"Too Complex for IAPT": Service-User Experiences of Accessing Specialist Services and the Process of Being Diagnosed with Borderline Personality Disorder

Niamh Ingram

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Doctor of Psychology
(Clinical Psychology)

School of Psychology
Faculty of Health and Medical Sciences
University of Surrey
Guildford, Surrey
United Kingdom
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**Abstract**

**Background:** There have been significant advances in research, treatment, policy and service provision for people diagnosed with a personality disorder in England. However, diagnoses such as borderline personality disorder (BPD), continue to be controversial due to the validity of the construct itself, the ability of clinicians to diagnose reliably, and the significant impact stigma can have on those diagnosed.

**Aims:** This study aims to provide a current service-user perspective on the diagnostic process in BPD within specialist PD outpatient services. It specifically focuses on how service-users perceive this process to influence how they understand themselves, given that past research has indicated a BPD diagnosis can influence self-concept, and understanding of their mental health, given research has highlighted a lack of clarity from professionals about the diagnosis.

**Method:** Data were collected from six in-depth interviews with people currently accessing complex needs services, within a London NHS trust, who had experienced the diagnostic process in BPD. Transcripts were analysed using interpretative phenomenological analysis (IPA).

**Results:** Two superordinate themes emerged from the data: “Making sense of a BPD diagnosis” which encapsulated participants’ experiences of understanding the diagnosis, in terms of whether it “fitted” from their perspective, how it made sense of traumatic and challenging past experiences and the clarity they received from professionals; “Struggling to get what I need from services” which captures participants’ experiences of needing to reach crisis point and exhaust all other treatment options before accessing specialist assessment and treatment.

**Conclusions:** Service-users continue to experience a lack of clarity during the diagnostic process in BPD, particularly within secondary care, and feel they struggle to access the specialist support they need. The diagnostic process is an opportunity to help service-users make sense of their current difficulties and past experiences, and to help them feel fully informed about treatment choices.
Acknowledgements

Firstly, I would like to say thank you to all those who gave their time to participate in this research. It was a real privilege to hear your stories and without your time, openness and honesty this project would not have been possible. It is so important for the voices of those accessing services to be heard and I hope you continue to share your experiences to change services for the better. I am also grateful to the staff members who helped me during the recruitment and interview stages of this project. Again, without this support the project would not have got off the ground.

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A big thank you to Ali, and my friends and family for being there with me throughout this journey. Your support has enabled me to do what I love. A special thanks to my mum who read countless drafts and kept my spirits high in the last stretch.

Finally, I want to dedicate this work to Rosie and my grandmother, Ismay, who I thought of often throughout this research and who will continue to inspire me to make health services better for all those who use them.
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Part One: Empirical Paper

"Too Complex for IAPT": Service-User Experiences of Accessing Specialist Services and the Process of Being Diagnosed with Borderline Personality Disorder
Abstract

*Background:* There have been significant advances in research, treatment, policy and service provision for people diagnosed with a personality disorder in England. However, diagnoses such as borderline personality disorder (BPD), continue to be controversial due to the validity of the construct itself, the ability of clinicians to diagnose reliably, and the significant impact stigma can have on those diagnosed.

*Aims:* This study aims to provide a current service-user perspective on the diagnostic process in BPD within specialist PD outpatient services. It specifically focuses on how service-users perceive this process to influence how they understand themselves, given that past research has indicated a BPD diagnosis can influence self-concept, and understanding of their mental health, given research has highlighted a lack of clarity from professionals about the diagnosis.

*Method:* Data were collected from six in-depth interviews with people currently accessing complex needs services, within a London NHS trust, who had experienced the diagnostic process in BPD. Transcripts were analysed using interpretative phenomenological analysis (IPA).

