned. Additionally, aspects of past offending behaviour can often lead to shame. Therefore, a non-judgemental, in-depth understanding of their experience and relational safety needs to be explicit, especially in forensic settings. This indicates the importance of knowing individuals’ histories, team formulation, training and supervision in forensic settings.

Given participants’ emphasis on a sense of purpose, community and connection, emphasised in the second group experiential themes: 2. ‘Developing awareness and taking the first steps to recovery’, and 3. ‘Anticipating and living the reality of recovery’, there may be an argument for specific further emphasis on occupations and education being provided alongside mental health treatment. These elements may be supported with links to occupational and educational services in the community, facilitating smooth and planned transitions to community life with the support of established connections and purpose.

As participants in this study highlighted the harm that can be caused by prejudice and lack of knowledge, outlined in group experiential theme 4 ('Overwhelmed by the power of a problematic system'), it is important to ensure that all staff working with BPD SUs are trained specifically for the role. This training could be facilitated by clinical psychologists with experience of working with this population. Psychological support and education could also be provided to those close to SUs. This may help them understand the condition better and therefore be better equipped to be supportive and more resilient themselves, enabling them to maintain consistency and perspective.

It may be useful to consider, or formulate, SUs' experiences from the Power, Threat, Meaning Framework (PTMF) (Johnstone L. & Boyle et al., 2018) perspective, as these areas appear to be significant influences represented in participants' narratives, throughout their lives from youth to receiving treatment for BPD as adults. The power of the systems has been ever present or unhelpfully absent for them, alongside the inter-relational power of adults when they were growing up. For many, these have been sources of repeated harm and traumas. Threat is something SUs seem particularly sensitive to, whether it be in the form of negative judgement, outright discrimination and prejudice or others not being able to understand them. This appears to hold meanings for SUs, especially in forensic care settings, that can influence their self-worth and identity in such a way as they can become barriers to recovery through their learned coping strategies or threat responses. Viewing BPD more as a set of natural responses to extreme experiences may seem less intimidating or blameworthy, than it is as a pathological entity, facilitating a service context more conducive to recovery. Bearing this and the study results in mind, one approach that may be helpful in understanding and working with people with BPD is the Trauma Informed Approach.

The themes in this study are reflected in trauma survivor movement narratives, particularly in relation to understanding themselves, their lives and the ability to form meaningful, stable relationships (SAMHSA, 2014). This led to the development of trauma informed approaches to care, whose six key principles: 1. Safety; 2. Trustworthiness and transparency; 3. Peer support; 4. Collaboration and mutuality; 5. Empowerment, voice and choice; 6. Cultural, historical and gender issues (SAMHSA, 2014); seem particularly relevant to the needs of people living and recovering with BPD. It also appears to be relevant in terms of how to respond to patterns of experience understood from a PTMF perspective. Staff in trauma informed services are taught about trauma and how organisational practices can trigger painful memories and re-traumatise clients. The trauma informed approach aims to avoid re-traumatising SUs and staff, which can lead to barriers and complications in recovery (SAMHSA, 2014). Given the experiential similarities and overlap between the trauma movement population and the participant sample in this study, the consistency of narratives and similarity of needs indicate a strong argument for services providing treatment for SUs with BPD adopting or continuing to use a trauma informed approach.

Conclusion

often has its genesis in traumatic and disrupted childhood experiences (Ahluwalia Cameron et al., 2018). This leads to mistrust and emotionally intensity, creating a barrier of mistrust between them and others. The combination of these leads to often dramatic and serious behaviours, increasing the risks of causing danger to themselves or others. Recovery requires the right knowledgeable and compassionate environment, trusting connections, goals, a sense of purpose and a variety of skills to support these.

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Appendices

Appendix A: Author guidelines for the Clinical Psychology Review

CLINICAL PSYCHOLOGY REVIEW

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DESCRIPTION

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Clinical Psychology Review publishes substantive reviews of topics germane to **clinical psychology**. Papers cover diverse issues including: psychopathology, psychotherapy, behavior therapy, cognition and cognitive therapies, behavioral medicine, community mental health, assessment, and child development. Papers should be cutting edge and advance the science and/or practice of clinical psychology.

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Gretchen Haas, University of Pittsburgh, Pittsburgh, Pennsylvania, United States of America

Psychosis, Schizophrenia, Major Depression, Suicide, Social cognition

Gerald Haeffel, University of Notre Dame, Notre Dame, Indiana, United States of America

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Depression, Cognition, Vulnerability, Stress, Reappraisal

Richard Hallam, London, United Kingdom

Case formulation, Concept of mental illness, Psychotherapy, Human evolution

Martin Harrow, University of Illinois Chicago College of Medicine, Chicago, Illinois, United States of America

Holly Hazlett-Stevens, University of Nevada Reno, Reno, Nevada, United States of America

Mindfulness, Mindfulness-based stress reduction, Anxiety, Worry

Eli Lebowitz, Yale School of Medicine, New Haven, Connecticut, United States of America

Childhood and adolescent anxiety and related disorders, Parent-based treatment

Ellen W. Leen-Feldner, University of Arkansas Bookstore, Fayetteville, Arkansas, United States of America

developmental psychopathology, adolescent anxiety, parenting, cannabidiol, anxiety

Carl Lejuez, The University of Kansas, Lawrence, Kansas, United States of America

Richard Moulding, Cairnmillar Institute, Camberwell, Australia

OCD, Anxiety, CBT, Treatment, Emotion Regulation

Kim Mueser, Boston University, Boston, Massachusetts, United States of America

Schizophrenia, Severe mental illness, Treatment, Psychiatric rehabilitation, Social skills

training, Family psychoeducation, Cognitive remediation

Jeremy Pettit, Florida International University, Miami, Florida, United States of America

depression, anxiety, suicidal thoughts and behaviors, attention bias, cognitive behavior

therapy, children, adolescents

Suzanne Pineles, VA Boston Health Care System Jamaica Plain Campus, Boston, Massachusetts, United States

of America

PTSD, Sex differences, Psychophysiology, Fear conditioning and extinction

Karen Rowa, McMaster University and St. Joseph’s Healthcare Hamilton, Anxiety Treatment and Research Clinic, Hamilton, Ontario, Canada

Cognitive Behavioural Therapy, Family Accommodation, Treatment Outcome, Hoarding Disorder

Kristalyn Salters-Pedneault, Eastern Connecticut State University, Willimantic, Connecticut, United States of

America

Anxiety, Fear, Trauma, Mindfulness, Acceptance

Donald Sharpe, University of Regina, Regina, Saskatchewan, Canada

Statistics, Methodology

Eric A. Storch, Baylor College of Medicine, Houston, Texas, United States of America

Obsessive-compulsive disorder

Bruce Wampold, University of Wisconsin-Madison, Madison, Wisconsin, United States of America

Psychotherapy effectiveness, Relative efficacy, Meta-analyses, Common factors

Carl F. Weems, Iowa State University, Ames, Iowa, United States of America

Emotional Development, Traumatic and Adverse Childhood Experiences, Intervention, Prevention, Implementation

Aviv Weinstein, Ariel University, Ari'el, Israel

Drug, alcohol and behavioral addictions, Brain imaging in addiction

Thomas A. Widiger, University of Kentucky, Lexington, Kentucky, United States of America

Sabine Wilhelm, Massachusetts General Hospital, Department of Psychiatry, Medford, Massachusetts, United

States of America

OCD, Body Dsymoprhic Disorder, Digital health, Smartphone based treatment

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GUIDE FOR AUTHORS

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Acknowledgements

Collate acknowledgements in a separate section at the end of the article before the references and do not, therefore, include them on the title page, as a footnote to the title or otherwise. List here those individuals who provided help during the research (e.g., providing language help, writing assistance or proof reading the article, etc.).

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Regardless of the application used other than Microsoft Office, when your electronic artwork is finalized, please 'Save as' or convert the images to one of the following formats (note the resolution requirements for line drawings, halftones, and line/halftone combinations given below):

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TIFF (or JPEG): Color or grayscale photographs (halftones), keep to a minimum of 300 dpi.

TIFF (or JPEG): Bitmapped (pure black & white pixels) line drawings, keep to a minimum of 1000 dpi.

TIFF (or JPEG): Combinations bitmapped line/half-tone (color or grayscale), keep to a minimum of 500 dpi.

Please do not:

- Supply files that are optimized for screen use (e.g., GIF, BMP, PICT, WPG); these typically have a low number of pixels and limited set of colors;
- Supply files that are too low in resolution;
- Submit graphics that are disproportionately large for the content.

Color artwork

Please make sure that artwork files are in an acceptable format (TIFF (or JPEG), EPS (or PDF), or MS Office files) and with the correct resolution. If, together with your accepted article, you submit usable color figures then Elsevier will ensure, at no additional charge, that these figures will appear in color online (e.g., ScienceDirect and other sites) regardless of whether or not these illustrations are reproduced in color in the printed version. **For color reproduction in print, you will receive information regarding the costs from Elsevier after receipt of your accepted article**. Please indicate your preference for color: in print or online only. Further information on the preparation of electronic artwork.

Figure captions

Ensure that each illustration has a caption. Supply captions separately, not attached to the figure. A caption should comprise a brief title (**not** on the figure itself) and a description of the illustration. Keep text in the illustrations themselves to a minimum but explain all symbols and abbreviations used.

Tables

Please submit tables as editable text and not as images. Tables can be placed either next to the relevant text in the article, or on separate page(s) at the end. Number tables consecutively in accordance with their appearance in the text and place any table notes below the table body. Be sparing in the use of tables and ensure that the data presented in them do not duplicate results described elsewhere in the article. Please avoid using vertical rules and shading in table cells.

References

Citations in the text should follow the referencing style used by the American Psychological Association. You are referred to the most recent publication manual of the American Psychological Association. Information can be found at https://apastyle.apa.org/

Citation in text

Please ensure that every reference cited in the text is also present in the reference list (and vice versa). Any references cited in the abstract must be given in full. Unpublished results and personal communications are not recommended in the reference list, but may be mentioned in the text. If these references are included in the reference list they should follow the standard reference style of the journal and should include a substitution of the publication date with either 'Unpublished results' or 'Personal communication'. Citation of a reference as 'in press' implies that the item has been accepted for publication.

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Web references

As a minimum, the full URL should be given and the date when the reference was last accessed. Any further information, if known (DOI, author names, dates, reference to a source publication, etc.), should also be given. Web references can be listed separately (e.g., after the reference list) under a different heading if desired, or can be included in the reference list.

Data references

This journal encourages you to cite underlying or relevant datasets in your manuscript by citing them in your text and including a data reference in your Reference List. Data references should include the following elements: author name(s), dataset title, data repository, version (where available), year, and global persistent identifier. Add [dataset] immediately before the reference so we can properly identify it as a data reference. The [dataset] identifier will not appear in your published article.

Preprint references

Where a preprint has subsequently become available as a peer-reviewed publication, the formal publication should be used as the reference. If there are preprints that are central to your work or that cover crucial developments in the topic, but are not yet formally published, these may be referenced.

Preprints should be clearly marked as such, for example by including the word preprint, or the name of the preprint server, as part of the reference. The preprint DOI should also be provided.

References in a special issue

Please ensure that the words 'this issue' are added to any references in the list (and any citations in the text) to other articles in the same Special Issue.

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Reference style

References should be arranged first alphabetically and then further sorted chronologically if necessary.

More than one reference from the same author(s) in the same year must be identified by the letters "a", "b", "c", etc., placed after the year of publication. **References should be formatted with a hanging indent (i.e., the first line of each reference is flush left while the subsequent lines are indented).**

Examples: Reference to a journal publication: Van der Geer, J., Hanraads, J. A. J., & Lupton R. A. (2000). The art of writing a scientific article. *Journal of Scientific Communications,* 163, 51-59.

Reference to a book: Strunk, W., Jr., &White, E. B. (1979). *The elements of style.* (3rd ed.). New York: Macmillan, (Chapter 4).

Reference to a chapter in an edited book: Mettam, G. R., & Adams, L. B. (1994). How to prepare an electronic version of your article. In B.S. Jones, & R. Z. Smith (Eds.), *Introduction to the electronic age* (pp. 281-304). New York: E-Publishing Inc.

[dataset] Oguro, M., Imahiro, S., Saito, S., Nakashizuka, T. (2015). *Mortality data for Japanese oak wilt disease and surrounding forest compositions.* Mendeley Data, v1. http://dx.doi.org/10.17632/xwj98nb39r.1

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relate to the video file's content. In order to ensure that your video or animation material is directly usable, please provide the file in one of our recommended file formats with a preferred maximum size of 150 MB per file, 1 GB in total. Video and animation files supplied will be published online in the electronic version of your article in Elsevier Web products, including ScienceDirect. Please supply 'stills' with your files: you can choose any frame from the video or animation or make a separate image. These will be used instead of standard icons and will personalize the link to your video data. For

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Below are a number of ways in which you can associate data with your article or make a statement about the availability of your data when submitting your manuscript. If you are sharing data in one of these ways, you are encouraged to cite the data in your manuscript and reference list. Please refer to the "References" section for more information about data citation. For more information on depositing, sharing and using research data and other relevant research materials, visit the research data page.

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Data statement

To foster transparency, we encourage you to state the availability of your data in your submission. This may be a requirement of your funding body or institution. If your data is unavailable to access or unsuitable to post, you will have the opportunity to indicate why during the submission process, for example by stating that the research data is confidential. The statement will appear with your published article on ScienceDirect. For more information, visit the Data Statement page.

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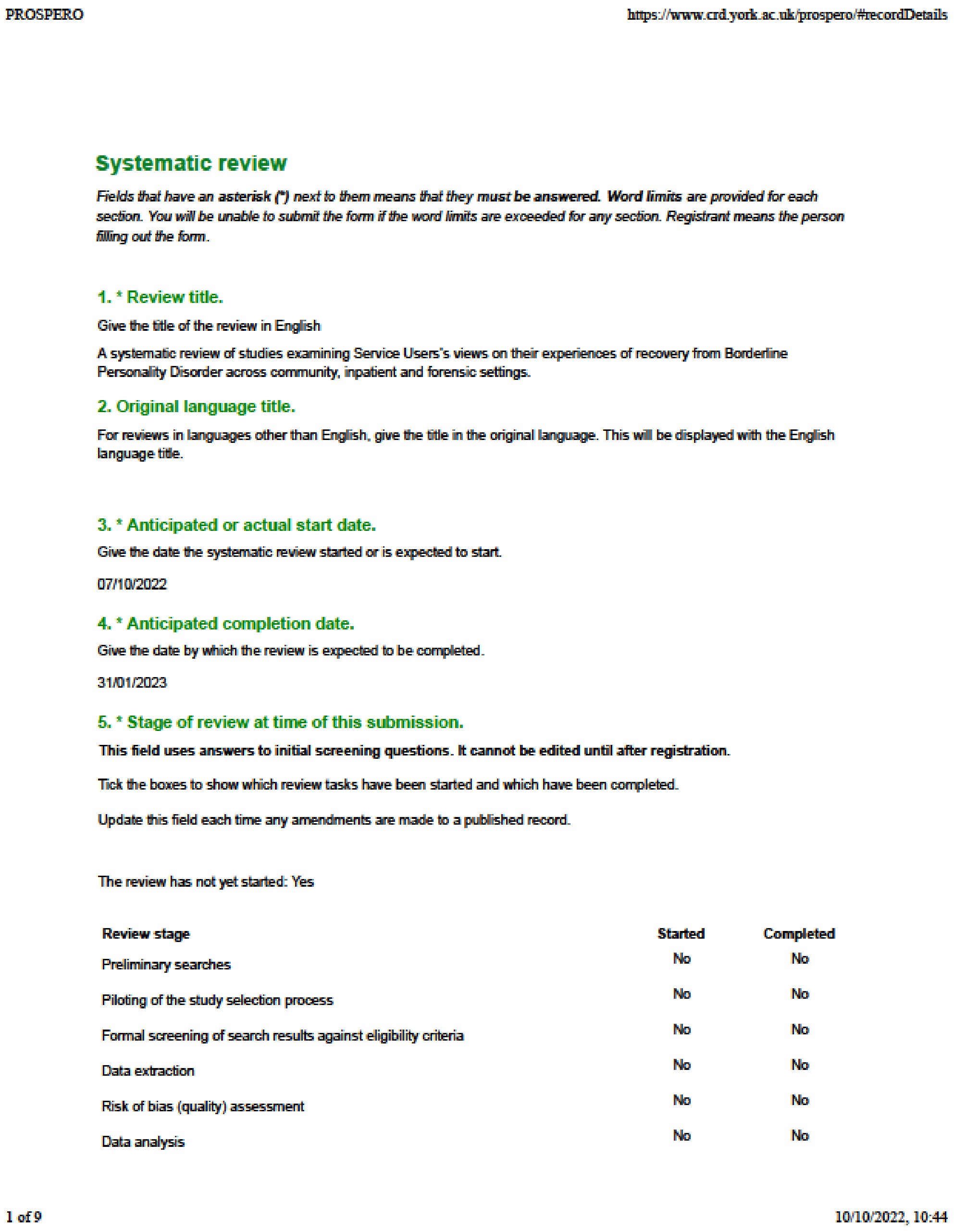
Appendix B: Table of Abbreviations

Table of Abbreviations	
APA	American Psychological Association
BPD	Borderline Personality Disorder
EUPD	Emotionally Unstable Personality Disorder
DBT	Dialectical Behaviour Therapy
MBT	Mentalisation Based Therapy
PD	Personality Disorder
DSM-5	Diagnostic and Statistical Manual – Fifth edition

Appendix C: Quality assessment summary table

Paper	Rating	Comments
To love and work: A longitudinal study of everyday life factors in recovery from borderline personality disorder Brin F. S. Grenyer. 2022.	++	A bit unclear in some respects such as how they took account of their own influence, but most points addressed in some way on CASP questions.
The lived experience of recovery in borderline personality disorder: a qualitative study. Fiona ng 2019	++	
Seeking to understand lived experiences of personal recovery in personality disorder in community and forensic settings a qualitative methods investigation. Andrew Shepherd, Caroline Sanders and Jenny Shaw 2017	++	Not specifically BPD in title but mainly BPD recruited.
Moving Toward Connectedness – A Qualitative Study of Recovery Processes for People With Borderline Personality Disorder. Kverne 2019	++	
Recovery, as Experienced by Women with Borderline Personality Disorder. Larivierre 2015	++	Narrow on some details such as own influence on study/participants etc.
Recovery in Borderline Personality Disorder (BPD): a qualitative study of service users' perspectives. Katsakou 2012	++	Robust. More reflection on own influence would have been helpful. Although GT takes this into account in methodology.
How do women with a diagnosis of Borderline Personality Disorder detained in secure and locked services perceive recovery? : a grounded theory. Canacott 2019	++	Thesis. Good but again more reflection on own influence etc would have been usefull.
Meaningful ways of understanding and measuring change for people with borderline personality disorder: A thematic analysis. McCusker 2018	++	
Consumer perspectives on personal recovery and borderline personality disorder. Donald 2017	++	Little reflection on own role explicitly in paper.

Appendix D: Prospero registration



Systematic review

Fields that have an ***asterisk (*)*** *next to them means that they* ***must be answered. Word limits*** *are provided for each section. You will be unable to submit the form if the word limits are exceeded for any section. Registrant means the person filling out the form.*

1. * Review title.

Give the title of the review in English

A systematic review of studies examining Service Users's views on their experiences of recovery from Borderline Personality Disorder across community, inpatient and forensic settings.

2. Original language title.

For reviews in languages other than English, give the title in the original language. This will be displayed with the English language title.

3. * Anticipated or actual start date.

Give the date the systematic review started or is expected to start.

07/10/2022

4. * Anticipated completion date.

Give the date by which the review is expected to be completed.

31/01/2023

5. * Stage of review at time of this submission.

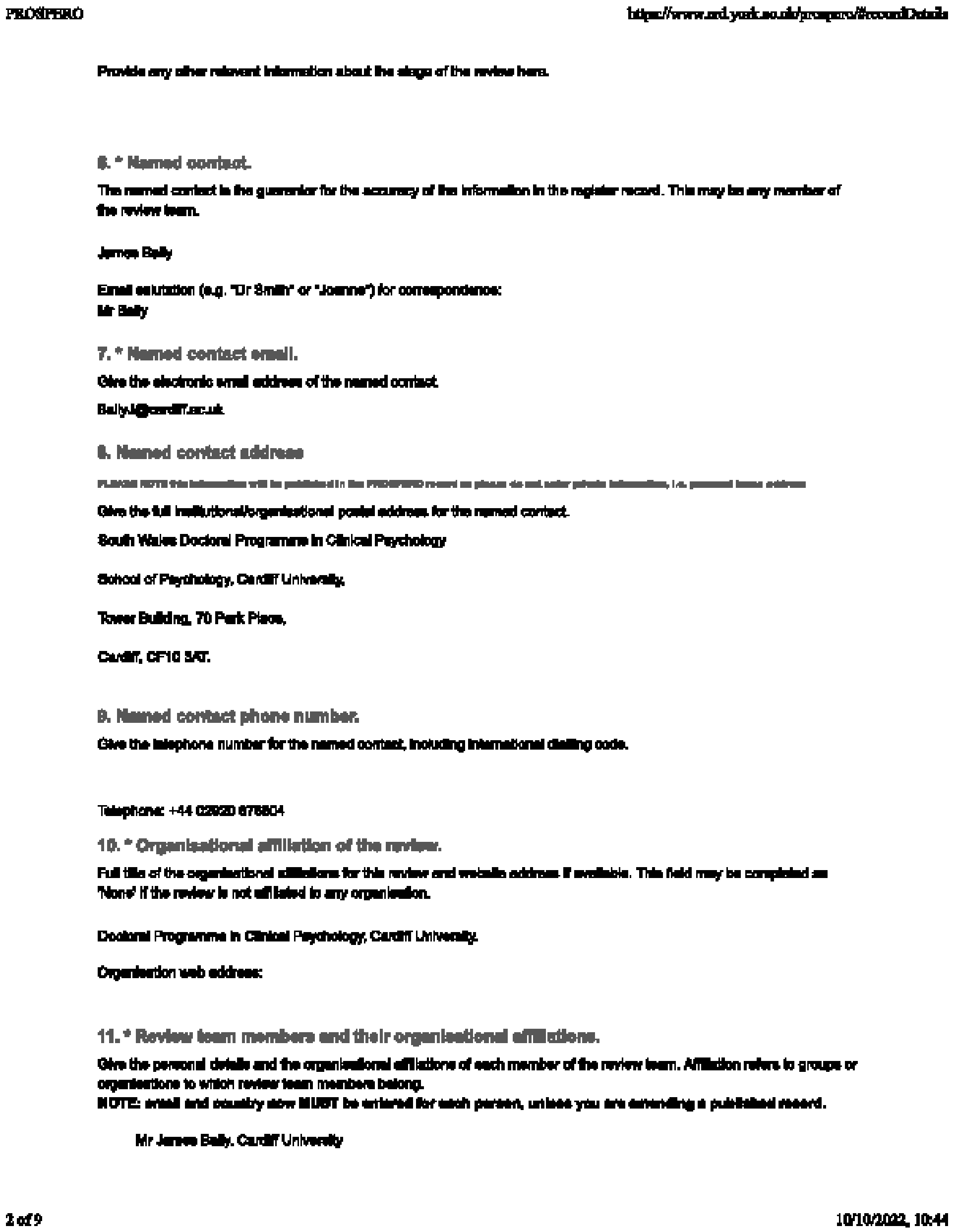
This field uses answers to initial screening questions. It cannot be edited until after registration.

Tick the boxes to show which review tasks have been started and which have been completed.

Update this field each time any amendments are made to a published record.

The review has not yet started: Yes

Review stage	**Started**	**Completed**
Preliminary searches	No	No
Piloting of the study selection process	No	No
Formal screening of search results against eligibility criteria	No	No
Data extraction	No	No
Risk of bias (quality) assessment	No	No
Data analysis	No	No



Provide any other relevant information about the stage of the review here.

6. * Named contact.

The named contact is the guarantor for the accuracy of the information in the register record. This may be any member of the review team.

James Bally

Email salutation (e.g. "Dr Smith" or "Joanne") for correspondence:
Mr Bally

7. * Named contact email.

Give the electronic email address of the named contact.

Bally.J@cardiff.ac.uk

8. Named contact address

PLEASE NOTE this information will be published in the PROSPERO record so please do not enter private information, i.e. personal home address

Give the full institutional/organisational postal address for the named contact.

South Wales Doctoral Programme in Clinical Psychology

School of Psychology, Cardiff University,

Tower Building, 70 Park Place,

Cardiff, CF10 3AT.

9. Named contact phone number.

Give the telephone number for the named contact, including international dialling code.

Telephone: +44 02920 876804

10. * Organisational affiliation of the review.

Full title of the organisational affiliations for this review and website address if available. This field may be completed as 'None' if the review is not affiliated to any organisation.

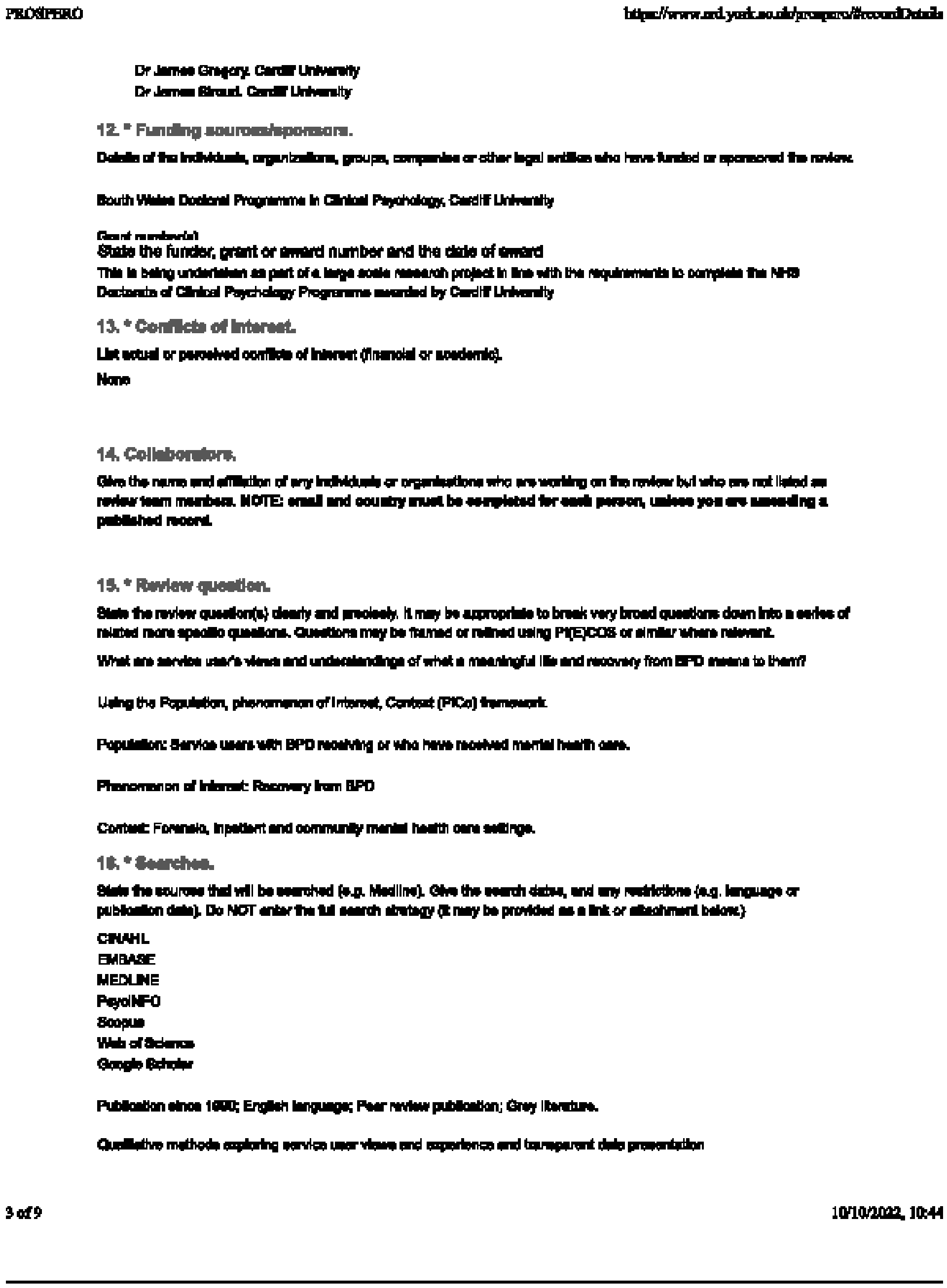
Doctoral Programme in Clinical Psychology, Cardiff University.

Organisation web address:

11. * Review team members and their organisational affiliations.

Give the personal details and the organisational affiliations of each member of the review team. Affiliation refers to groups or organisations to which review team members belong.
NOTE: email and country now MUST be entered for each person, unless you are amending a published record.

Mr James Bally. Cardiff University



PROSPERO https://www.crd.york.ac.uk/prospero/#recordDetails

Dr James Gregory. Cardiff University
Dr James Stroud. Cardiff University

12. * Funding sources/sponsors.

Details of the individuals, organizations, groups, companies or other legal entities who have funded or sponsored the review.

South Wales Doctoral Programme in Clinical Psychology, Cardiff University

Grant number(s)

State the funder, grant or award number and the date of award

This is being undertaken as part of a large scale research project in line with the requirements to complete the NHS Doctorate of Clinical Psychology Programme awarded by Cardiff University

13. * Conflicts of interest.

List actual or perceived conflicts of interest (financial or academic).

None

14. Collaborators.

Give the name and affiliation of any individuals or organisations who are working on the review but who are not listed as review team members. NOTE: email and country must be completed for each person, unless you are amending a published record.

15. * Review question.

State the review question(s) clearly and precisely. It may be appropriate to break very broad questions down into a series of related more specific questions. Questions may be framed or refined using PI(E)COS or similar where relevant.

What are service user's views and understandings of what a meaningful life and recovery from BPD means to them?

Using the Population, phenomenon of Interest, Context (PICo) framework.

Population: Service users with BPD receiving or who have received mental health care.

Phenomenon of interest: Recovery from BPD

Context: Forensic, inpatient and community mental health care settings.

16. * Searches.

State the sources that will be searched (e.g. Medline). Give the search dates, and any restrictions (e.g. language or publication date). Do NOT enter the full search strategy (it may be provided as a link or attachment below.)

CINAHL
EMBASE
MEDLINE
PsycINFO
Scopus
Web of Science
Google Scholar

Publication since 1990; English language; Peer review publication; Grey literature.

Qualitative methods exploring service user views and experience and transparent data presentation

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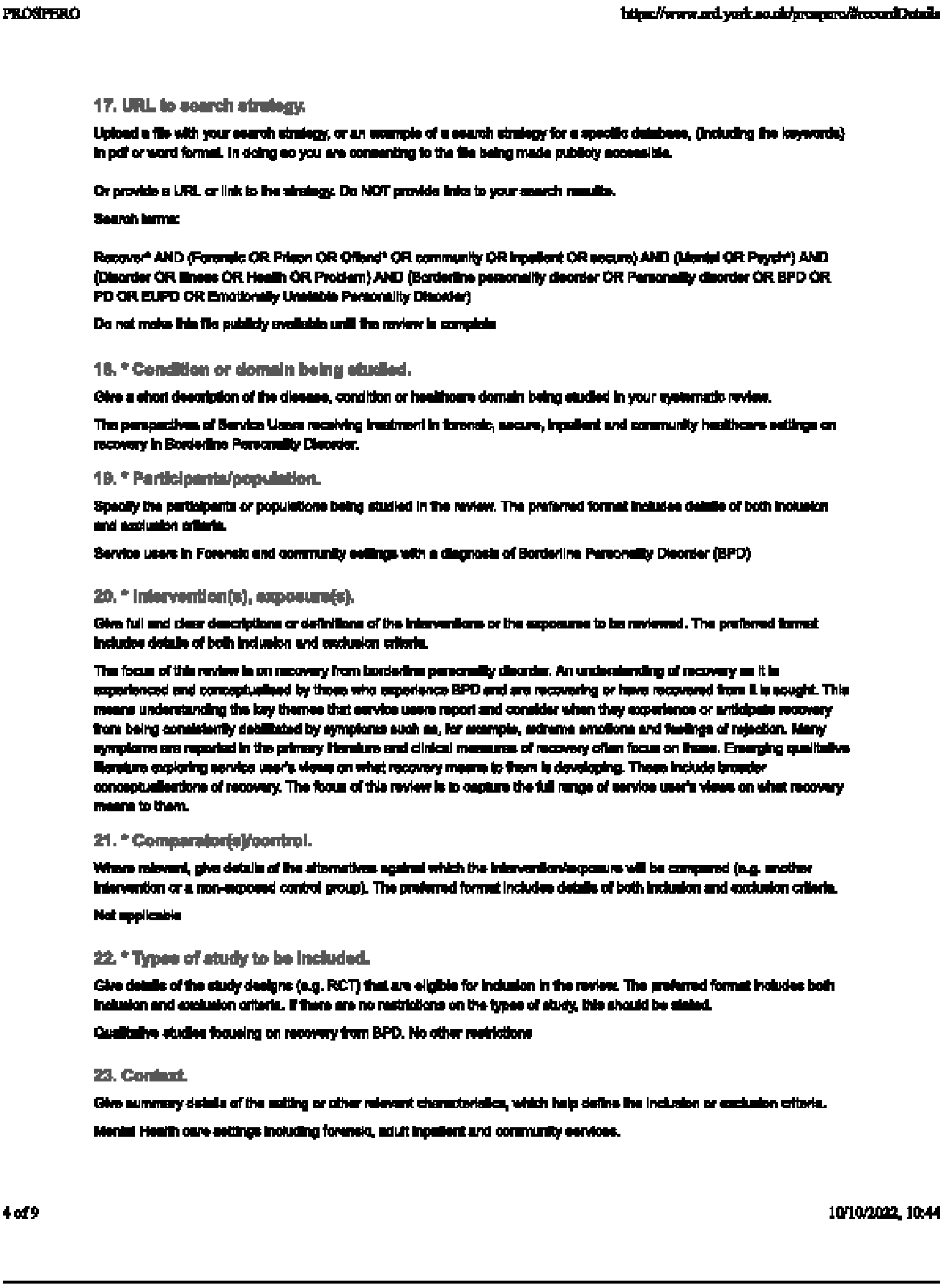


17. URL to search strategy.

Upload a file with your search strategy, or an example of a search strategy for a specific database, (including the keywords) in pdf or word format. In doing so you are consenting to the file being made publicly accessible.

Or provide a URL or link to the strategy. Do NOT provide links to your search results.

Search terms:

Recover* AND (Forensic OR Prison OR Offend* OR community OR inpatient OR secure) AND (Mental OR Psych*) AND (Disorder OR illness OR Health OR Problem) AND (Borderline personality disorder OR Personality disorder OR BPD OR PD OR EUPD OR Emotionally Unstable Personality Disorder)

Do not make this file publicly available until the review is complete

18. * Condition or domain being studied.

Give a short description of the disease, condition or healthcare domain being studied in your systematic review.

The perspectives of Service Users receiving treatment in forensic, secure, inpatient and community healthcare settings on recovery in Borderline Personality Disorder.

19. * Participants/population.

Specify the participants or populations being studied in the review. The preferred format includes details of both inclusion and exclusion criteria.

Service users in Forensic and community settings with a diagnosis of Borderline Personality Disorder (BPD)

20. * Intervention(s), exposure(s).

Give full and clear descriptions or definitions of the interventions or the exposures to be reviewed. The preferred format includes details of both inclusion and exclusion criteria.

The focus of this review is on recovery from borderline personality disorder. An understanding of recovery as it is experienced and conceptualised by those who experience BPD and are recovering or have recovered from it is sought. This means understanding the key themes that service users report and consider when they experience or anticipate recovery from being consistently debilitated by symptoms such as, for example, extreme emotions and feelings of rejection. Many symptoms are reported in the primary literature and clinical measures of recovery often focus on these. Emerging qualitative literature exploring service user's views on what recovery means to them is developing. These include broader conceptualisations of recovery. The focus of this review is to capture the full range of service user's views on what recovery means to them.

21. * Comparator(s)/control.

Where relevant, give details of the alternatives against which the intervention/exposure will be compared (e.g. another intervention or a non-exposed control group). The preferred format includes details of both inclusion and exclusion criteria.

Not applicable

22. * Types of study to be included.

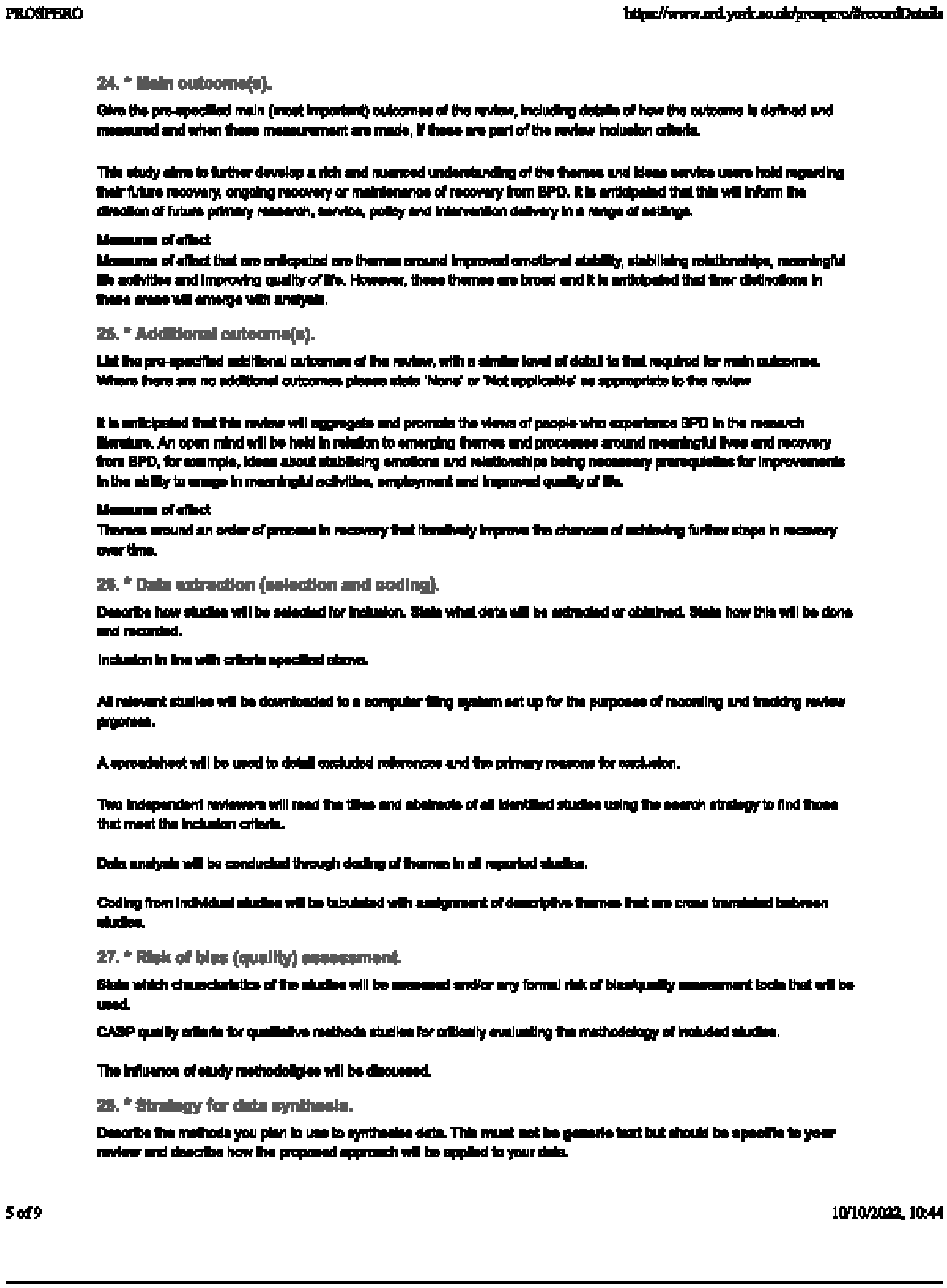
Give details of the study designs (e.g. RCT) that are eligible for inclusion in the review. The preferred format includes both inclusion and exclusion criteria. If there are no restrictions on the types of study, this should be stated.

Qualitative studies focusing on recovery from BPD. No other restrictions

23. Context.

Give summary details of the setting or other relevant characteristics, which help define the inclusion or exclusion criteria.

Mental Health care settings including forensic, adult inpatient and community services.



24. * Main outcome(s).

Give the pre-specified main (most important) outcomes of the review, including details of how the outcome is defined and measured and when these measurement are made, if these are part of the review inclusion criteria.

This study aims to further develop a rich and nuanced understanding of the themes and ideas service users hold regarding their future recovery, ongoing recovery or maintenance of recovery from BPD. It is anticipated that this will inform the direction of future primary research, service, policy and intervention delivery in a range of settings.

Measures of effect

Measures of effect that are anticipated are themes around improved emotional stability, stabilising relationships, meaningful life activities and improving quality of life. However, these themes are broad and it is anticipated that finer distinctions in these areas will emerge with analysis.

25. * Additional outcome(s).

List the pre-specified additional outcomes of the review, with a similar level of detail to that required for main outcomes. Where there are no additional outcomes please state 'None' or 'Not applicable' as appropriate to the review

It is anticipated that this review will aggregate and promote the views of people who experience BPD in the research literature. An open mind will be held in relation to emerging themes and processes around meaningful lives and recovery from BPD, for example, ideas about stabilising emotions and relationships being necessary prerequisites for improvements in the ability to engage in meaningful activities, employment and improved quality of life.

Measures of effect

Themes around an order of process in recovery that iteratively improve the chances of achieving further steps in recovery over time.

26. * Data extraction (selection and coding).

Describe how studies will be selected for inclusion. State what data will be extracted or obtained. State how this will be done and recorded.

Inclusion in line with criteria specified above.

All relevant studies will be downloaded to a computer filing system set up for the purposes of recording and tracking review progress.

A spreadsheet will be used to detail excluded references and the primary reasons for exclusion.

Two independent reviewers will read the titles and abstracts of all identified studies using the search strategy to find those that meet the inclusion criteria.

Data analysis will be conducted through coding of themes in all reported studies.

Coding from individual studies will be tabulated with assignment of descriptive themes that are cross translated between studies.

27. * Risk of bias (quality) assessment.

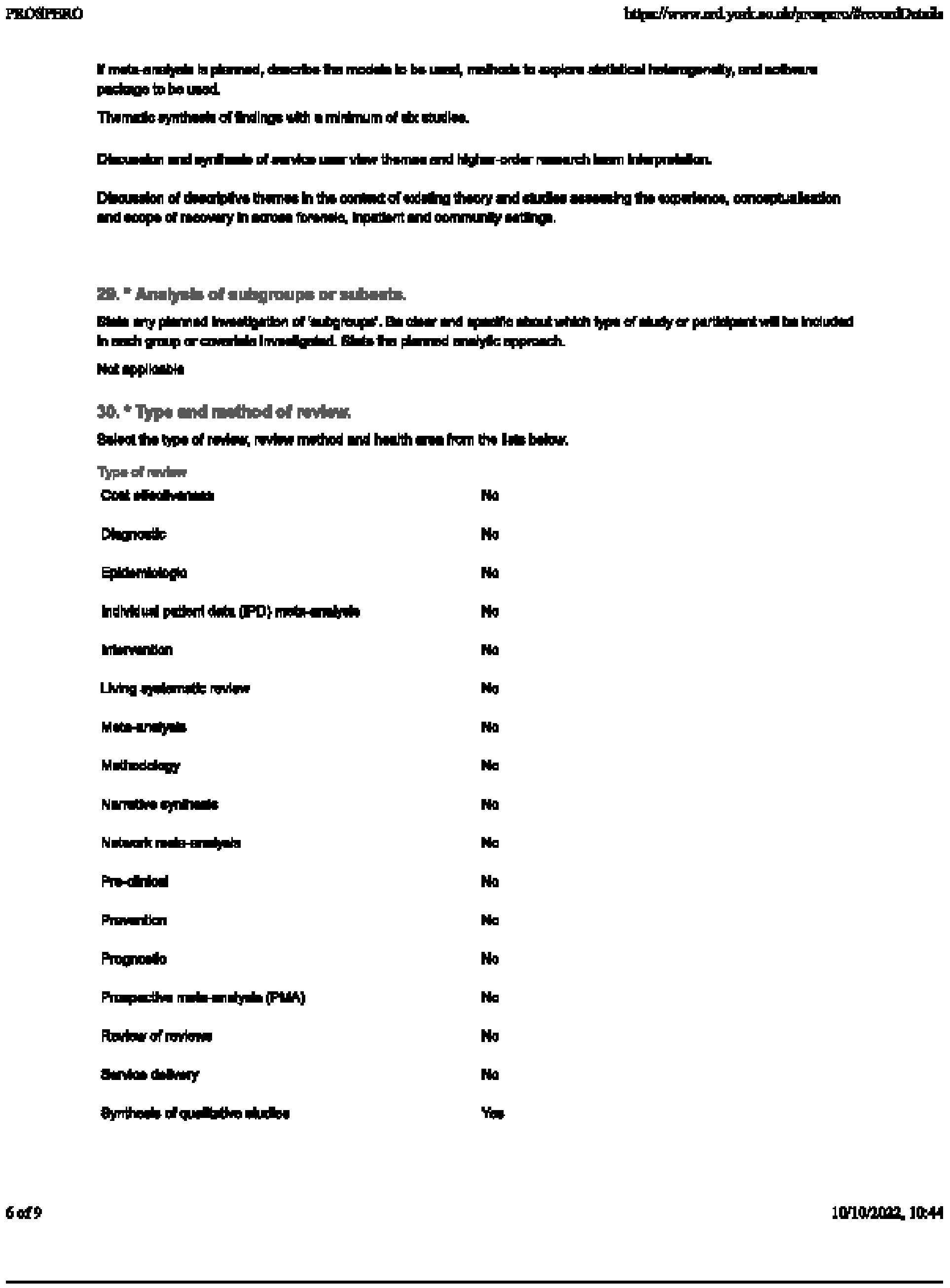
State which characteristics of the studies will be assessed and/or any formal risk of bias/quality assessment tools that will be used.