*Results:* Two superordinate themes emerged from the data: “Making sense of a BPD diagnosis” which encapsulated participants’ experiences of understanding the diagnosis, in terms of whether it “fitted” from their perspective, how it made sense of traumatic and challenging past experiences and the clarity they received from professionals; “Struggling to get what I need from services” which captures participants’ experiences of needing to reach crisis point and exhaust all other treatment options before accessing specialist assessment and treatment.

*Conclusions:* Service-users continue to experience a lack of clarity during the diagnostic process in BPD, particularly within secondary care, and feel they struggle to access the specialist support they need. The diagnostic process is an opportunity to help service-users make sense of their current difficulties and past experiences, and to help them feel fully informed about treatment choices.
1. Introduction

Borderline personality disorder (BPD) is one of the most widely used personality disorder (PD) diagnoses in the UK (McManus, Bebbington, Jenkins, & Brugha, 2016). In previous research, service-users have reported feeling confused about what BPD means and hopeless about the future (e.g. Horn, Johnstone & Brooke, 2007; Nehls, 1999). In 2003, the National Institute for Mental Health in England (NIMH(E)) released the report ‘Personality Disorder: No Longer a Diagnosis of Exclusion’ which highlighted that service-users were being excluded from services across England. Since this report, there have been significant changes in service provision, training, research and policy to better support the needs of those diagnosed with BPD. However, it is unclear what service-users’ current experiences are of the diagnostic process within dedicated PD services, in light of these changes, and how this process is perceived by service users to impact on their sense of self and their difficulties.

1.1. Borderline personality disorder: A contentious diagnosis

Although estimates vary, personality disorders, including BPD, are believed to be highly prevalent across the UK and Europe (Beckwith, Moran & Reilly, 2014). Researchers have questioned the use of the diagnosis based on the following evidence: there is significant overlap between different PDs and other mental health diagnoses, and a poor understanding of the biological underpinning of maladaptive personality traits (Sarkark & Duggan, 2010); the empirical basis used to support the changes to diagnostic criteria in the Diagnostic and Statistical Manual of Mental Disorders (5th ed.; DSM–5; American Psychiatric Association, 2013) is of poor quality (Widiger, 2011; Zimmerman, 2011); client and therapist factors impact on the accuracy of diagnosis (Liebman & Burnette, 2013); and service-users and professionals perceive the diagnosis to be a pejorative and stigmatising label (Nehls, 1999; Stalker, Ferguson, & Barclay, 2005; Sulzer, Muenchow, Potvin, Harris & Gigot, 2016). Some have argued that BPD is an example of how medical classification is failing to meet the needs of service-users,
whose distress is an understandable reaction to trauma and complex social factors (Johnstone, 2014). This has prompted arguments for a ‘paradigm shift’ in mental health to move to formulation-driven approaches (Awenat et al., 2013) and the development of an alternative framework, the ‘Power, Threat, Meaning Framework’ (Johnstone et al., 2018). This framework attempts to provide a way of making sense of mental distress, unusual experiences and troubling behaviour as understandable responses and coping strategies to threatening experiences.