CASP quality criteria for qualitative methods studies for critically evaluating the methodology of included studies.

The influence of study methodoligies will be discussed.

28. * Strategy for data synthesis.

Describe the methods you plan to use to synthesise data. This must not be generic text but should be specific to your review and describe how the proposed approach will be applied to your data.



If meta-analysis is planned, describe the models to be used, methods to explore statistical heterogeneity, and software package to be used.

Thematic synthesis of findings with a minimum of six studies.

Discussion and synthesis of service user view themes and higher-order research team interpretation.

Discussion of descriptive themes in the context of existing theory and studies assessing the experience, conceptualisation and scope of recovery in across forensic, inpatient and community settings.

29. * Analysis of subgroups or subsets.

State any planned investigation of 'subgroups'. Be clear and specific about which type of study or participant will be included in each group or covariate investigated. State the planned analytic approach.

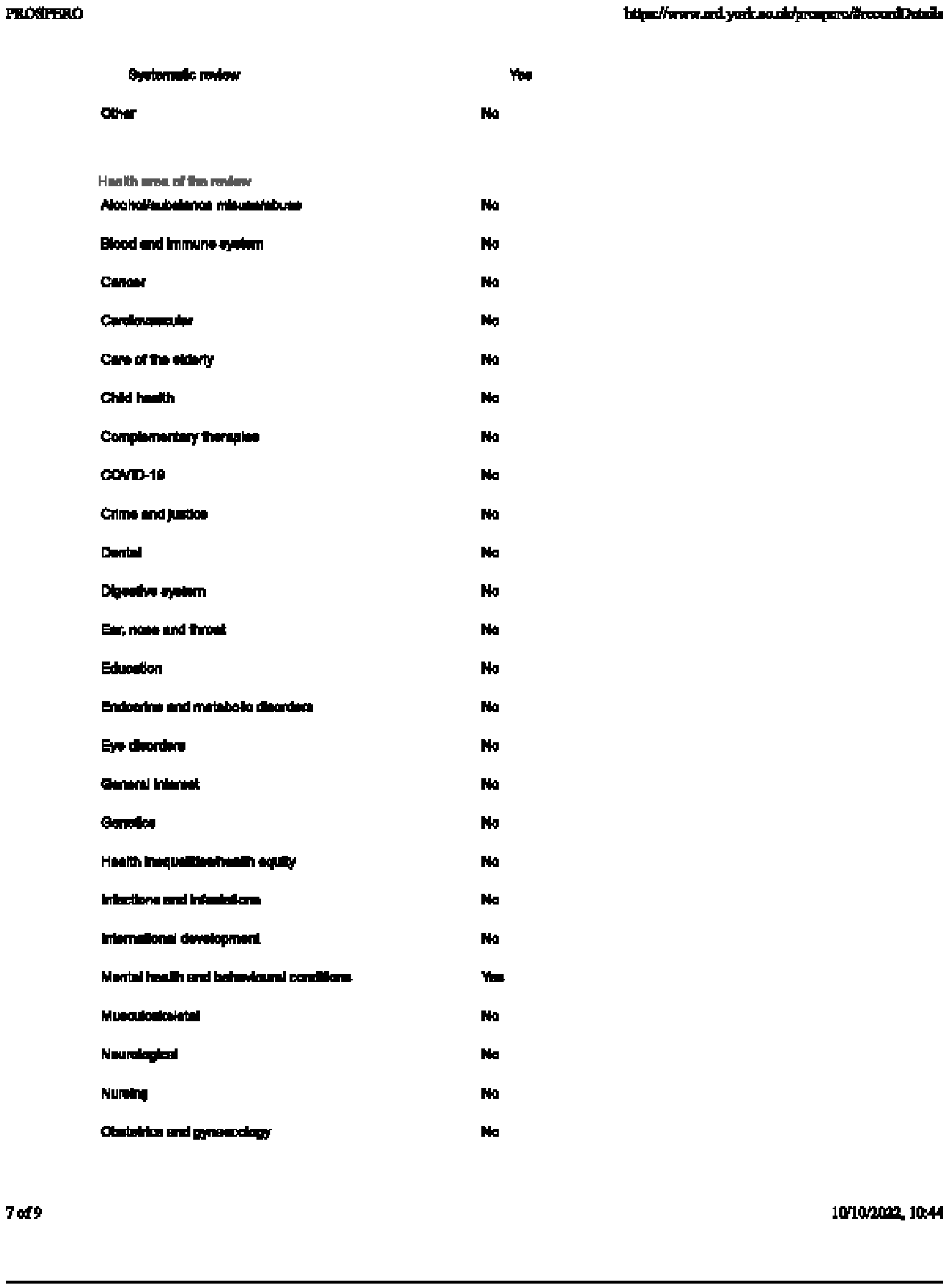
Not applicable

30. * Type and method of review.

Select the type of review, review method and health area from the lists below.

Type of review

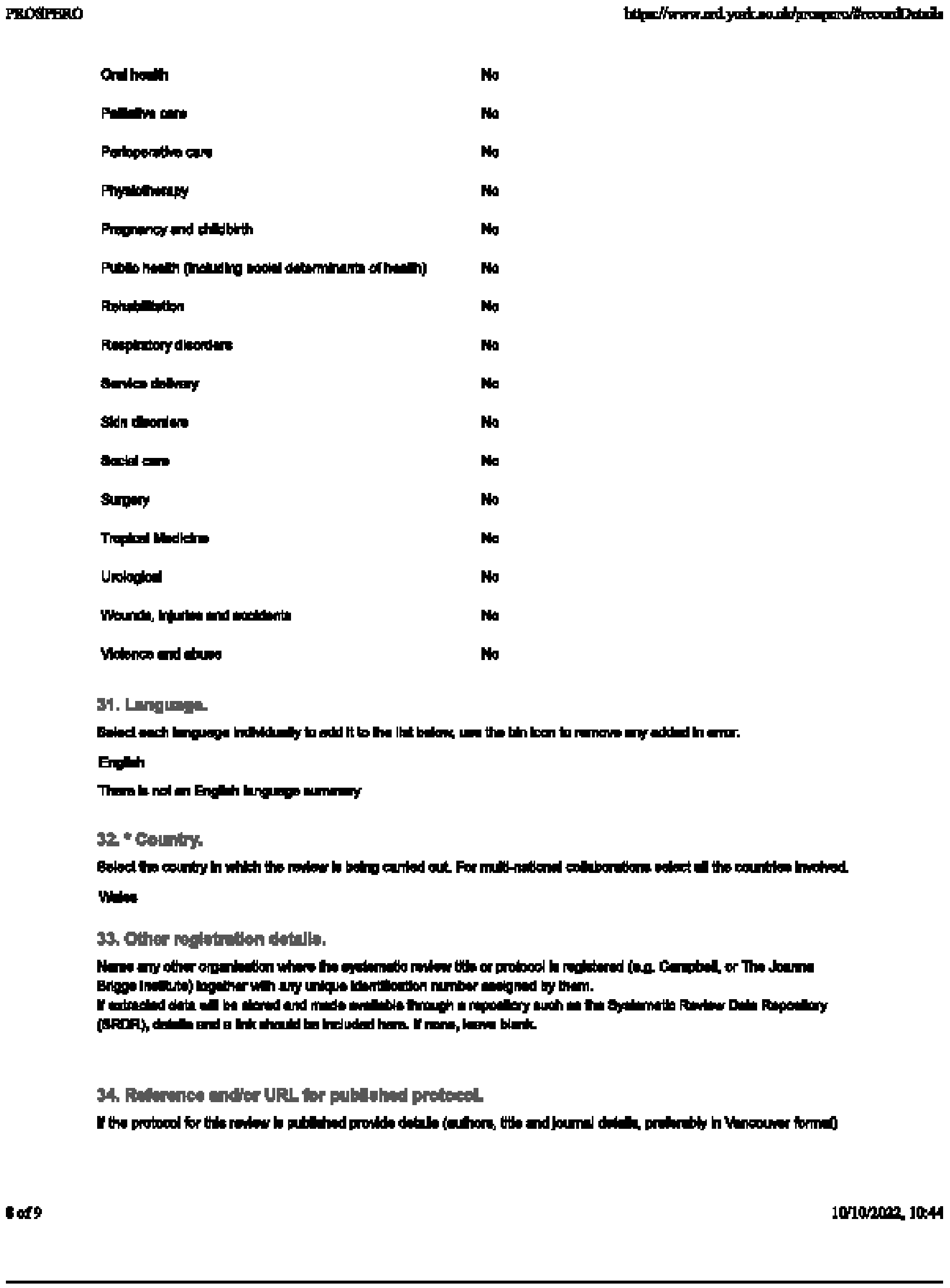
Cost effectiveness	No
Diagnostic	No
Epidemiologic	No
Individual patient data (IPD) meta-analysis	No
Intervention	No
Living systematic review	No
Meta-analysis	No
Methodology	No
Narrative synthesis	No
Network meta-analysis	No
Pre-clinical	No
Prevention	No
Prognostic	No
Prospective meta-analysis (PMA)	No
Review of reviews	No
Service delivery	No
Synthesis of qualitative studies	Yes



Systematic review	Yes
Other	No

Health area of the review

Alcohol/substance misuse/abuse	No
Blood and immune system	No
Cancer	No
Cardiovascular	No
Care of the elderly	No
Child health	No
Complementary therapies	No
COVID-19	No
Crime and justice	No
Dental	No
Digestive system	No
Ear, nose and throat	No
Education	No
Endocrine and metabolic disorders	No
Eye disorders	No
General interest	No
Genetics	No
Health inequalities/health equity	No
Infections and infestations	No
International development	No
Mental health and behavioural conditions	Yes
Musculoskeletal	No
Neurological	No
Nursing	No
Obstetrics and gynaecology	No



Oral health	No
Palliative care	No
Perioperative care	No
Physiotherapy	No
Pregnancy and childbirth	No
Public health (including social determinants of health)	No
Rehabilitation	No
Respiratory disorders	No
Service delivery	No
Skin disorders	No
Social care	No
Surgery	No
Tropical Medicine	No
Urological	No
Wounds, injuries and accidents	No
Violence and abuse	No

31. Language.

Select each language individually to add it to the list below, use the bin icon to remove any added in error.

English

There is not an English language summary

32. * Country.

Select the country in which the review is being carried out. For multi-national collaborations select all the countries involved.

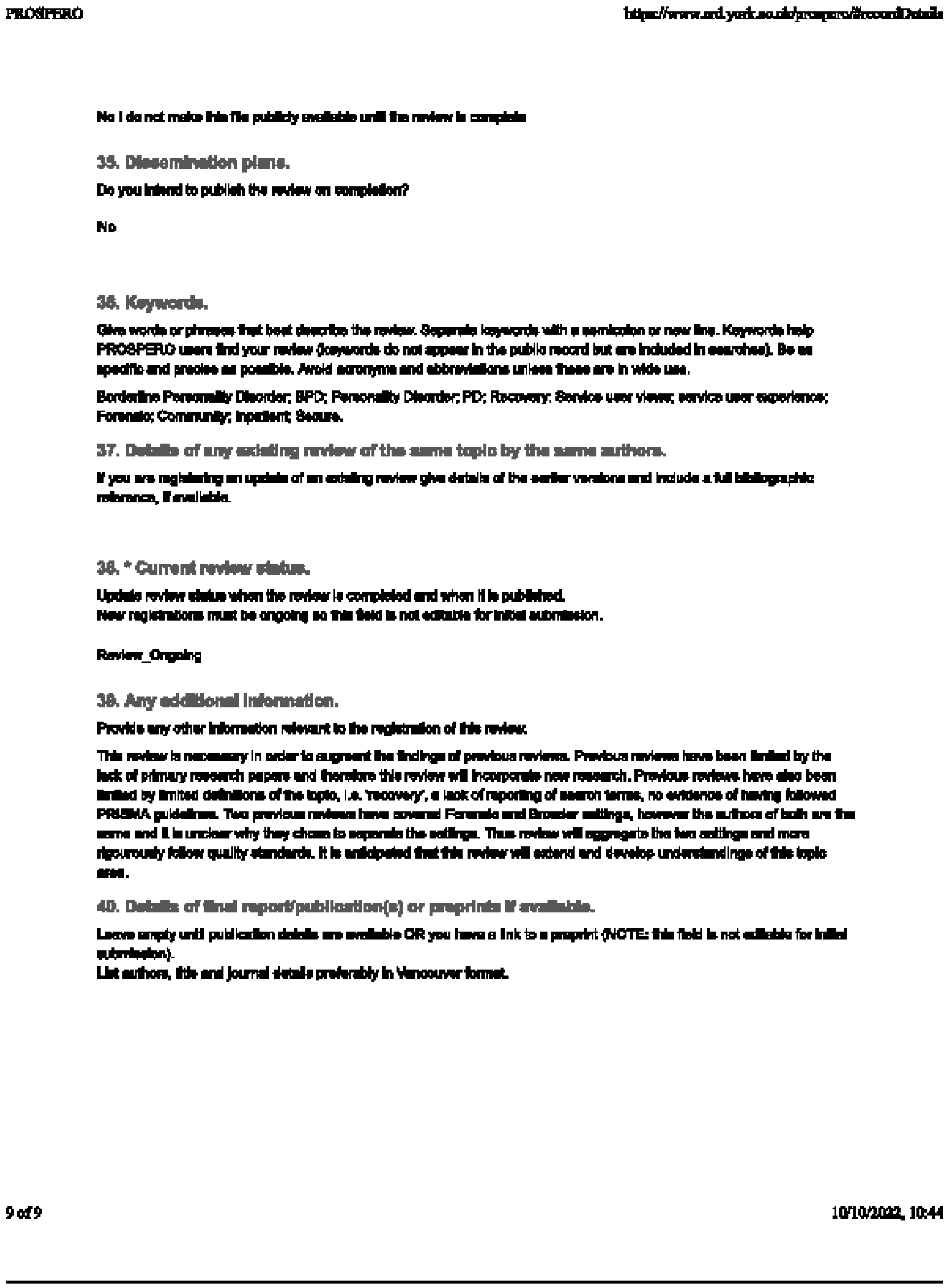
Wales

33. Other registration details.

Name any other organisation where the systematic review title or protocol is registered (e.g. Campbell, or The Joanna Briggs Institute) together with any unique identification number assigned by them.
If extracted data will be stored and made available through a repository such as the Systematic Review Data Repository (SRDR), details and a link should be included here. If none, leave blank.

34. Reference and/or URL for published protocol.

If the protocol for this review is published provide details (authors, title and journal details, preferably in Vancouver format)



No I do not make this file publicly available until the review is complete

35. Dissemination plans.

Do you intend to publish the review on completion?

No

36. Keywords.

Give words or phrases that best describe the review. Separate keywords with a semicolon or new line. Keywords help PROSPERO users find your review (keywords do not appear in the public record but are included in searches). Be as specific and precise as possible. Avoid acronyms and abbreviations unless these are in wide use.

Borderline Personality Disorder; BPD; Personality Disorder; PD; Recovery: Service user views; service user experience; Forensic; Community; Inpatient; Secure.

37. Details of any existing review of the same topic by the same authors.

If you are registering an update of an existing review give details of the earlier versions and include a full bibliographic reference, if available.

38. * Current review status.

Update review status when the review is completed and when it is published.
New registrations must be ongoing so this field is not editable for initial submission.

Review_Ongoing

39. Any additional information.

Provide any other information relevant to the registration of this review.

This review is necessary in order to augment the findings of previous reviews. Previous reviews have been limited by the lack of primary research papers and therefore this review will incorporate new research. Previous reviews have also been limited by limited definitions of the topic, i.e. 'recovery', a lack of reporting of search terms, no evidence of having followed PRISMA guidelines. Two previous reviews have covered Forensic and Broader settings, however the authors of both are the same and it is unclear why they chose to separate the settings. This review will aggregate the two settings and more rigourously follow quality standards. It is anticipated that this review will extend and develop understandings of this topic area.

40. Details of final report/publication(s) or preprints if available.

Leave empty until publication details are available OR you have a link to a preprint (NOTE: this field is not editable for initial submission).
List authors, title and journal details preferably in Vancouver format.

Appendix E: Search terms and syntax for databases

Database	Search terms
APA Psycinfo, Embase, Medline,	• Borderline Personality Disorder OR BPD OR emotionally unstable personality disorder OR eupd AND recover* AND experience* OR view* OR perspective* OR attitude* OR feelings OR thoughts
Proquest	• "Borderline Personality Disorder" OR (BPD) OR(emotionally unstable personality disorder) OR (eupd) AND (recover*) AND (experience* OR view* OR perspective* OR attitude* OR feelings OR thoughts
PubMed	• (borderline personality disorder) OR BPD OR (emotionally unstable personality disorder) OR (eupd) AND (Recover*) AND (experience*) • (borderline personality disorder) OR BPD OR (eupd) AND (Recover*) AND (view*) • (borderline personality disorder) OR BPD OR (eupd) AND (Recover*) AND (attitudes) • (borderline personality disorder) OR BPD OR (eupd) AND (Recover*) AND (feelings) • (borderline personality disorder) OR BPD OR (eupd) AND (Recover*) AND (thoughts)

Appendix F: Reflexive statement

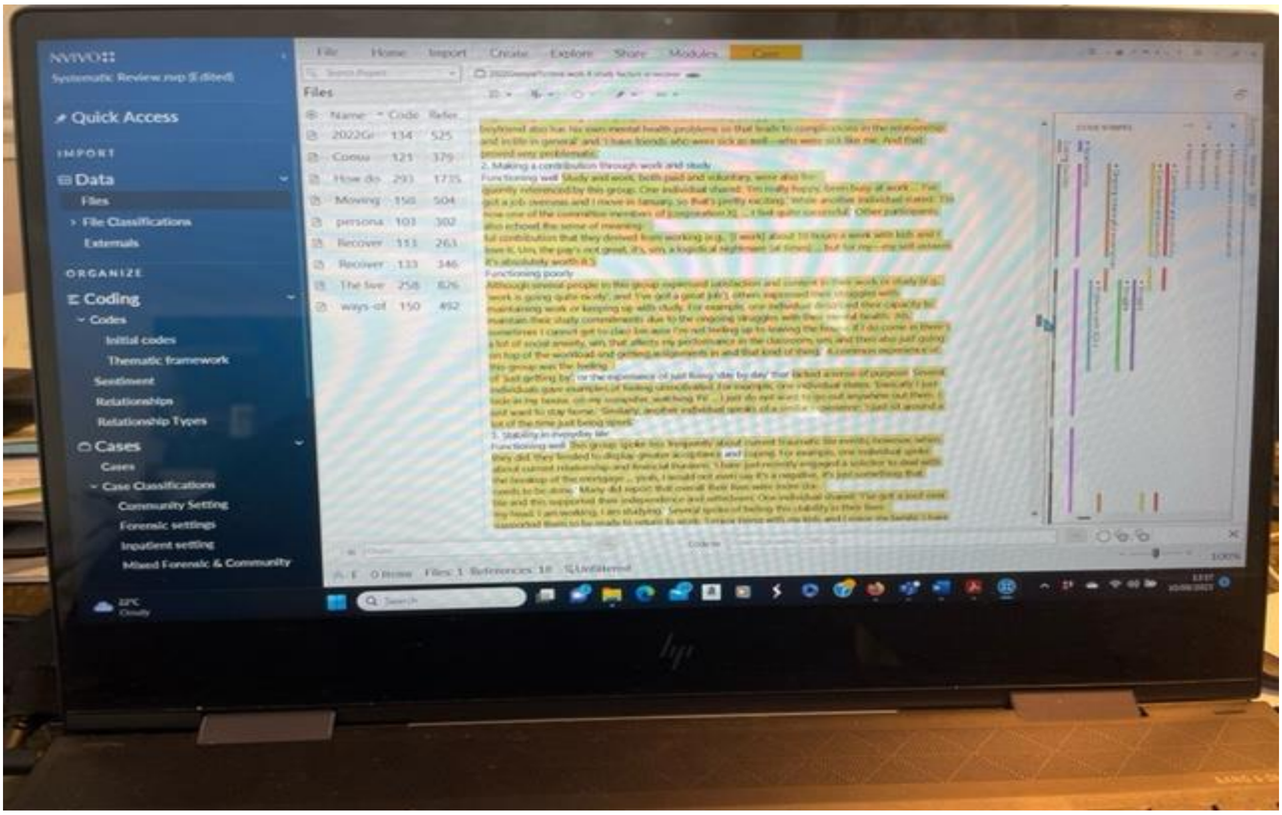
Reflexive Statement

The main researcher is a 45-year-old white Irish/British man with no personal experience of BPD. They is a trainee clinical psychologist with experience of working with adult and adolescent individuals experiencing mental illness, are neurodiverse, have acquired brain impairment or disability. Through clinical experience they has seen the developmental impact on individuals of poor mental health and difficult or traumatic experiences. Throughout training and clinical work, they has employed a range of therapeutic and theoretical approaches, with an interest in ACT (Acceptance and Commitment Therapy), Systemic approaches and CBT (Cognitive Behavioural Therapy).

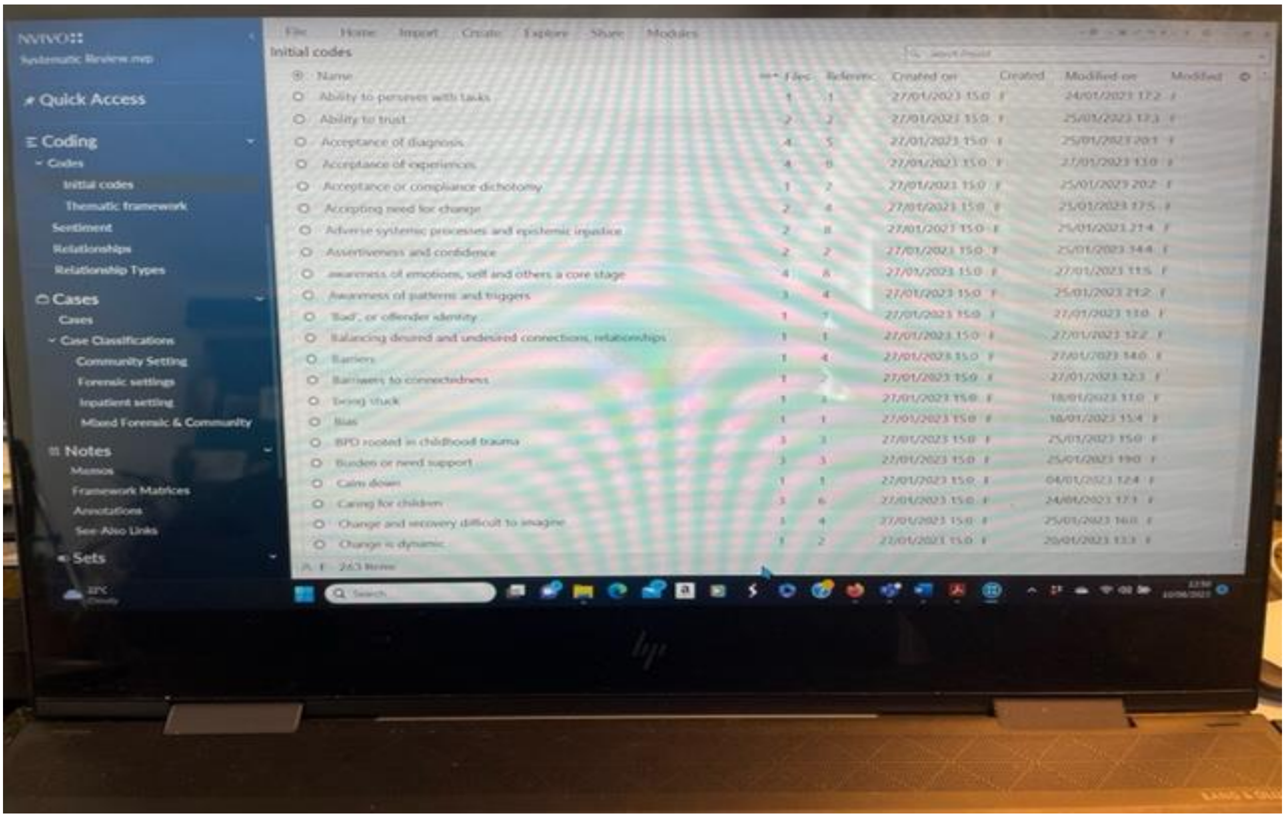
The research supervisors were Clinical Psychologists/Academic tutors specialising in adult mental health and adult forensic mental health, frequently supporting SUs with BPD. James Stroud has worked clinically within adult mental health services for 22 years and provided academic supervision for the project. Their academic and clinical reflections derived from interests primarily in BPD and complex trauma, and the treatment approach of Schema Therapy. They offered reflections on the process of recovery from a developmental and clinical perspective, and provided critical reflective oversight throughout analytical framework development.

The main researcher analysed the data independently and analysis stages were verified by the supervisory team. Research supervision involved discussing nuances and themes from the eight interviews throughout the analytical process. This enabled exploration of ideas, understanding of clinical practice implications and monitoring of interview schedule efficacy. Additionally, supervision was used to help the main researcher process the impact of traumatic narratives and manage any vicarious trauma related to this. Research supervisors encouraged reflection on the influence of the researchers' own assumptions and values on interpretation of the data, enhancing their awareness of how the findings were being co-constructed between the participants and themselves.

Appendix G: NVIVO codes page (Grenyer et al.,2020), and NVIVO initial codes list screen



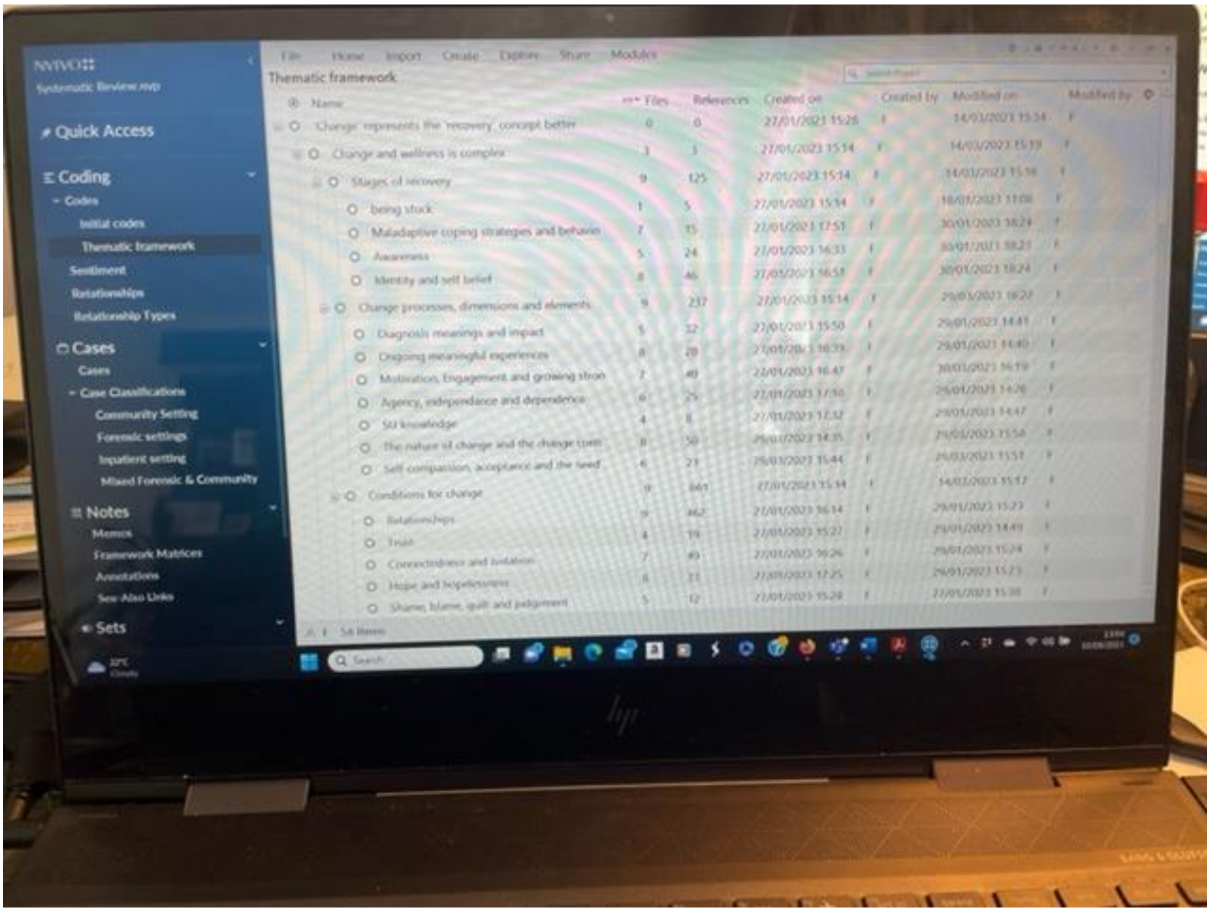
Name	Code	Refer.
2022Gr	134	525
Consu	121	379
How do	293	1735
Moving	150	504
persona	101	302
Recover	113	263
Recover	133	346
The live	258	626
ways of	150	492



Initial codes

Name	Files	Referenc	Created on	Created	Modified on	Modified
Ability to persevere with tasks	1	1	27/01/2023 15:0	F	24/01/2023 17:2	F
Ability to trust	2	2	27/01/2023 15:0	F	25/01/2023 17:3	F
Acceptance of diagnosis	4	5	27/01/2023 15:0	F	25/01/2023 20:1	F
Acceptance of experiences	4	8	27/01/2023 15:0	F	27/01/2023 13:0	F
Acceptance or compliance dichotomy	1	2	27/01/2023 15:0	F	25/01/2023 20:2	F
Accepting need for change	2	4	27/01/2023 15:0	F	25/01/2023 17:5	F
Adverse systemic processes and epistemic injustice	2	8	27/01/2023 15:0	F	25/01/2023 21:4	F
Assertiveness and confidence	2	2	27/01/2023 15:0	F	25/01/2023 14:4	F
awareness of emotions, self and others a core stage	4	8	27/01/2023 15:0	F	27/01/2023 11:5	F
Awareness of patterns and triggers	3	4	27/01/2023 15:0	F	25/01/2023 21:2	F
'Bad', or offender identity	1	1	27/01/2023 15:0	F	27/01/2023 13:0	F
Balancing desired and undesired connections, relationships	1	1	27/01/2023 15:0	F	27/01/2023 12:2	F
Barriers	1	4	27/01/2023 15:0	F	27/01/2023 14:0	F
Barriers to connectedness	1	2	27/01/2023 15:0	F	27/01/2023 12:3	F
Being stuck	1	3	27/01/2023 15:0	F	18/01/2023 11:0	F
Bias	1	1	27/01/2023 15:0	F	18/01/2023 15:4	F
BPD rooted in childhood trauma	3	3	27/01/2023 15:0	F	25/01/2023 15:0	F
Burden or need support	3	3	27/01/2023 15:0	F	25/01/2023 19:0	F
Calm down	1	1	27/01/2023 15:0	F	04/01/2023 12:4	F
Caring for children	3	6	27/01/2023 15:0	F	24/01/2023 17:1	F
Change and recovery difficult to imagine	3	4	27/01/2023 15:0	F	25/01/2023 16:0	F
Change is dynamic	1	2	27/01/2023 15:0	F	20/01/2023 13:3	F

263 Items



Thematic framework

Name	Files	References	Created on	Created by	Modified on	Modified by
'Change' represents the 'recovery' concept better	0	0	27/01/2023 15:26	F	14/03/2023 15:34	F
Change and wellness is complex	3	3	27/01/2023 15:14	F	14/03/2023 15:19	F
Stages of recovery	9	125	27/01/2023 15:14	F	14/03/2023 15:16	F
being stuck	1	5	27/01/2023 15:34	F	18/01/2023 11:08	F
Maladaptive coping strategies and behavio	7	15	27/01/2023 17:51	F	30/01/2023 18:24	F
Awareness	5	24	27/01/2023 16:33	F	30/01/2023 18:23	F
Identity and self belief	8	46	27/01/2023 16:53	F	30/01/2023 18:24	F
Change processes, dimensions and elements	9	237	27/01/2023 15:14	F	29/03/2023 16:22	F
Diagnosis meanings and impact	5	32	27/01/2023 15:50	F	29/01/2023 14:41	F
Ongoing meaningful experiences	8	20	27/01/2023 16:39	F	29/01/2023 14:40	F
Motivation, Engagement and growing stron	7	40	27/01/2023 16:47	F	30/03/2023 16:19	F
Agency, independance and dependence	6	25	27/01/2023 17:16	F	29/01/2023 14:26	F
SU knowledge	4	8	27/01/2023 17:32	F	29/01/2023 14:47	F
The nature of change and the change cont	8	50	29/01/2023 14:35	F	29/03/2023 15:54	F
Self compassion, acceptance and the need	6	21	29/01/2023 15:44	F	29/03/2023 15:51	F
Conditions for change	9	661	27/01/2023 15:14	F	14/03/2023 15:17	F
Relationships	9	462	27/01/2023 16:14	F	29/01/2023 15:23	F
Trust	4	19	27/01/2023 15:27	F	29/01/2023 14:49	F
Connectedness and isolation	7	49	27/01/2023 16:26	F	29/01/2023 15:24	F
Hope and hopelessness	8	31	27/01/2023 17:25	F	29/01/2023 15:23	F
Shame, blame, guilt and judgement	5	12	27/01/2023 15:28	F	27/01/2023 15:38	F

Appendix H: Example of codes

Systematic Review

Codes\\Initial codes

Name
Ability to persever with tasks
Ability to trust
Acceptance of diagnosis
Acceptance of experiences
Acceptance or compliance dichotomy
Accepting need for change
Adverse systemic processes and epistemic injustice
Assertiveness and confidence
awareness of emotions, self and others a core stage
Awareness of patterns and triggers
'Bad', or offender identity
Balancing desired and undesired connections, relationships
Barriers
Barriwers to connectedness
being stuck
Bias
BPD rooted in childhood trauma
Burden or need support
Calm down

Name
Caring for children
Change and recovery difficult to imagine
Change is dynamic
Change is hard work
Change is multifacted
Change is possible
Change is scary and difficult
Change means loss of identity
Change over time
Change, recovery, wellness is complex
Clinican skills needed
Communication of change
Compassion
Conclusions
Conditions for change
Conflict with clinicians
Constructing positive identity challenging
Construction of change
Context of treatment
Contribution and productivity
Coping
Coping skills
Curiosity about self key
Cycles of dysfunction

Name
Dare to be brave, to change
developing awareness of emotions and thoughts
Developing emotional regulation
Development and learning
diagnosis
Diagnosis delay
diagnosis of BPD a turning point in understanding
Differences between Community and forensic settings
Differences between recovered and not recovered
Dimensions, elements of recovery
Discharge as the beginning of recovery
Distrust
Effective treatment
Effective treatment challenging
Emotion tolerance skills
Emotional intensity
Emotional support
Enduring emptiness
Enduring nature
Engagemenent with treatment and services
Engagement in meaninful activities and relatinships
Engagement in recovery process
Facets of life
Fear of developing sense of self

Name
Feeling safe and wanting to explore
Feeling understood
Feelings of shame and lonliness
Financial insecurity
Fluctuation in recovery
Forensic demands
Forensic setting
Fragile identity
Gains in Self-belief
Growing stronger
Growth within individuals
Half of individuals expereince recovery after 10 years
Having normal life, feeling good about self
Health proffessional knowledge crucial
Holistic understanding of recovery in BPD
Hope and optimism
Hope can be generated
Hopelessness and failure
Hoplessness
I am not alone

Appendix I: Thematic framework development (in NVIVO)

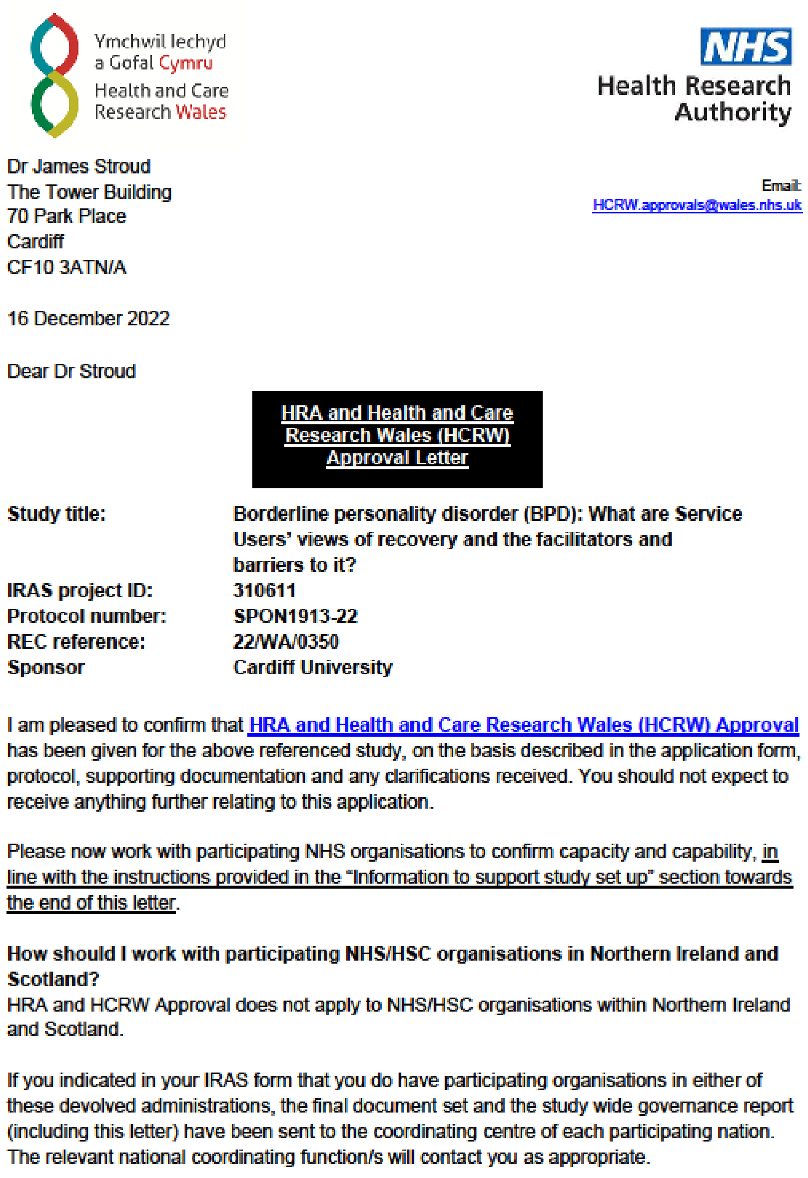
Codes\\Thematic framework

Name
'Change' represents the 'recovery' concept better
Change and wellness is complex
Change processes, dimensions and elements
Agency, independance and dependence
Diagnosis meanings and impact
Motivation, Engagement and growing stronger
Ongoing meaningful experiences
Self-compassion, acceptance and the need for change
SU knowledge
The nature of change and the change continuum
Conditions for change
Connectedness and isolation
Hope and hopelessness
Problems with ADLs
Relationships
Shame, blame, guilt and judgement
Treatment
Adverse systemic processes and epistemic injustice
Forensic, secure settings
Differences between Community and forensic settings
Discharge as the beginning of recovery
Forensic demands

Name
Time
Unique challenges
Trust
Measuring change problematic
Differences between recovered and not recovered
Importance of meaningful, relevant measures
Recovery compared to self and others
Skills needed for change
Coping skills
Emotion management skills
Life skills
Reflection skills
Self-management skills
Skills development
Thinking skills
Stages of recovery
Awareness
being stuck
Identity and self belief
Maladaptive coping strategies and behaviours
Describing recovery
Others understanding of recovery in BPD
Personal recovery conceptualisation
SU view of change

Name
Non recovery
'Normality'
Satisfaction
Skepticism about symptom reduction
Stability
SU views help
What SU's are recovering from
SUs experience of transient, changing and intense symptoms
Symptom reduction
Symptoms part of my identity

Appendix J: HRA approval letter



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

Dr James Stroud
The Tower Building
70 Park Place
Cardiff
CF10 3ATN/A

Email:
HCRW.approvals@wales.nhs.uk

16 December 2022

Dear Dr Stroud

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**Borderline personality disorder (BPD): What are Service Users' views of recovery and the facilitators and barriers to it?**
IRAS project ID:	**310611**
Protocol number:	**SPON1913-22**
REC reference:	**22/WA/0350**
Sponsor	**Cardiff University**

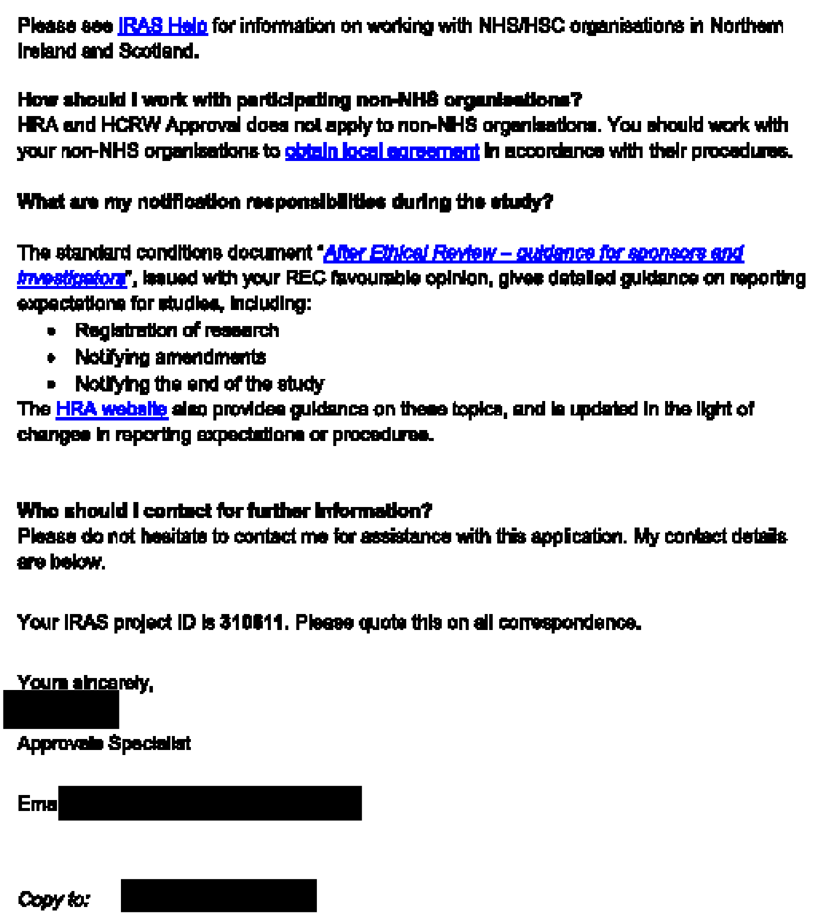
I am pleased to confirm that HRA and Health and Care Research Wales (HCRW) Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.



Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

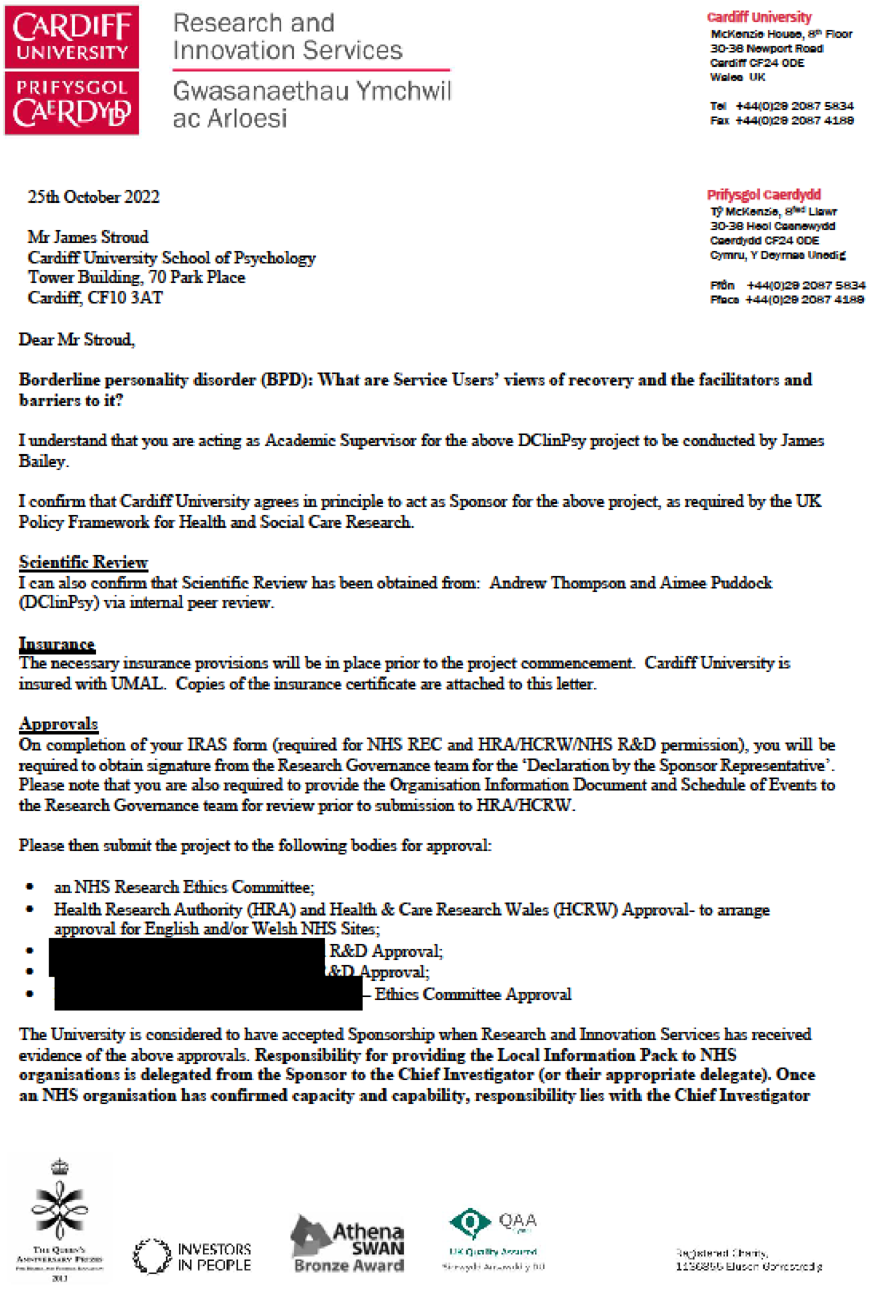
Your IRAS project ID is 310611. Please quote this on all correspondence.

Yours sincerely,
[redacted]
Approvals Specialist

Ema [redacted]

Copy to: [redacted]

Appendix K: Research and Innovation services sponsorship letter



Research and Innovation Services
Gwasanaethau Ymchwil ac Arloesi

Cardiff University
McKenzie House, 8th Floor
30-36 Newport Road
Cardiff CF24 0DE
Wales UK

Tel +44(0)29 2087 5834
Fax +44(0)29 2087 4189

Prifysgol Caerdydd
Tŷ McKenzie, 8fed Llawr
30-36 Heol Casnewydd
Caerdydd CF24 0DE
Cymru, Y Deyrnas Unedig

Ffôn +44(0)29 2087 5834
Ffacs +44(0)29 2087 4189

25th October 2022

Mr James Stroud
Cardiff University School of Psychology
Tower Building, 70 Park Place
Cardiff, CF10 3AT

Dear Mr Stroud,

Borderline personality disorder (BPD): What are Service Users' views of recovery and the facilitators and barriers to it?

I understand that you are acting as Academic Supervisor for the above DClinPsy project to be conducted by James Bailey.

I confirm that Cardiff University agrees in principle to act as Sponsor for the above project, as required by the UK Policy Framework for Health and Social Care Research.

<u>Scientific Review</u>
I can also confirm that Scientific Review has been obtained from: Andrew Thompson and Aimee Puddock (DClinPsy) via internal peer review.

<u>Insurance</u>
The necessary insurance provisions will be in place prior to the project commencement. Cardiff University is insured with UMAL. Copies of the insurance certificate are attached to this letter.

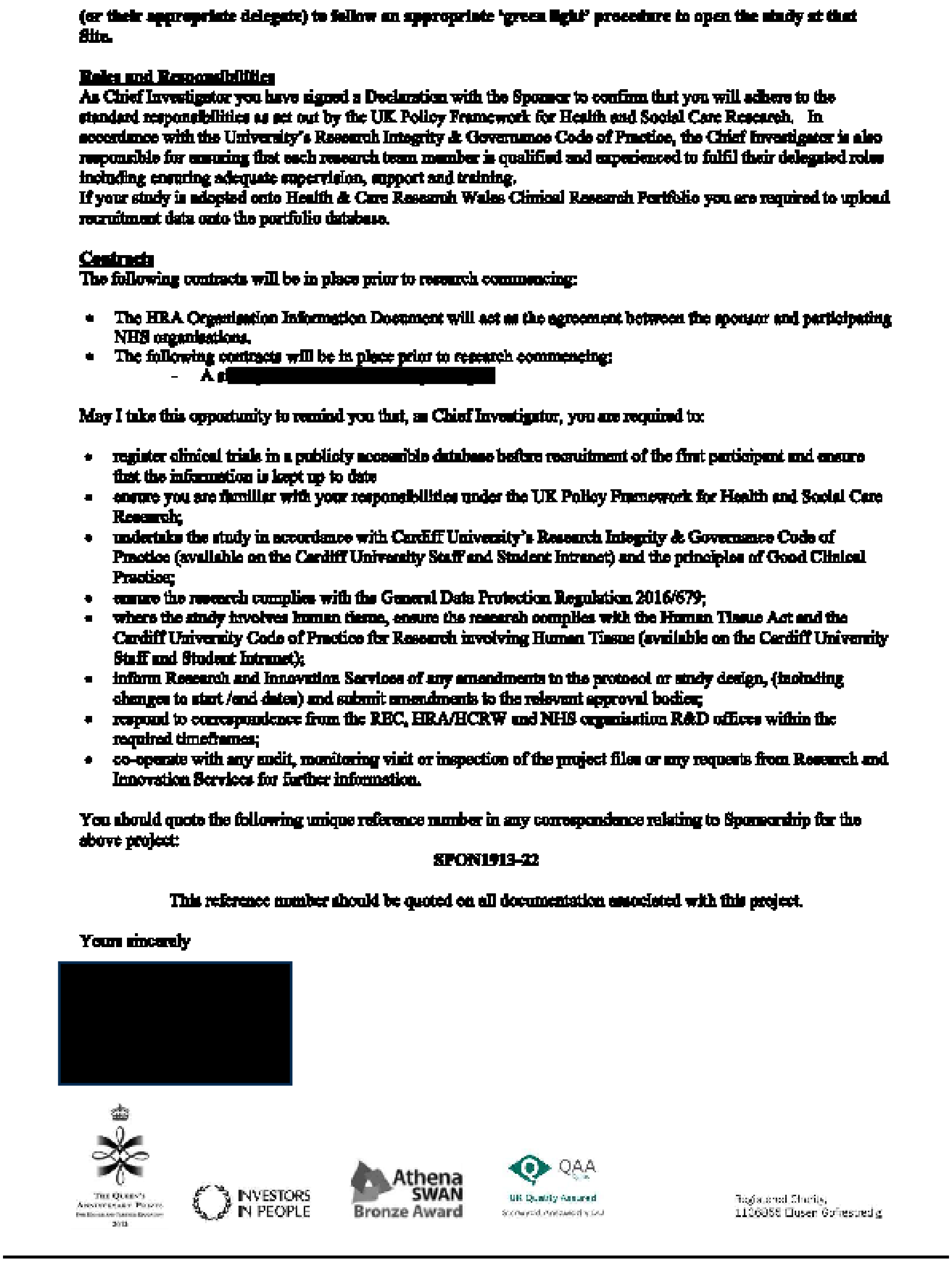
<u>Approvals</u>
On completion of your IRAS form (required for NHS REC and HRA/HCRW/NHS R&D permission), you will be required to obtain signature from the Research Governance team for the 'Declaration by the Sponsor Representative'. Please note that you are also required to provide the Organisation Information Document and Schedule of Events to the Research Governance team for review prior to submission to HRA/HCRW.

Please then submit the project to the following bodies for approval:

- an NHS Research Ethics Committee;
- Health Research Authority (HRA) and Health & Care Research Wales (HCRW) Approval- to arrange approval for English and/or Welsh NHS Sites;
- [redacted] R&D Approval;
- &D Approval;
- [redacted] – Ethics Committee Approval

The University is considered to have accepted Sponsorship when Research and Innovation Services has received evidence of the above approvals. **Responsibility for providing the Local Information Pack to NHS organisations is delegated from the Sponsor to the Chief Investigator (or their appropriate delegate). Once an NHS organisation has confirmed capacity and capability, responsibility lies with the Chief Investigator**

Registered Charity, 1136855 Elusen Gofrestredig



(or their appropriate delegate) to follow an appropriate 'green light' procedure to open the study at that Site.

Roles and Responsibilities
As Chief Investigator you have signed a Declaration with the Sponsor to confirm that you will adhere to the standard responsibilities as set out by the UK Policy Framework for Health and Social Care Research. In accordance with the University's Research Integrity & Governance Code of Practice, the Chief Investigator is also responsible for ensuring that each research team member is qualified and experienced to fulfil their delegated roles including ensuring adequate supervision, support and training.
If your study is adopted onto Health & Care Research Wales Clinical Research Portfolio you are required to upload recruitment data onto the portfolio database.

Contracts
The following contracts will be in place prior to research commencing:

- The HRA Organisation Information Document will act as the agreement between the sponsor and participating NHS organisations.
- The following contracts will be in place prior to research commencing:
  - A [redacted]

May I take this opportunity to remind you that, as Chief Investigator, you are required to:

- register clinical trials in a publicly accessible database before recruitment of the first participant and ensure that the information is kept up to date
- ensure you are familiar with your responsibilities under the UK Policy Framework for Health and Social Care Research;
- undertake the study in accordance with Cardiff University's Research Integrity & Governance Code of Practice (available on the Cardiff University Staff and Student Intranet) and the principles of Good Clinical Practice;
- ensure the research complies with the General Data Protection Regulation 2016/679;
- where the study involves human tissue, ensure the research complies with the Human Tissue Act and the Cardiff University Code of Practice for Research involving Human Tissue (available on the Cardiff University Staff and Student Intranet);
- inform Research and Innovation Services of any amendments to the protocol or study design, (including changes to start /end dates) and submit amendments to the relevant approval bodies;
- respond to correspondence from the REC, HRA/HCRW and NHS organisation R&D offices within the required timeframes;
- co-operate with any audit, monitoring visit or inspection of the project files or any requests from Research and Innovation Services for further information.

You should quote the following unique reference number in any correspondence relating to Sponsorship for the above project:

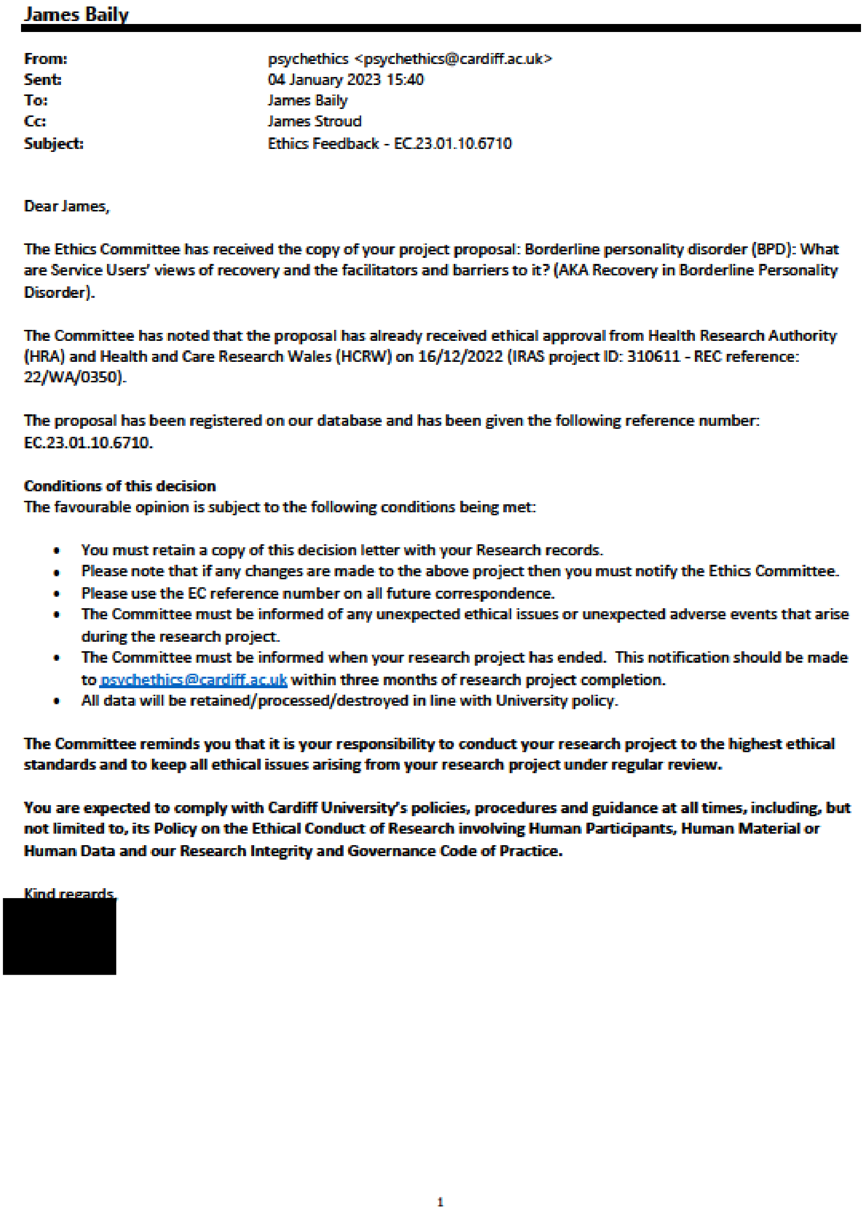
SPON1913-22

This reference number should be quoted on all documentation associated with this project.

Yours sincerely

[redacted]

Appendix L: School of Psychology ethical approval



James Baily

From: psychethics <psychethics@cardiff.ac.uk>
Sent: 04 January 2023 15:40
To: James Baily
Cc: James Stroud
Subject: Ethics Feedback - EC.23.01.10.6710

Dear James,

The Ethics Committee has received the copy of your project proposal: Borderline personality disorder (BPD): What are Service Users' views of recovery and the facilitators and barriers to it? (AKA Recovery in Borderline Personality Disorder).

The Committee has noted that the proposal has already received ethical approval from Health Research Authority (HRA) and Health and Care Research Wales (HCRW) on 16/12/2022 (IRAS project ID: 310611 - REC reference: 22/WA/0350).

The proposal has been registered on our database and has been given the following reference number: EC.23.01.10.6710.

Conditions of this decision
The favourable opinion is subject to the following conditions being met:

- You must retain a copy of this decision letter with your Research records.
- Please note that if any changes are made to the above project then you must notify the Ethics Committee.
- Please use the EC reference number on all future correspondence.
- The Committee must be informed of any unexpected ethical issues or unexpected adverse events that arise during the research project.
- The Committee must be informed when your research project has ended. This notification should be made to psychethics@cardiff.ac.uk within three months of research project completion.
- All data will be retained/processed/destroyed in line with University policy.

The Committee reminds you that it is your responsibility to conduct your research project to the highest ethical standards and to keep all ethical issues arising from your research project under regular review.

You are expected to comply with Cardiff University's policies, procedures and guidance at all times, including, but not limited to, its Policy on the Ethical Conduct of Research involving Human Participants, Human Material or Human Data and our Research Integrity and Governance Code of Practice.

Kind regards,

[redacted]

1

Appendix M: Interview schedule

DOCUMENT CONTROL TABLE

Document Title: Interview Guide v1.0 21.10.22

Author, job title, division: James Baily, Trainee Clinical Psychologist, Psychology

Version Number: 1.0

Document Status:

Date approved:

Approved by:

Effective date:

Date of next review: n/a

Superseded version: n/a

DOCUMENT HISTORY

Version	Date	Author	Notes on revisions
0.1	**11.12.21**	**James Baily**	

0.2	**07.02.22**	**James Baily**	**Revisions based on feedback from field researchers and academic supervisors.**
0.3	**08.02.22**	**James Baily**	**Revisions based on feedback from service user representative.**
0.4	**22.07.22**	**James Baily**	**Revisions based on feedback from SU rep and supervisors.**
1.0	**21.10.22**	**James Baily**	**Revisions based on feedback from research Governance.**

CARDIFF
UNIVERSITY
PRIFYSGOL
CAERDYDD

Interview Guide

Borderline personality disorder (BPD): What are past and present forensic Service Users' views of recovery and the facilitators and barriers to it?

Aims:

To give service users a sense of being listened to and that their perspective is important.

To establish an understanding of what forensic service users view as 'recovery'.

To develop a theory around how facilitators and barriers to service user's recovery work in the forensic setting.

Before commencing the interview ensure the participant is comfortable, take time to have some friendly chat and when ready revisit confidentiality and the check the participant has read the information sheets, and that they are happy to sign the consent form. Offer to go through the information sheet or consent form with them if they like.

Initial open-ended questions:

Can you tell me a little about you and your life?

Prompts:

- Are you from Wales?
- How would you describe your upbringing?
- How was school for you?
- What were your friends like?
- What interests did you have growing up?
- When did you leave your parent's home?
- What did you do when you left school?

I wondered whether you'd be ok with me asking you to tell me a little about some good periods in your life so far?

I'm also curious about some times in your life when things were more challenging and what that was like for you?

I wondered, of course within what you are comfortable sharing, what kind of things contributed to how you felt at this time?

What was life like before coming here, or what was happening for you at the time?

Did you become aware at any point when you were growing up that you were experiencing some difficulties before you were diagnosed?

Thinking about your personal experiences/experience and skills, how do these help you to live your every day life?

Intermediate questions:

I wonder if it would it be ok to describe your mental health as it is now and how it affects your life?

Could you tell me a little about what ‘recovery’ means to you?

Could I ask you how important ‘getting better’, having a ‘meaningful life’ or ‘recovery’ is to you?

Do you feel these are all the same thing, or are they different?

What would life look like to you if you felt you had recovered?

How do you think that might be possible?

Would you be happy to tell me a little about how your relationships with friends, family and/or staff affect how you can live a meaningful life, recover?

I wonder what your thoughts are on what you think the service thinks getting better/recovery means?

Have you found that there have been particular people, services or therapies (group/one to one) that have been helpful in supporting you?

What would you say it is about them / the service / therapies that have been helpful?

What do you think gets in the way of ‘getting better’/ having a ‘meaningful life’/ ‘recovery’

Ending questions

Is there any good advice and tips you would like to give to someone newly diagnosed with BPD and/or coming into this ward?

What do you think is important to remember or do to live a meaningful life, here in ….. and in the future?

How would you like to picture your life in a few year’s time?

Is there something else you would like me to know more about that I haven’t touched on?

I wonder if there are any questions you would like to ask me?

Appendix N: Participant information sheet

Participant information sheet for taking part in the research:

"Borderline personality disorder (BPD); What are Patients' views of recovery and the facilitators and barriers to it?"

This leaflet is an invitation to take part in research to explore your views of what "recovery" from or with borderline personality disorder (BPD) means to you, the things that help you to move towards this and those that do not. We think this is very important to understand better. It is also important to us that you understand as much about this project as possible before you agree to taking part.

It is *YOUR* decision whether or not you want to participate.

Please feel free to ask any questions you wish once you have read this information, and we will answer them as well as we can.

- **Why have you been chosen to take part in this research?**

  You are being asked to participate in this research because you are receiving care for emotional challenges, and have received a diagnosis of borderline personality disorder (BPD).

- **What is the reason for this research?**

  The purpose of this research is to better understand your ideas about what recovery with BPD means to you and how this is both the same, and different to what services and professionals understand recovery to be. We are also interested in listening to your ideas about what helps you to recover, and what gets in the way. Understanding these things better is hoped to be useful for improving services that support people in similar situations as you.

- **What will participating in this research look like?**

If you decide to take part, you will have an interview with a researcher which will take no longer than 60 minutes. The researcher will ask you questions about what you think recovering from BPD is and those things that do and do not help in your efforts to achieve this.

- **How will this be useful to you?**

  You might find that it is beneficial to think with someone about what recovery means to you and to have your opinion listened to and reflected in research literature. Your ideas may lead to improvements in how professionals and services work with you and others with similar experiences in the future.

  We will be offering £20 worth of high-street shop vouchers as a thank you for taking part.