1.2. Impact of BPD diagnosis on service-users

A review of the literature (Ingram, 2018) revealed that the perceived negative impact of being diagnosed with BPD has been well documented (Horn, Johnstone & Brooke, 2007; Bilderbeck, Saunders, Price & Goodwin, 2014; Morris, Smith & Alwin, 2014; Nehls, 1999; Ramon, Castillo & Morant 2001; Richardson & Tracey, 2015), though the quality of these studies varies. Service-users have expressed feeling defined by their diagnosis (Morris, Smith & Alwin, 2014), labelled (Nehls, 1999) and that their personality has been rejected (Horn, Johnstone & Brooke, 2007). Researchers have published findings that indicate that service-users’ self-concepts have been impacted by the diagnosis with participants reporting feelings of worthlessness and hopelessness (Ramon, Castillo & Morant 2001), and of being “bad”, “difficult” or a “trouble maker” (Horn, Johnstone & Brooke, 2007; Morris, Smith & Alwin, 2014). Service-users have also expressed that they were made to believe their difficulties were untreatable (Horn, Johnstone & Brooke, 2007; Richardson & Tracey, 2015) and shared experiences of the diagnosis leading to no treatment (Nehls, 1999). However, some studies have highlighted mixed responses towards BPD (Horn, Johnstone & 2007). For some service-users, the diagnosis was perceived to contextualise and explain life-long difficulties and reduce blame (Bilderbeck, Saunders, Price & Goodwin, 2014; Lovell & Hardy, 2015; Richardson & Tracey, 2015; Morris, Smith & Alwin, 2014;).
Morris, Smith and Alwin (2014) and Richardson and Tracey (2015) posited that the diagnostic process in BPD influences how service-users feel about the diagnosis, themselves and their recovery. Service-users have reported a lack of information and explanation at diagnosis which has led to confusion and a rejection of the diagnosis (Fromene & Guerin, 2014; Horn, Johnstone & Brooke, 2007; Lawn & Mahon, 2015; Morris, Smith & Alwin, 2014; Nehls, 1999). This evidence supports the idea that individual psychological events, such as receiving a diagnosis, can force people to rethink who they are (Jaspal & Breakwell, 2014).

Identity Process Theory (IPT: Breakwell, 1986, 1988, 1992, 1993, 2001; Vignoles et al., 2002) posits that social representations, like psychiatric diagnosis, determine the content of an individual’s identity and the value placed upon these components. This theory assumes people have agency over the construction of their identity and are motivated to absorb and make room for new information (assimilation-accommodation) and evaluate the content of their identity (evaluation), in order to belong and have purpose in life (Vignoles et al., 2002). Threats to identity occur when new information threatens someone’s sense of belonging or meaning. People engage in coping strategies to avoid this content being absorbed into their identity structure or evaluated as negative (e.g. denial or reconceptualization; Breakwell, 1986). We might assume that a diagnosis of BPD is a potential threat to identity. However, to date there has been no research that specifically focuses on service-users’ experiences of the diagnostic process itself and how it influences identity. This is particularly interesting given ‘identity disturbance’ is a criterion for BPD (DSM–5; American Psychiatric Association, 2013)

1.3. The impact of guidance and policy on the development of dedicated personality disorder services

Historically, service-users diagnosed with PD have had difficulties accessing services and appropriate treatment, with their needs understood as entrenched and untreatable personality
problems rather than a formal mental illness. However, subsequent research has highlighted not only the high needs and the economic cost of this group (Chiesa, Fonagy, Holmes, Drahorad, & Harrison-Hall, 2002; McCrone, Dhanasiri, Patel, Knapp & Lawton-Smith, 2008), but also that there are evidence-based psychological treatments which have positive outcomes (Bateman & Fonagy, 2008, 2009; Linehan et al., 2006) that are cost-effective (Meuldijk, McCarthy, Bourke & Grenyer, 2017).

In 2003, the National Institute for Mental Health in England (NIMH(E)) released the report “Personality Disorder: No Longer a Diagnosis of Exclusion”. This highlighted that despite the high prevalence and need of those being diagnosed with PD, there was a deficit in PD services in England. At the time, only 17% of mental health trusts reported having a dedicated PD service. Moreover, service-users were being directed through inappropriate care pathways (e.g. A&E or inpatient admissions) and mental health professionals were reported to have inadequate skills, expertise or training to support people with PD. NIMH(E) (2003) guidance stipulated the need for significant developments in specialist PD services and training to better support the needs of people accessing services. Furthermore, it called for research to support this development and greater service-user involvement in developing best-practice.

Since the development of this guidance, our knowledge of PD has increased due to a large body of research (Paris, 2007b). Longitudinal studies have confirmed that recovery is possible for people diagnosed with BPD (Zanarini, Frankenburg, Reich & Fitzmaurice, 2012) and there is a strong evidence-base for specialist treatments such as dialectical behaviour therapy (DBT; Linehan et al., 2006) and mentalization-based therapy (MBT; Bateman & Fonagy, 2008, 2009). Research has informed guidelines and policies such as National Institute for Health and Care Excellence (NICE, 2009) which provides up-to-date guidance for clinicians assessing, diagnosing and treating. This guidance recommends transparency about the diagnosis, clearly explaining the assessment process and the use and meaning of the term BPD, and outlines the
role of specialist services in providing assessment and intervention for individuals with high needs and risk.

Although service provisions across England have increased with 84% of NHS organisations reporting to have at least one dedicated PD service, only 55% of these organisations have equal access to all service-users across localities (Dale et al., 2017). Despite significant developments some service-users are still being excluded from care pathways. A recent literature review performed by Evans et al. (2017), raised that there are current discrepancies between what research has shown to be effective and the reality of what is being provided following NIMH(E) guidance. These findings mirror the recent consensus statement for people diagnosed with PD: “Shining lights in dark corners of people’s lives” (Lamb, Sibbald, & Stirzaker, 2018). In this statement, service-users in collaboration with several mental health organisations, highlighted how services continue to fail to meet the needs of those diagnosed with PD. This statement called for the following: early intervention before mental health difficulties become more pervasive; wide availability of evidence-based interventions; consideration of complex social issues that impact on the development of PD; and trauma-informed and formulation-driven approaches.

1.4. Objectives

A review of the literature (Ingram, 2018) revealed that no research has been conducted to specifically explore service-user experiences and perceptions of the diagnostic process and how this influences identity and understanding. Instead studies have used varying methodology, of varying quality, to explore people’s lived experiences of BPD. Furthermore, there has been no research specifically recruiting service-users from within specialist PD services in England, who have recent experiences of being diagnosed following the development of both NIMH(E) and NICE guidance (2009; updated in 2015). Due to the limited
empirical literature focusing on the diagnostic process, an exploratory study was necessary to develop a future evidence base to guide research.

The broad aim of this study was to explore a current service-user perspective, following the development and implementation of NIMH(E) (2003) and NICE (2009) guidelines, on the diagnostic process in BPD within specialist PD outpatient services. The research question specifically focused on service-users’ perceptions of how the diagnostic process influenced their understanding of themselves and their mental health, given that past research has indicated a BPD diagnosis to influence self-concept and that professionals provide limited information at diagnosis. To gain a comprehensive understanding of the unique experiences of service-users, and provide opportunities for spontaneous findings (Turner, Barlow & Ilbury, 2002), an interpretive phenomenological approach was adopted. As such, the epistemological position of this work was social constructionist, holding that meaning is co-constructed through language and that there is no single objective truth to be discovered. BPD is viewed as a social construct that was developed to make sense of a specific set of experiences. The final aim of this study was to consider findings in relation to specific guidance set out by NIMH(E) (2003) and NICE (2009) on diagnosis delivery and care pathways, to explore service-users’ experiences within the context of the implementation of these guidelines.

2. Method

2.1 Design

Interpretative Phenomenological Analysis (IPA; Smith & Osborn, 2003) was the methodology that guided recruitment, interview design and data analysis for a small purposive sample of volunteer participants. Although other design approaches were considered in the development of this project, IPA was chosen as the most suitable in answering the research question for several reasons. Firstly, this approach is useful when research has open and broad research
aims to explore how people understand themselves and their experiences. IPA allowed for an in-depth understanding of how participants made sense of their identity and mental health through their experiences of diagnosis. Compared to other approaches such as Thematic Analysis (Braun & Clark, 2006), IPA is more focused on ideographic information about each participant and the nuances within the group, rather than looking immediately across the group for what is common. Through treating each participant’s interview as a single case, comprehensive detail was captured about each participant’s unique understanding of themselves and their experiences which illuminated and enriched the experiences held within the group.