- **Will there be any down sides to taking part in this research?**

  Taking part in this research will not negatively affect the treatment or services you receive. If at any time during the interview you feel upset, you can choose to stop. You can also choose to take a break or discuss your concerns with the researcher who has experience of working together with people who experience emotional and psychological difficulties. The researcher will also debrief you when the interview has been completed.

  Those staff who you work with currently will be aware you are taking part in this research and you are welcome to speak to them later if you feel you would like support.

- **Questionnaire for demographic information**

  We will ask you to complete an anonymous questionnaire that will ask you for details such as your age, sex and ethnicity. This is for background information and will not be linked to your personal data.

- **How will the information you provide be kept?**

  The interview will be recorded on an electronic device. This information is strictly confidential and personal details such as your name will not be used for research purposes. All information stored electronically will be protected by password and any devices will be kept in a locked filing cabinet and or secure facilities. All information will be handled and stored in accordance with the Data Protection Act (2018) and General Data Protection Regulation (GDPR, 2018). Data will be stored securely on secure Cardiff University systems for 15 years after the study has been completed. The only people who will see patient's information are those who are involved in the research. No other services or professionals such as GPs or other members of participant's care team other than those directly working with them in the research settings will be informed of their participation.

  Confidentiality will only be broken in specific circumstances which include if you disclose that you are at risk of making a suicide attempt or of being a risk to another person. In this scenario the services involved in your care will be informed.

If you require any further information about the study, you may speak to the clinicians involved in your care who will liaise with the research team.

You do not have to take part in this research if you do not want to. If you do take part, you may stop taking part at any time. This will not affect the care you receive.

How will we use information about you?

We will need to use information from you for this research project.

This information will include your name, initials, contact details and information that you may wish to provide about your health and any medication you may be taking. People will use this information to do the research or to check your records to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

We will use direct quotations from your interview responses to explore your thoughts and opinions about what recovery means to you within the research report. This data will be anonymised through the use of a pseudonym so that you cannot be identified.

The audio recording of your interview will be transcribed by the researcher or by a professional transcriber who has a confidentiality agreement in place with Cardiff University.

We will keep all information about you safe and secure.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

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.

What happens if you disclose information about any unethical practice or mistreatment?

In the event that you disclose any information of this nature, Swansea Bay University Health Board guidelines will be followed.

Where can you find out more about how your information is used?

You can find out more about how we use your information:

  - by asking the researcher (James Baily) or their supervisors;
  - by reading the Cardiff University Data Protection Policy: https://www.cardiff.ac.uk/public-information/policies-and-procedures/data-protection
  - by contacting the Cardiff University Data Protection Officer by email: inforequest@cardiff.ac.uk or in writing to: Data Protection Officer, Compliance and Risk, University Secretary's Office, Cardiff University, McKenzie House, 30-36 Newport Road, Cardiff CF24 0DE

- **Has this research been approved by a relevant ethical review panel?**

  This research study has been reviewed and approved by an NHS Research Ethics Committee (Wales Research Ethics Committee 6), the Health Research Authority (HRA), University Health Board Research & Development department.

  You will be able to contact and request further information about this study through your care team who will liaise with the research team to answer any questions you have.

What if something goes wrong?

If something goes wrong and you are harmed as a result of taking part in the study, you may have ground for compensation but you may have to pay your own legal fees. Cardiff University will provide indemnity and compensation in the event of a claim by, or on behalf of participants, for negligent harm as a result of the study design and/or in respect of the protocol authors/research team. Cardiff University cannot provide non-negligent harm cover.

Who is conducting the research?
The research is managed by researchers at Cardiff University. The lead researcher is James Baily, who is currently training to become a Clinical Psychologist on the South Wales DClinPsy programme.

If you have any questions about the study, or wish to discuss it in more detail, please contact James on: [redacted]

James' supervisors are:

Dr James Stroud:

[redacted]

Dr James Gregory:

[redacted]

Independent point of contact:

If you have any concerns about the study or your experience of it you may speak to any member of staff involved in your care that is not part of the research team. You may also:

- Use the [redacted] dedicated email [redacted].LetsTalk@wales.nhs.uk
- Or you cemail

The study is Sponsored by Cardiff University. It has been reviewed scientifically by the South Wales Doctorate in Clinical Psychology scientific review panel, in the School of Psychology, Cardiff University.

Appendix O: Staff information sheet

DOCUMENT CONTROL TABLE

Document Title: Staff information sheet v1.0 21.10.22

Author, job title, division: James Baily, Trainee Clinical Psychologist, Psychology

Version Number: 1.0

Document Status:

Date approved:

Approved by:

Effective date:

Date of next review: n/a

Superseded version: n/a

DOCUMENT HISTORY

Version	Date	Author	Notes on revisions
0.1	**06.02.22**	**James Baily**	**Reviewed by service user representative, field researchers and academic supervisors.**
0.2	**21.09.22**	**James Baily**	**Amendments made based on review by Research Governance (Cardiff University).**
1.0	**21.10.22**	**James Baily**	**Amendments made based on review by Research Governance (Cardiff University).**

Information sheet for staff working with participants in the research:

“Borderline personality disorder (BPD); What are Service Users’ views of recovery and the facilitators and barriers to it?”

We are inviting some of the service users you support to take part in research that we think may be important for better understanding their views on what recovery means to them. It is hoped that this will be useful in the planning and delivery of support to service users with a diagnosis of Borderline Personality Disorder (BPD).

Please feel free to ask the researcher any questions if you would like further information.

- **Why have your service users been identified to take part in this research?**

  They have been chosen for this research due to being treated for BPD in an NHS or a private setting.

  The participant inclusion / exclusion criteria for this study are defined below:

  Inclusion
  Male and female adults (18yrs +) receiving care in NHS and private settings. Service users with a primary diagnosis of BPD and may have co-morbid diagnoses. Service Users who have capacity to understand the process, give informed consent and are willing to participate.

  Exclusion
  Service users whose primary diagnosis is not BPD. Service users who have disengaged from services/interventions. Service users who are in crisis. Service Users who may pose a risk to researcher. Service users who are unable to give informed consent.

  Service users will also be offered £20 high street shop vouchers as a thank you for taking part in the study.

- **What is the purpose of this research?**

The current research literature around Borderline Personality Disorder broadly focuses on a number of areas including the experiences of professionals working with people who have a diagnosis of BPD, the experiences of people who have a diagnosis of BPD and how different kinds of interventions work for these service users. However, there is less focus on people with this diagnosis with regard to what recovery means to them and what they feel either helps or hinders their journey to recovery. This research aims to explore service user's ideas about what recovery is and what facilitates and gets in the way of this process. A service user representative affiliated with the South Wales Doctoral Programme in Clinical Psychology at Cardiff University was consulted in the development of the finalised interview questions.

- **What will participation in this research look like for the service users you work with?**

  Service users will be asked to take part in an interview which will last not more than 60 minutes, however it is likely that interviews will be between 30-45 minutes in duration.

- **How will your service-users and service benefit from taking part in this research?**

  Potential benefits for your service users include having a space explicitly meant for their views to be listened to about their experiences and in particular, what they think recovery is. It is hoped that this will help broaden the literature on this topic, which in due course can be used to guide how services support this cohort of service users. It also increases the service user's voice in the literature, which is difficult to do due to the context and ethical challenges inherent in research.

- **Are there any potential risks for your service users by taking part in this research?**

  Taking part in this research will not affect the participant's treatment or your role. It is possible that having an interview on this topic may be upsetting for service users as it may involve talking about emotive topics. Participants may pause the interview or withdraw from the study at any time.

- **What will happen to the information that service users provide?**

  The interview will be recorded on an encrypted, secure electronic device. This information is strictly confidential and personal details such as service user's names will not be used for research purposes. All information will be handled and stored in accordance with the Data Protection Act (2018) and General Data Protection Regulation (GDPR, 2018) . Electronic data will be protected by passwords and devices will be kept in a locked filing cabinet and or secure facilities. Data will be stored securely on secure Cardiff University systems for 15 years after the study has been completed. The only people who will see service user's information are those who are involved in the research. No other services or professionals such as GPs or other members of participant's care team other than those directly working with them in the research settings will be informed of their participation.

Confidentiality will only be broken in specific circumstances which include if service users disclose that they are at risk of making a suicide attempt or of being a risk to another person. In this scenario you will be informed immediately.

Service Users do not have to take part in this research if they do not want to. If they do take part, they may stop participating at any time. This will not affect the care they receive.

Participants may withdraw by advising staff in your setting that they wish to withdraw, who can advise the research team, or by indicating a wish to withdraw to the researcher in person during the interview.

The researchers will not need to record any personal identifiable information, data or anything that would identify you, as a member of staff.

- **Has this research been approved by a relevant ethical review panel?**

  This research study has been reviewed and approved by an NHS Research Ethics Committee, the Health Research Authority (HRA), University Health Board R&D.

- You will be able to contact and request further information about this study through using the contact details below. Queries and requests to withdraw may be addressed to the research team contact. The independent contact is listed should there be any concerns about the study that staff feel they need to raise.

- Contacts:
  - Research Team: James Baily (Researcher) [redacted]
  - Supervisors:
    - Dr James Stroud:

      [redacted]

    - Dr James Gregory:

      [redacted]

  - Independent point of contact:
    - If either a participant or staff member has any concerns, the complaint procedure within your service may be contacted.

- **What if something goes wrong?**
  Negligent harm: Cardiff University will provide indemnity and compensation in the event of a claim by, or on behalf of participants, for negligent harm as a result of the study design and/or in respect of the protocol authors/research team. Cardiff University cannot provide non-negligent harm cover.

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

  The results of this study will be examined by Cardiff University and upon approval it is anticipated that they will be published in peer reviewed journal. There is potential for this study to be disseminated through conferences and internally within Cardiff University and the NHS. It is also anticipated that it will be disseminated to private hospital staff locations where the research is also being conducted.

- **Who is organising and funding this study?**

  This study is being organised by James Baily (Researcher) with the guidance and support of the academic supervisor and team allocated to them through Cardiff University. This is an unfunded piece of research forming part of the researcher’s thesis submission for the Cardiff University Doctorate in Clinical Psychology.

- **Thank you!**

  Thank you very much for taking the time to read this information sheet, and for helping the researcher with this project.

Appendix P: Consent form

DOCUMENT CONTROL TABLE

Document Title: Participant Consent Form v1.0 21.10.22

Author, job title, division: James Baily, Trainee Clinical Psychologist, Psychology

Version Number: v1.0

Document Status:

Date approved:

Approved by:

Effective date:

Date of next review: n/a

Superseded version: n/a

DOCUMENT HISTORY

Version	Date	Author	Notes on revisions
0.1	**02.09.22**	**James Baily**	**Reviewed by service user representative, field researchers and academic supervisors.**
0.2	**21.09.22**	**James Baily**	**Amendments made on the basis of review by research governance team, Cardiff University.**

1.0	**21.10.22**	**James Baily**	**Amendments made on the basis of review by research governance team, Cardiff University.**

CARDIFF
UNIVERSITY
PRIFYSGOL
CAERDYDD

Participant Consent Form

Title of research project: "Borderline personality disorder (BPD); What are Patient's views of recovery and the facilitators and barriers to it?"

Researchers: James Baily (Chief researcher, Trainee Clinical Psychologist), Dr James Stroud (Research Supervisor).

Written Consent Form

Participant ID:

Name of Participant:

Name of Researcher:

Please write your initials in each box once you are satisfied that you agree with the statement. Thank you.

1. I confirm that I have read the Participant Information Sheet (Version 1.0, dated 21/10/22) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I agree to take part in an interview with a member of the research team about what recovery with borderline personality disorder means to me lasting up to 60 minutes. ☐

3. I agree to have my interview audio recorded and held confidentially for the purposes of transcription. ☐

4. I agree for the researchers to use verbatim ('word-for-word') quotes from the interviews. I understand that these will be anonymous and I will not be identifiable from the quotes. ☐

5. I understand that the information I have provided for this study will be held confidentially by the research team and that confidentiality will only be broken if I disclose Information that indicates I am at risk of attempting suicide, or harm myself or others. ☐

6. I understand that my research data will be held anonymously and retained for 15 years, in line with Cardiff University's retention policy. ☐

7. I understand that I can stop participating at any time without giving any reason and without my medical care being affected. ☐

8. I freely consent to participate in this study. ☐

Participant signature: Date:

Witness/ Researcher Signature: Date:

Two copies of the consent form to be completed- one retained by the Researcher and one provided to the participant to keep.

Appendix Q: Demographic questionnaire

DOCUMENT CONTROL TABLE

Document Title: Demographic Information Questionnaire v1.0 21.10.22

Author, job title, division: James Baily, Trainee Clinical Psychologist, Psychology

Version Number: 1.0

Document Status:

Date approved:

Approved by:

Effective date:

Date of next review:

Superseded version:

DOCUMENT HISTORY

Version	Date	Author	Notes on revisions

1.0	**11.10.22**	**James Baily**	

Demographic information

What is your gender?

- Female
- Male
- Prefer not to say

What is your marital status?

- Divorced or separated
- Married/civil partnership
- Single
- Widowed
- Prefer not to say

What is your age?

- 18-29
- 30-39
- 40-49
- 50-59
- 60-69
- 70+

What is your ethnic group?

- Asian, Asian British, Asian English, Asian Scottish or Asian Welsh

  - Bangladeshi
  - Indian
  - Pakistani
  - Any other Asian background - please specify:

- Black, Black British, Black English, Black Scottish or Black Welsh African
  - Caribbean
  - Any other Black background - please specify:

- Mixed
  - White & Asian
  - White & Black African
  - White & Black Caribbean
  - Any other Mixed background - please specify:

- White
  - British - English
  - British - Scottish
  - British - Welsh
  - Any other British (white) background - please specify: Irish
  - Any other White background - please specify:

- Chinese/Middle Eastern/Other ethnic background Chinese
  - Middle Eastern/North African
  - Any other background - please specify:

- Prefer not to say

Please provide details of any diagnosed mental health conditions:

____
____
____
____
____

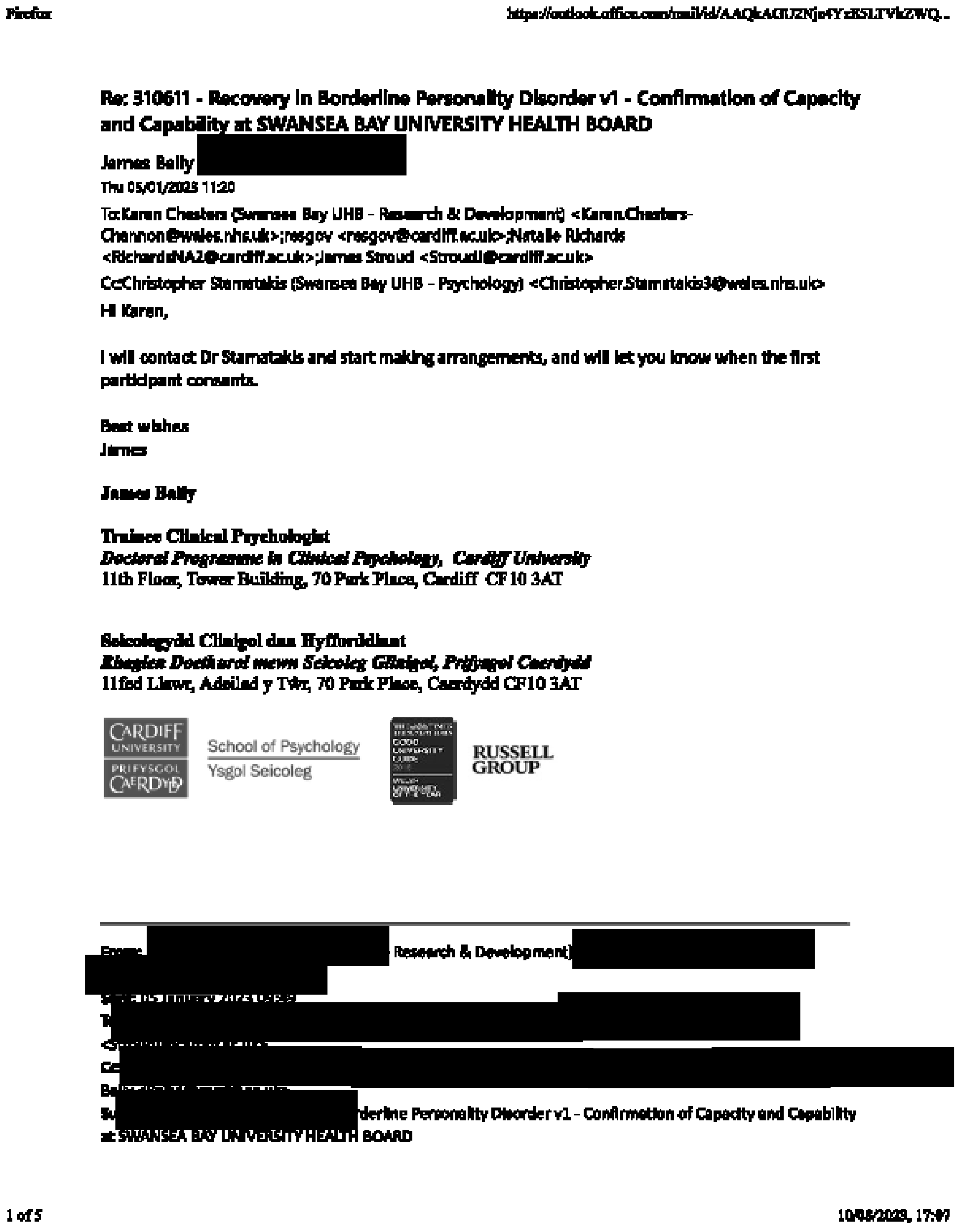
- Prefer not to say

Length of time of your current admission:

- Less than a year
- 1-2 years
- 2-3 years

- 3-4 years
- 4-5 years
- Over 5 years
- Prefer not to say

Appendix R: XXXXX Healthboard Research and Development team /Research Governance and Innovation team correspondence for the green light to start research.



Re: 310611 - Recovery in Borderline Personality Disorder v1 - Confirmation of Capacity and Capability at SWANSEA BAY UNIVERSITY HEALTH BOARD

James Baily [redacted]
Thu 05/01/2023 11:20
To:Karen Chesters (Swansea Bay UHB – Research & Development) <Karen.Chesters-Channon@wales.nhs.uk>;resgov <resgov@cardiff.ac.uk>;Natalie Richards <RichardsNA2@cardiff.ac.uk>;James Stroud <StroudJ@cardiff.ac.uk>
Cc:Christopher Stamatakis (Swansea Bay UHB – Psychology) <Christopher.Stamatakis3@wales.nhs.uk>

Hi Karen,

I will contact Dr Stamatakis and start making arrangements, and will let you know when the first participant consents.

Best wishes
James

James Baily

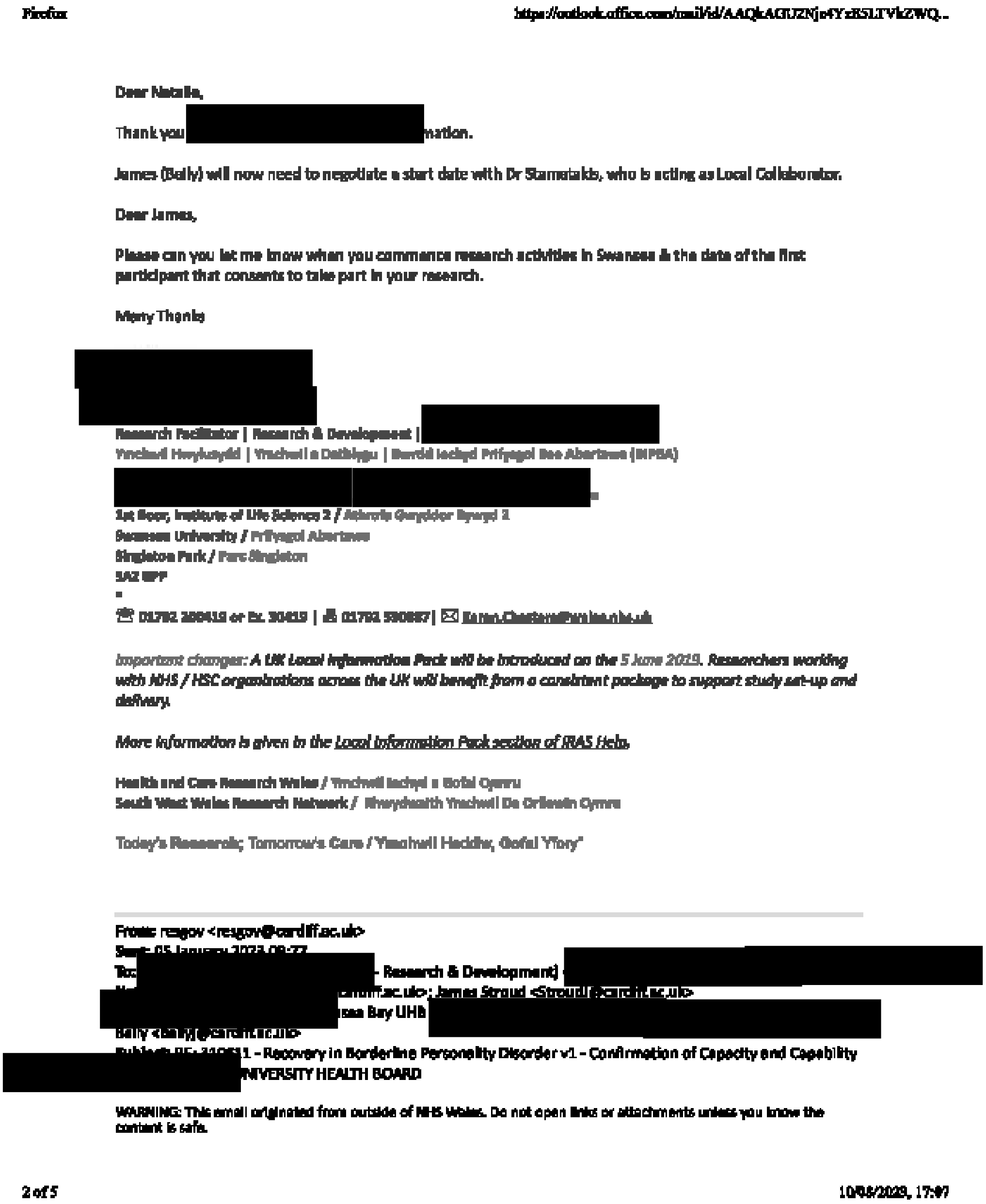
Trainee Clinical Psychologist
Doctoral Programme in Clinical Psychology, Cardiff University
11th Floor, Tower Building, 70 Park Place, Cardiff CF10 3AT

Seicolegydd Clinigol dan Hyfforddiant
Rhaglen Doethurol mewn Seicoleg Glinigol, Prifysgol Caerdydd
11fed Llawr, Adeilad y Tŵr, 70 Park Place, Caerdydd CF10 3AT

School of Psychology
Ysgol Seicoleg

RUSSELL GROUP

From: [redacted] Research & Development) [redacted]
[redacted]
To: [redacted]
Cc: [redacted]
Su[redacted]derline Personality Disorder v1 – Confirmation of Capacity and Capability at SWANSEA BAY UNIVERSITY HEALTH BOARD



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Dear Natalie,

Thank you [redacted]mation.

James (Baily) will now need to negotiate a start date with Dr Stamatakis, who is acting as Local Collaborator.

Dear James,

Please can you let me know when you commence research activities in Swansea & the date of the first participant that consents to take part in your research.

Many Thanks

[redacted]

Research Facilitator | Research & Development | [redacted]
Ymchwil Hwylusydd | Ymchwil a Datblygu | Bwrdd Iechyd Prifysgol Bae Abertawe (BIPBA)
[redacted]
1st floor, Institute of Life Science 2 / Athrofa Gwyddor Bywyd 2
Swansea University / Prifysgol Abertawe
Singleton Park / Parc Singleton
SA2 8PP

☎ 01792 200419 or Ext. 30419 | 🖷 01792 530887 | ✉ Karen.Chesters@wales.nhs.uk

Important changes: A UK Local Information Pack will be introduced on the 5 June 2019. Researchers working with NHS / HSC organisations across the UK will benefit from a consistent package to support study set-up and delivery.

More information is given in the Local Information Pack section of IRAS Help.

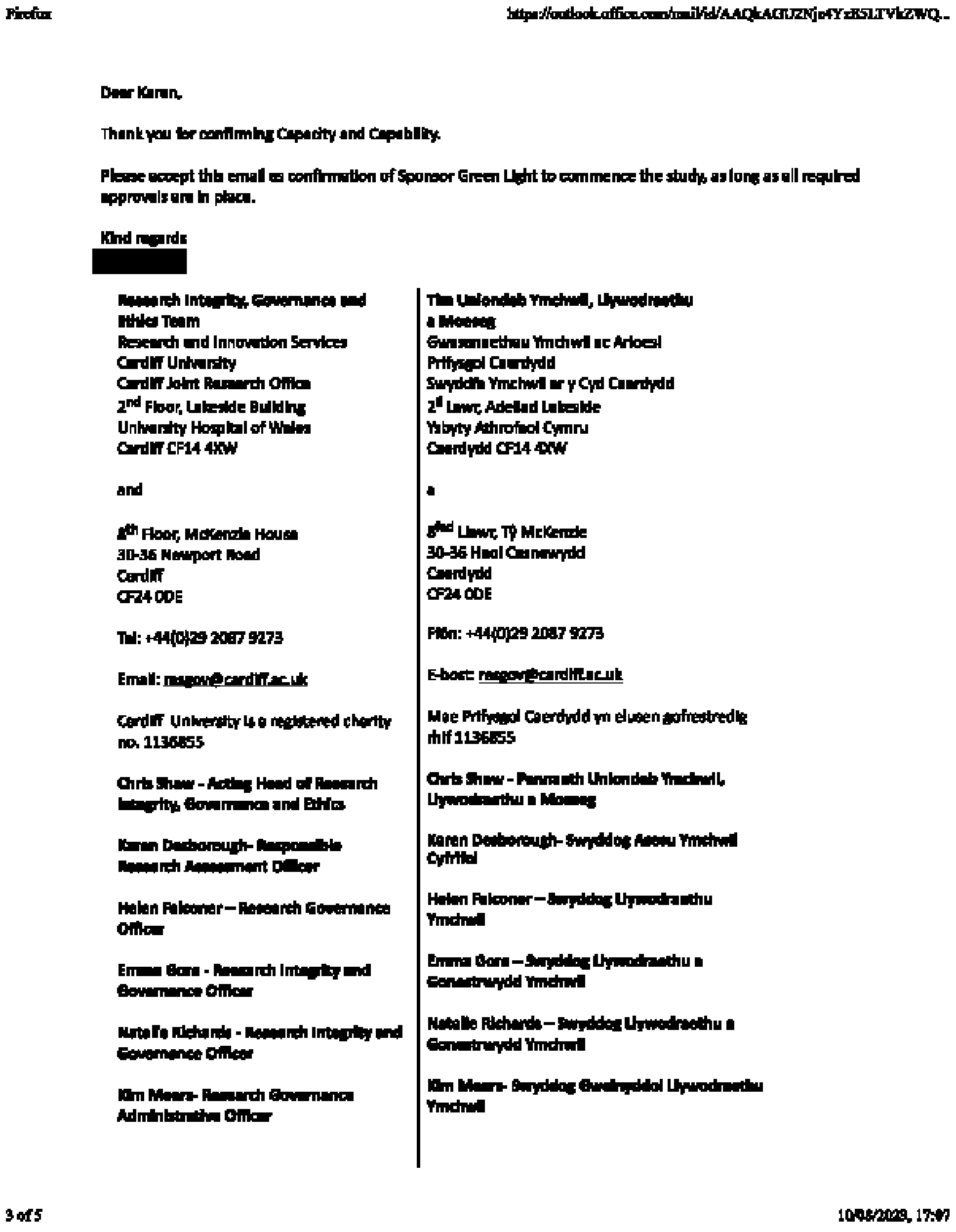
Health and Care Research Wales / Ymchwil Iechyd a Gofal Cymru
South West Wales Research Network / Rhwydwaith Ymchwil De Orllewin Cymru

Today's Research; Tomorrow's Care / 'Ymchwil Heddiw, Gofal Yfory'

From: resgov <resgov@cardiff.ac.uk>
Sent: [redacted]
To: [redacted] – Research & Development) [redacted]
[redacted]cardiff.ac.uk>; James Stroud <StroudJ@cardiff.ac.uk>
[redacted]sea Bay UHB [redacted]
Baily <BailyJ@cardiff.ac.uk>
Subject: RE: [redacted] – Recovery in Borderline Personality Disorder v1 – Confirmation of Capacity and Capability
[redacted]NIVERSITY HEALTH BOARD

WARNING: This email originated from outside of NHS Wales. Do not open links or attachments unless you know the content is safe.

2 of 5 10/08/2023, 17:07



Dear Karen,

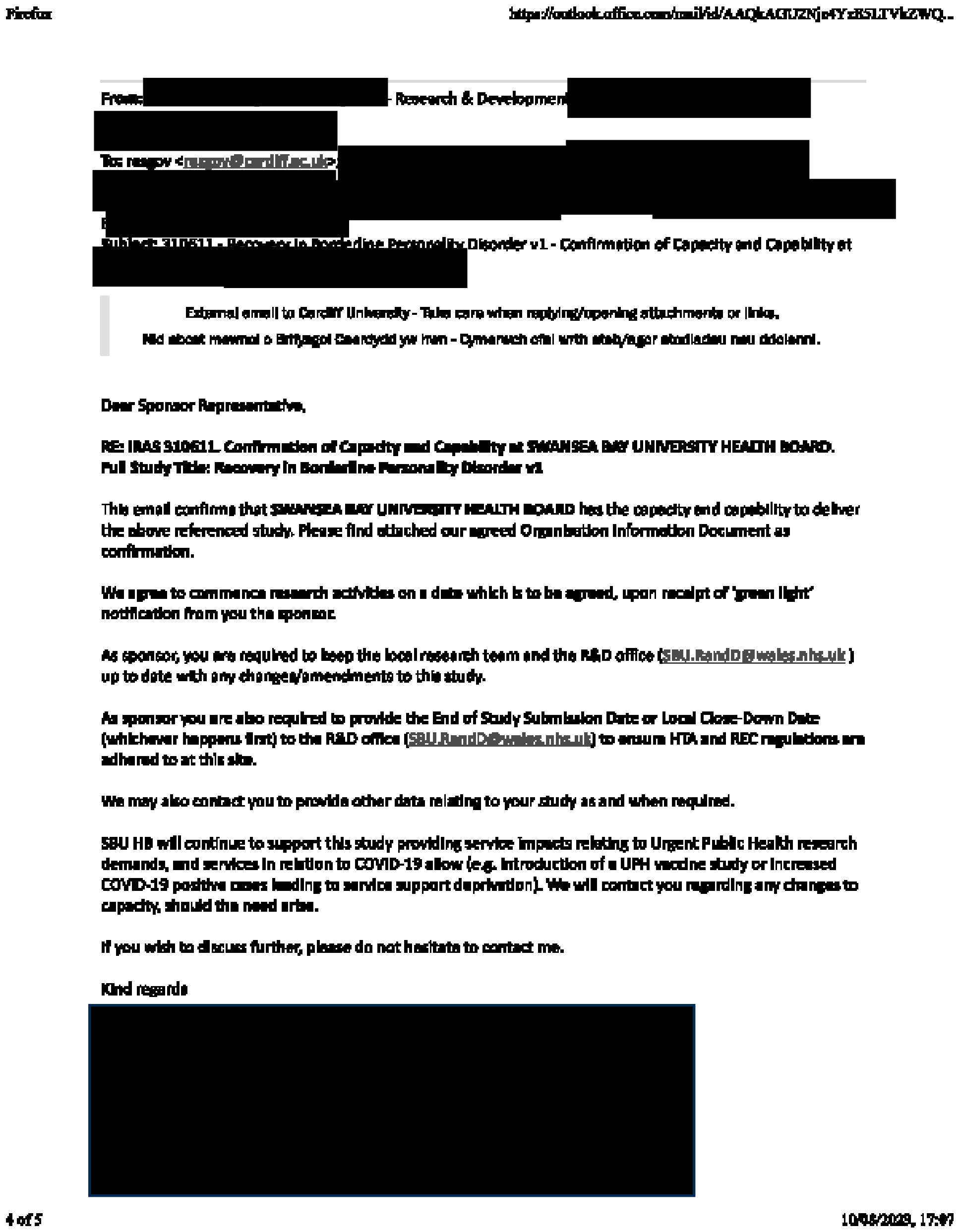
Thank you for confirming Capacity and Capability.

Please accept this email as confirmation of Sponsor Green Light to commence the study, as long as all required approvals are in place.

Kind regards

[redacted]

Research Integrity, Governance and Ethics Team Research and Innovation Services Cardiff University Cardiff Joint Research Office 2nd Floor, Lakeside Building University Hospital of Wales Cardiff CF14 4XW	**Tîm Uniondeb Ymchwil, Llywodraethu a Moeseg** Gwasanaethau Ymchwil ac Arloesi Prifysgol Caerdydd Swyddfa Ymchwil ar y Cyd Caerdydd 2il Llawr, Adeilad Lakeside Ysbyty Athrofaol Cymru Caerdydd CF14 4XW
and	a
8th Floor, McKenzie House 30-36 Newport Road Cardiff CF24 0DE	8fed Llawr, Tŷ McKenzie 30-36 Heol Casnewydd Caerdydd CF24 0DE
Tel: +44(0)29 2087 9273	Ffôn: +44(0)29 2087 9273
Email: resgov@cardiff.ac.uk	E-bost: resgov@cardiff.ac.uk
Cardiff University is a registered charity no. 1136855	Mae Prifysgol Caerdydd yn elusen gofrestredig rhif 1136855
Chris Shaw - Acting Head of Research Integrity, Governance and Ethics	Chris Shaw - Pennaeth Uniondeb Ymchwil, Llywodraethu a Moeseg
Karen Desborough- Responsible Research Assessment Officer	Karen Desborough- Swyddog Asesu Ymchwil Cyfrifol
Helen Falconer – Research Governance Officer	Helen Falconer – Swyddog Llywodraethu Ymchwil
Emma Gore - Research Integrity and Governance Officer	Emma Gore – Swyddog Llywodraethu a Gonestrwydd Ymchwil
Natalie Richards - Research Integrity and Governance Officer	Natalie Richards – Swyddog Llywodraethu a Gonestrwydd Ymchwil
Kim Mears- Research Governance Administrative Officer	Kim Mears- Swyddog Gweinyddol Llywodraethu Ymchwil



Firefox https://outlook.office.com/mail/id/AAQkAGUZNjc4YzE5LTVkZWQ...

From: [redacted] - Research & Development [redacted]

To: resgov <resgov@cardiff.ac.uk> [redacted]

Subject: [redacted] Disorder v1 - Confirmation of Capacity and Capability at [redacted]

External email to Cardiff University - Take care when replying/opening attachments or links.

Nid ebost mewnol o Brifysgol Caerdydd yw hwn - Cymerwch ofal wrth ateb/agor atodiadau neu ddolenni.

Dear Sponsor Representative,

RE: IRAS 310611. Confirmation of Capacity and Capability at SWANSEA BAY UNIVERSITY HEALTH BOARD.
Full Study Title: Recovery in Borderline Personality Disorder v1

This email confirms that **SWANSEA BAY UNIVERSITY HEALTH BOARD** has the capacity and capability to deliver the above referenced study. Please find attached our agreed Organisation Information Document as confirmation.

We agree to commence research activities on a date which is to be agreed, upon receipt of 'green light' notification from you the sponsor.

As sponsor, you are required to keep the local research team and the R&D office (SBU.RandD@wales.nhs.uk) up to date with any changes/amendments to this study.

As sponsor you are also required to provide the End of Study Submission Date or Local Close-Down Date (whichever happens first) to the R&D office (SBU.RandD@wales.nhs.uk) to ensure HTA and REC regulations are adhered to at this site.

We may also contact you to provide other data relating to your study as and when required.

SBU HB will continue to support this study providing service impacts relating to Urgent Public Health research demands, and services in relation to COVID-19 allow (e.g. introduction of a UPH vaccine study or increased COVID-19 positive cases leading to service support deprivation). We will contact you regarding any changes to capacity, should the need arise.

If you wish to discuss further, please do not hesitate to contact me.

Kind regards

[redacted]

4 of 5 10/08/2022, 17:07

[redacted]

Important changes: A UK Local Information Pack will be introduced on the 5 June 2019. Researchers working with NHS / HSC organisations across the UK will benefit from a consistent package to support study set-up and delivery.

More information is given in the Local Information Pack section of IRAS Help.

Health and Care Research Wales / Ymchwil Iechyd a Gofal Cymru
South West Wales Research Network / Rhwydwaith Ymchwil De Orllewin Cymru

Today's Research; Tomorrow's Care / Ymchwil Heddiw, Gofal Yfory'

Rydym yn croesawu gohebiaeth yn y Gymraeg neu'r Saesneg. Atebir gohebiaeth Gymraeg yn y Gymraeg, ac ni fydd hyn yn arwain at oedi.
We welcome correspondence in Welsh or English. Welsh language correspondence will be replied to in Welsh, and this will not lead to a delay.
Mae'r neges hon yn gyfrinachol. Os nad chi yw derbynnydd bwriadedig y neges, rhowch wybod i'r anfonwr ar unwaith. Dylai unrhyw un o'r datganiadau neu'r sylwadau a wneir uchod gael eu hystyried fel rhai personol ac nid o reidrwydd yn rhai a wneir gan y Bwrdd Iechyd, na chan unrhyw ran gyfansoddol o'r Bwrdd Iechyd neu gorff cysylltiedig. Dylech fod yn ymwybodol, o dan delerau Deddf Rhyddid Gwybodaeth 2000, y gallai fod yn ofynnol i'r Bwrdd Iechyd gyhoeddi cynnwys unrhyw e-bost neu ohebiaeth a dderbynnir.
This message is confidential. If you are not the intended recipient of the message, then please notify the sender immediately. Any of the statements or comments made above should be regarded as personal and not necessarily those of the Health Board, any constituent part or connected body. Please be aware that under the terms of the Freedom of information Act 2000, the Health Board may be required to make public the content of any email received.

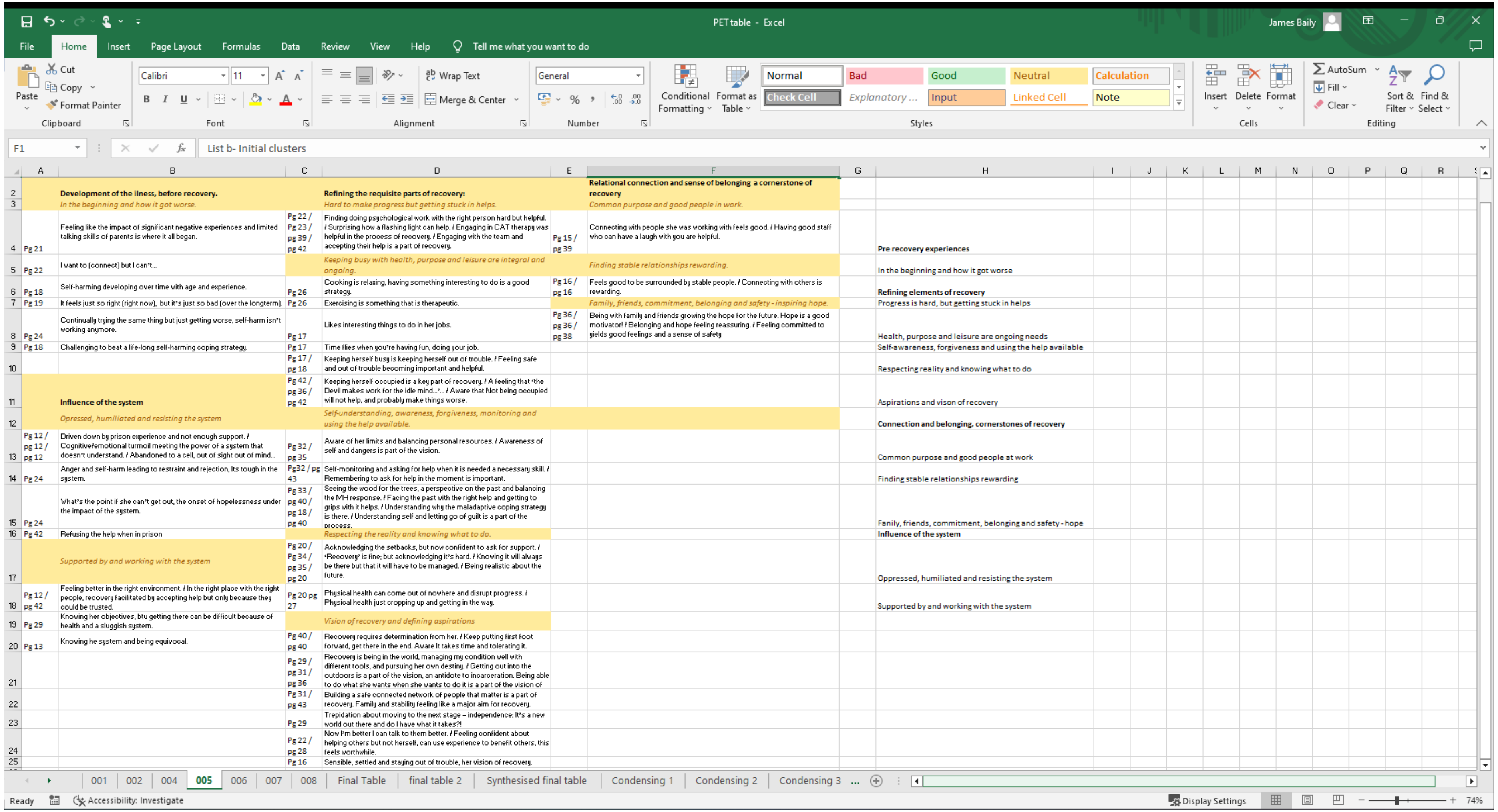
Appendix S: Examples of coded transcript (Participant 2,4 and 8)

Experiential statement	**Original transcript**	***Exploratory notes***
	008 So, I'm hoping it may –	
	JB Well done, congratulations.	
	008 Thank you.	
	JB That sounds like a really big milestone to me.	
Others' successes a model for progress and source of hope.	008 Yeah. I've seen other patients that have unescorted leave and they – maybe six to nine months' later they are the ones stepping down because they are able to, they are able to control things. And that allows them to then move to the next stage, which allows them to have more community time, more time by themselves. The ability to cook their own meals and not have to be served what is coming from the kitchens.	*Seeing the positive progress of other inpatients modelling the possibilities and the path and engendering hope.*
	JB Okay, so that's –	
	008 So –	
	JB That sounds like a big goal or aspiration for you?	
Emotional self-management, good relationships and functional independence.	008 Yeah. I'd like to just have, as I say, like, as much of an independent life as possible but also meet people that can help with my life as well. So, I'm not completely like shutting myself off from everybody. But having good relationships and the ability to manage my day-to-day life without having to ring people up for support all the time.	*Recovery vision involves being able to self-manage emotionally and form and maintain positive relational connections with others without having to rely on them.* Experiencing things **'coming at me'-:** *Feeling embattled/overwhelmed?*

	004	And that's me in that circle, I've got al this coming at me.	
Embattled and overwhelmed by everyday events and learning to cope.	**JB**	**You do amazingly well to cope with that.**	
	004	And –	Feeling meds are a necessary evil, but they work. Identifying a preference for therapy. *Hint that there are a range of things needed for recovery.*
Cautious about medication, a useful tool but not the only one, e.g., talking therapy.	**JB**	**So, what – what do you do to cope with all of that stuff?**	
	004	Well, medication is a big one for me. But I don't – really like taking medication. I'd rather therapy instead of medication.	
	JB	**Okay. And what – what's good about therapy?**	
	004	Like therapy is – like I work with –	Getting to know a staff member well and making plans – *Planning and structure needed for recovery? Feeling stability?*
Relational connection needed before thinking about recovery process could happen.	**JB**	**Chris?**	
Connection, planning and structure a part of attaining recovery.	004	Yes, [Name/staff]. And they's gone onto the other side now. They's not with us anymore, we've got somebody else and – but we've done a lot of work, me and {Names/staff], and going through all care plans and things to get to know me a bit better.	*Developing awareness with support from staff.*
	JB	**Okay.**	
	004	To get to know my triggers and things.	*Planning resulted in getting self-regulation time when they needs it.*
	JB	**So, that feels like that's helpful?**	

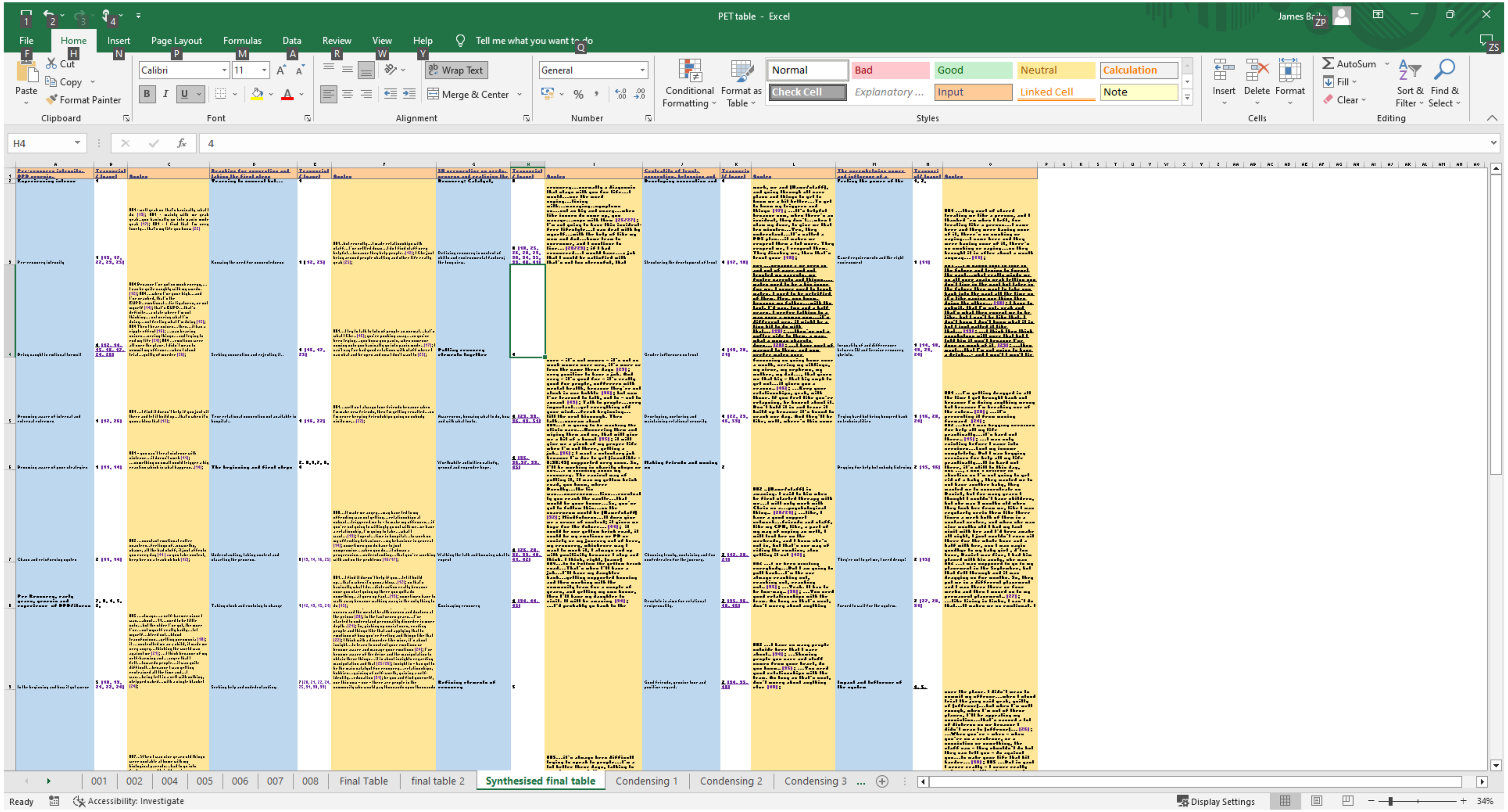
'The beast' won't go down easy, it'll take skills.	ahhm yeah it's about owning their, because they's a part of you anyway, so you take control, keep their on a leash uh huh. JB – oh right so keeping busy kind of ehhm not having any substances that you can take, uhm, arranging different activities by the sounds it, what kinda stuff… 002 – reaching out as well , reaching out is a big thing,	Skills – using distraction 'keeping busy' helps feel numb. *Personifying the illness as a 'their' now, or their other self? Respect their but be in charge = recovery? Control again!* **'Reaching out'**-: *connecting to others? A sense of looking for something.*
Seeking safe relational connection, staff or friends.	JB – OK, reaching out to who? 002 – like, I have a good support network, JB – OK, is that friends or staff,	The access to connection for support of different hues, *system of supportive people? Interacting (making it possible?) with skills development **'riding the emotion' -; Surfing analogy?** Riding the wave until you come in?*
Seeking specific support to tolerate intense emotions.	002 – friends and staff, like my CPN, like, a part of my way of coping as well, I will text their on the weekends, and I know they's not in, but that's one way of riding the emotion, also getting it out, JB – so what does they do for you, your CPN, you text their do you?	
Self-worth impacted by not being able to forgive themselves. Trusting someone to contain and support their making a difference.	002 – we text, we ring, we go out and have coffees and that, they's really good to me, and I believe, a couple of years back when I relapsed, cos I didn't feel worthy of being released, because of my index offence, but couple of years ago in the moment when I relapsed they was like just tell me the truth, speaking nice innit, and I broke down and I told their, so I told their everything, in that moment I think I needed someone to just show me they cared and that it won't like, nothing I said or done was gonna harm me or anybody else around me so they'd been a big influence into me changin and managing …	Connection – availability – access = enjoying/benefiting from connecting. Experiencing low-self worth -impacting hope and motivation? Needing to be honest and open without fear of rejection and getting it.Low ebb. Needing to know no harm to self or others…**'Big influence' – impact of caring/trusted staff.**
	JB – so it sounds like it was important that you couldn't shock their, and ahhm whatever you said they was still gonna be nice back to you…	
Waking up and seeing the wood for the trees with compassion.	002 – yeah , they showed me they cared and that's what I needed … all my life I've needed you know like, I grew up and I wanted to be a mammy, but the truth was, the story is that I needed to be mothered, I needed to be cared for, ahhm I think that what it sparked the BPD off,	Awareness and realisating own needs and explanation for experiences – *self-forgiveness?*
	JB – OK, so did it feel like you hadn't been cared for ? 002 – yeah, I didn't feel loved as achild, I know that JB – OK, and what happened because of that?	

Appendix T: Examples of personal experiential theme development tables with quotes



F1: List b- Initial clusters

	A	B	C	D	E	F	G	H
2		**Development of the ilness, before recovery.**		**Refining the requisite parts of recovery:**		**Relational connection and sense of belonging a cornerstone of recovery**		
3		*In the beginning and how it got worse.*		*Hard to make progress but getting stuck in helps.*		*Common purpose and good people in work.*		
4	Pg 21	Feeling like the impact of significant negative experiences and limited talking skills of parents is where it all began.	Pg 22 / Pg 23 / pg 39 / pg 42	Finding doing psychological work with the right person hard but helpful. / Surprising how a flashing light can help. / Engaging in CAT therapy was helpful in the process of recovery. / Engaging with the team and accepting their help is a part of recovery.	Pg 15 / pg 39	Connecting with people she was working with feels good. / Having good staff who can have a laugh with you are helpful.		**Pre recovery experiences**
5	Pg 22	I want to (connect) but I can't...		*Keeping busy with health, purpose and leisure are integral and ongoing.*		*Finding stable relationships rewarding.*		In the beginning and how it got worse
6	Pg 18	Self-harming developing over time with age and experience.	Pg 26	Cooking is relaxing, having something interesting to do is a good strategy.	Pg 16 / pg 16	Feels good to be surrounded by stable people. / Connecting with others is rewarding.		**Refining elements of recovery**
7	Pg 19	It feels just so right (right now), but it's just so bad (over the longterm).	Pg 26	Exercising is something that is therapeutic.		*Family, friends, commitment, belonging and safety - inspiring hope.*		Progress is hard, but getting stuck in helps
8	Pg 24	Continually trying the same thing but just getting worse, self-harm isn't working anymore.	Pg 17	Likes interesting things to do in her jobs.	Pg 36 / pg 36 / pg 38	Being with family and friends growing the hope for the future. Hope is a good motivator! / Belonging and hope feeling reassuring. / Feeling committed to yields good feelings and a sense of safety		Health, purpose and leisure are ongoing needs
9	Pg 18	Challenging to beat a life-long self-harming coping strategy.	Pg 17	Time flies when you're having fun, doing your job.				Self-awareness, forgiveness and using the help available
10			Pg 17 / pg 18	Keeping herself busy is keeping herself out of trouble. / Feeling safe and out of trouble becoming important and helpful.				Respecting reality and knowing what to do
11		**Influence of the system**	Pg 42 / pg 36 / pg 42	Keeping herself occupied is a key part of recovery. / A feeling that 'the Devil makes work for the idle mind...'... / Aware that Not being occupied will not help, and probably make things worse.				Aspirations and vison of recovery
12		*Opressed, humiliated and resisting the system*		*Self-understanding, awareness, forgiveness, monitoring and using the help available.*				**Connection and belonging, cornerstones of recovery**
13	Pg 12 / pg 12 / pg 12	Driven down by prison experience and not enough support. / Cognitive/emotional turmoil meeting the power of a system that doesn't understand. / Abandoned to a cell, out of sight out of mind...	Pg 32 / pg 35	Aware of her limits and balancing personal resources. / Awareness of self and dangers is part of the vision.				Common purpose and good people at work
14	Pg 24	Anger and self-harm leading to restraint and rejection, Its tough in the system.	Pg32 / pg 43	Self-monitoring and asking for help when it is needed a necessary skill. / Remembering to ask for help in the moment is important.				Finding stable relationships rewarding
15	Pg 24	What's the point if she can't get out, the onset of hopelessness under the impact of the system.	Pg 33 / pg 40 / pg 18 / pg 40	Seeing the wood for the trees, a perspective on the past and balancing the MH response. / Facing the past with the right help and getting to grips with it helps. / Understanding why the maladaptive coping strategy is there. / Understanding self and letting go of guilt is a part of the process.				Fanily, friends, commitment, belonging and safety - hope
16	Pg 42	Refusing the help when in prison		*Respecting the reality and knowing what to do.*				**Influence of the system**
17		*Supported by and working with the system*	Pg 20 / Pg 34 / pg 35 / pg 20	Acknowledging the setbacks, but now confident to ask for support. / 'Recovery' is fine; but acknowledging it's hard. / Knowing it will always be there but that it will have to be managed. / Being realistic about the future.				Oppressed, humiliated and resisting the system
18	Pg 12 / pg 42	Feeling better in the right environment. / In the right place with the right people, recovery facilitated by accepting help but only because they could be trusted.	Pg 20 pg 27	Physical health can come out of nowhere and disrupt progress. / Physical health just cropping up and getting in the way.				Supported by and working with the system
19	Pg 29	Knowing her objectives, btu getting there can be difficult because of health and a sluggish system.		*Vision of recovery and defining aspirations*				
20	Pg 13	Knowing he system and being equivocal.	Pg 40 / pg 40	Recovery requires determination from her. / Keep putting first foot forward, get there in the end. Aware It takes time and tolerating it.				
21			Pg 29 / pg 31 / pg 36	Recovery is being in the world, managing my condition well with different tools, and pursuing her own destiny. / Getting out into the outdoors is a part of the vision, an antidote to incarceration. Being able to do what she wants when she wants to do it is a part of the vision of				
22			Pg 31 / pg 43	Building a safe connected network of people that matter is a part of recovery. Family and stability feeling like a major aim for recovery.				
23			Pg 29	Trepidation about moving to the next stage – independence; It's a new world out there and do I have what it takes?!				
24			Pg 22 / pg 28	Now I'm better I can talk to them better. / Feeling confident about helping others but not herself, can use experience to benefit others, this feels worthwhile.				
25			Pg 16	Sensible, settled and staying out of trouble, her vision of recovery.				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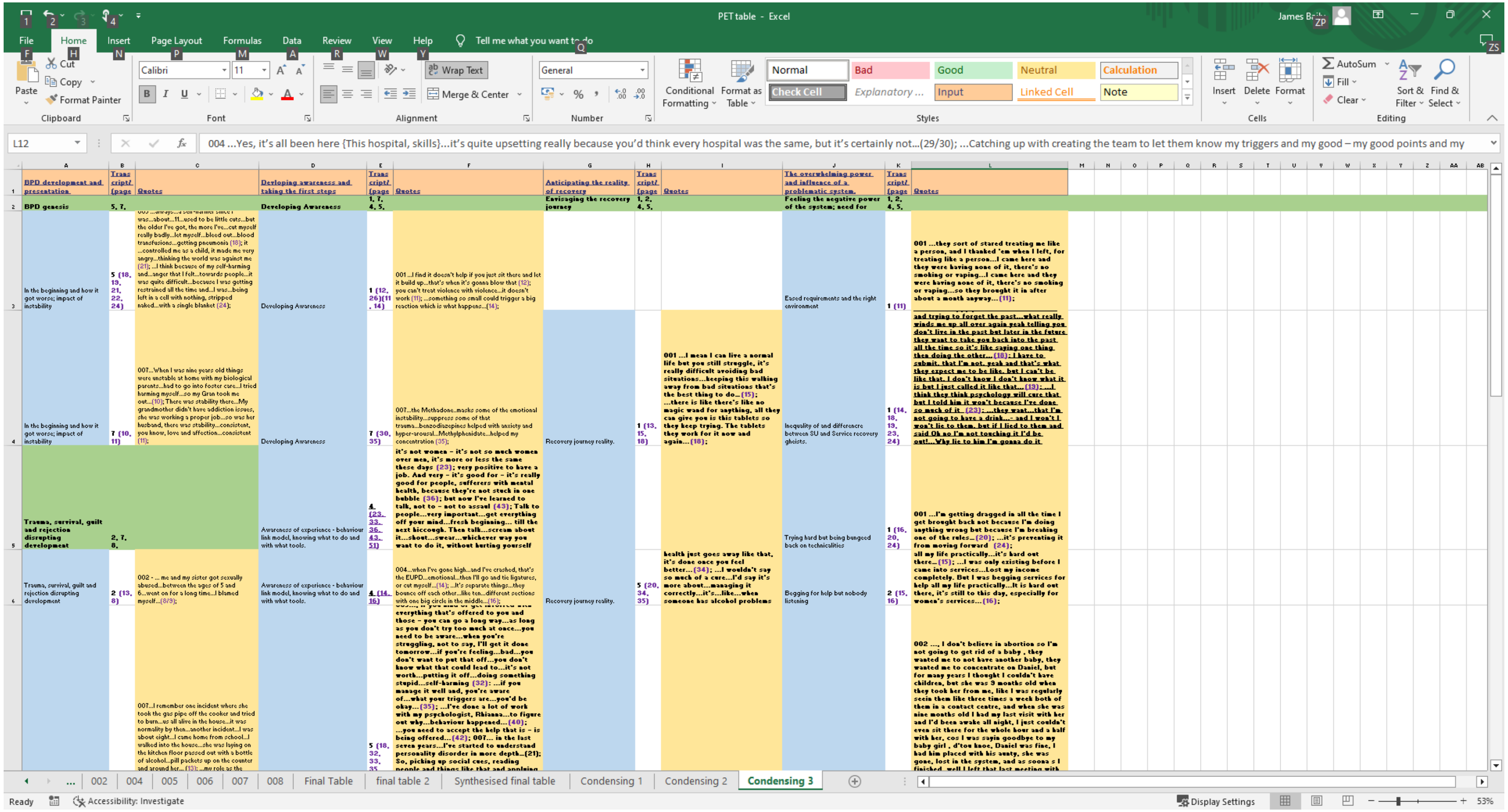

004 ...Yes, it's all been here {This hospital, skills}...it's quite upsetting really because you'd think every hospital was the same, but it's certainly not...(29/30); ...Catching up with creating the team to let them know my triggers and my good – my good points and my

	A	B	C	D	E	F	G	H	I	J	K	L
1	BPD development and presentation	Transcript/ (page	Quotes	Devloping awareness and taking the first steps	Transcript/ (page	Quotes	Anticipating the reality of recovery	Transcript/ (page	Quotes	The overwhelming power and influence of a problematic system.	Transcript/ (page	Quotes
2	**BPD genesis**	5, 7,		**Developing Awareness**	1, 7, 4, 5,		**Envisaging the recovery journey**	1, 2, 4, 5,		**Feeling the negative power of the system; need for**	1, 2, 4, 5,	
3	In the beginning and how it got worse; impact of instability	5 (18, 19, 21, 22, 24)	was...about...11...used to be little cuts...but the older I've got, the more I've...cut myself really badly...let myself...bleed out...blood transfusions...getting pneumonia (18); it ...controlled me as a child, it made me very angry...thinking the world was against me (21); ...I think because of my self-harming and...anger that I felt...towards people...it was quite difficult...because I was getting restrained all the time and...I was...being left in a cell with nothing, stripped naked...with a single blanket (24);	Developing Awareness	1 (12, 26)(11, 14)	001 ...I find it doesn't help if you just sit there and let it build up...that's when it's gonna blow that (12); you can't treat violence with violence...it doesn't work (11); ...something so small could trigger a big reaction which is what happens...(14);				Eased requirements and the right environment	1 (11)	001 ...they sort of stared treating me like a person, and I thanked 'em when I left, for treating like a person...I came here and they were having none of it, there's no smoking or vaping...I came here and they were having none of it, there's no smoking or vaping...so they brought it in after about a month anyway...(11);
4	In the beginning and how it got worse; impact of instability	7 (10, 11)	007...When I was nine years old things were unstable at home with my biological parents...had to go into foster care...I tried harming myself...so my Gran took me out...(10); There was stability there...My grandmother didn't have addiction issues, she was working a proper job...so was her husband, there was stability...consistent, you know, love and affection...consistent (11);	Developing Awareness	7 (30, 35)	007...the Methadone..masks some of the emotional instability...suppress some of that trauma...benzodiazepines helped with anxiety and hyper-arousal...Methylphenidate...helped my concentration (35);	Recovery journey reality.	1 (13, 15, 18)	001 ...I mean I can live a normal life but you still struggle, it's really difficult avoiding bad situations...keeping this walking away from bad situations that's the best thing to do...(15); ...there is like there's like no magic wand for anything, all they can give you is this tablets so they keep trying. The tablets they work for it now and again...(18);	Inequality of and differencre between SU and Service recovery gheists.	1 (14, 18, 19, 23, 24)	and trying to forget the past...what really winds me up all over again yeah telling you don't live in the past but later in the future they want to take you back into the past all the time so it's like saying one thing then doing the other...(18); I have to submit, that I'm not, yeah and that's what they expect me to be like, but I can't be like that, I don't know I don't know what it is but I just called it like that...(19); ...I think they think psychology will cure that but I told him it won't because I've done so much of it (23); ...they want...that I'm not going to have a drink...- and I won't I won't lie to them, but if I lied to them and said Oh no I'm not touching it I'd be out!...Why lie to him I'm gonna do it
5	**Trauma, survival, guilt and rejection disrupting development**	2, 7, 8,		Awareness of experience - behaviour link model, knowing what to do and with what tools.	4 (23, 33, 36, 43, 51)	it's not women – it's not so much women over men, it's more or less the same these days (23); very positive to have a job. And very – it's good for – it's really good for people, sufferers with mental health, because they're not stuck in one bubble (36); but now I've learned to talk, not to – not to assaul (43); Talk to people...very important...get everything off your mind...fresh beginning... till the next hiccough. Then talk...scream about it...shout...swear...whichever way you want to do it, without hurting yourself				Trying hard but being bungeed back on technicalities	1 (16, 20, 24)	001 ...I'm getting dragged in all the time I get brought back not because I'm doing anything wrong but because I'm breaking one of the rules...(20); ...it's preventing it from moving forward (24);
6	Trauma, survival, guilt and rejection disrupting development	2 (13, 8)	002 - ... me and my sister got sexually abused...between the ages of 5 and 6...went on for a long time...I blamed myself...(8/9);	Awareness of experience - behaviour link model, knowing what to do and with what tools.	4 (14, 16)	004...when I've gone high...and I've crashed, that's the EUPD...emotional...then I'll go and tie ligatures, or cut myself...(14); ...It's separate things...they bounce off each other...like ten...different sections with one big circle in the middle...(16);	Recovery journey reality.	5 (20, 34, 35)	health just goes away like that, it's done once you feel better...(34); ...I wouldn't say so much of a cure...I'd say it's more about...managing it correctly...it's...like...when someone has alcohol problems	Begging for help but nobody listening	2 (15, 16)	all my life practically...it's hard out there...(15); ...I was only existing before I came into services...Lost my income completely. But I was begging services for help all my life practically...It is hard out there, it's still to this day, especially for women's services...(16);
7		5 (18, 32, 33, 35	007...I remember one incident where she took the gas pipe off the cooker and tried to burn...us all alive in the house...it was normality by then...another incident...I was about eight...I came home from school...I walked into the house...she was laying on the kitchen floor passed out with a bottle of alcohol...pill packets up on the counter and around her... (13); ...my role as the			everything that's offered to you and those – you can go a long way...as long as you don't try too much at once...you need to be aware...when you're struggling, not to say, I'll get it done tomorrow...if you're feeling...bad...you don't want to put that off...you don't know what that could lead to...it's not worth...putting it off...doing something stupid...self-harming (32); ...if you manage it well and, you're aware of...what your triggers are...you'd be okay...(35); ...I've done a lot of work with my psychologist, Rhianna...to figure out why...behaviour happened...(40); ...you need to accept the help that is – is being offered...(42); 007... in the last seven years...I've started to understand personality disorder in more depth...(21); So, picking up social cues, reading people and things like that and applying						002 ..., I don't believe in abortion so I'm not going to get rid of a baby , they wanted me to not have another baby, they wanted me to concentrate on Daniel, but for many years I thought I couldn't have children, but she was 9 months old when they took her from me, like I was regularly seein them like three times a week both of them in a contact centre, and when she was nine months old I had my last visit with her and I'd been awake all night, I just couldn't even sit there for the whole hour and a half with her, cos I was sayin goodbye to my baby girl , d'tou knoe, Daniel was fine, I had him placed with his aunty, she was gone, lost in the system, and as soona s I finished, well I left that last meeting with