2.2 Participants

2.2.1 Recruitment Sites

The focus of this research was on the current experiences of people being diagnosed within specialist outpatient PD services. As such, service-leads from three complex needs services (CNS) within an NHS London trust were approached via email for recruitment. Two services agreed to support the recruitment of this study. Participants were recruited from more than one service to ensure the project was not a service-evaluation and to give participants anonymity. The researcher performed background research into the services (online search and discussions with service-leads) to establish that they were compliant with NIMH(E) guidance for the development of specialist PD services: providing specialist treatment for individuals with a PD diagnosis (i.e. DBT and MBT); employing professionals with specialist training in PD; and engaging in multi-disciplinary team working (in this case, psychiatry and psychotherapy). Due to the differing structures of the services, participant recruitment differed slightly. In both cases, potential participants who met the inclusion criteria were first identified and approached by their care team who provided them with a participant information sheet outlining the project. However, one service did this within a pre-treatment group setting, whilst the other approached potential participants within 1:1 sessions. The former service then invited the researcher to the
group to discuss the study and gain service-user consent to be contacted for participation. The latter service provided the researcher with potential participants’ contact details if the consent was gained during 1:1 sessions. Those who expressed an interest and consented to their contact details being shared were then contacted by the researcher by email and then phone to discuss any queries, check participants met the inclusion criteria, and to book appropriate locations and dates for interviews.

2.2.2 Sampling Strategy

The sample size recommended for IPA studies at a Doctoral level is between 4 and 10 (Hefferon & Gil-Rodriguez, 2011; Smith, Flowers & Larkin, 2009). Small samples are a pre-requisite for IPA as this approach requires an in-depth analysis of the individual’s world of meaning before looking for commonality and nuance across the group (Smith, Flowers & Larkin, 2009). Service-leads identified eight potential participants who met the following inclusion criteria: 1) they had an experience of being diagnosed with BPD or emotionally unstable PD (EUPD) within a CNS, 2) they received this diagnosis after 2010 i.e. following NICE (2009), 3) they were aware of this diagnosis, 4) they were fluent in English, and 5) the care team did not believe taking part in the study would increase their risk of harm. These criteria were necessary to recruit a homogenous sample, answer the research question and add to the current literature. One potential participant was excluded from the study because they were not currently engaging with their care team and a second was excluded because correspondence with the researcher suggested that taking part in the study could be destabilising to their mental health. These exclusion criteria were important in protecting participants from potential harm. Interviews were therefore conducted with a final sample of 6 participants.

IPA studies require the sample to be homogenous to perform analysis across a defined group of participants that will help answer the research questions (Smith & Osborn, 2003).
Homogeneity can be interpreted differently across studies depending on the research question (Smith, Flowers & Larkin, 2009). In this case, homogeneity referred to the participants all being service-users with a diagnosis of BPD or EUPD, living in the community and having had a recent (post 2010) experience of being diagnosed within specialist outpatient PD services. Both men and women were invited to take part in this study, as despite the reported gender differences in clinical presentations of BPD (Sansone & Sansone, 2011), there was no research, or established theory, at study development to indicate that gender influences how individuals experience receiving a BPD diagnosis.

### 2.2.3. Sample

Demographic data was collected verbally from participants within interviews. Participants were 5 women and 1 man who met the inclusion criteria. Four participants were engaging in DBT treatment and two had been in a pre-treatment psychoeducation group for MBT for over 10 weeks. All participants were White British, within the age range of 20-45 (mean age 33.5) and had been diagnosed between 2015-2018 in a CNS. All participants had experiences of being diagnosed with other mental health conditions including depression, anxiety, post-traumatic stress disorder (PTSD), post-natal depression and autism. To protect participants’ identity, further demographic information will not be specified here or matched with individual participants. Aliases (Table 1.) were generated using a random name generator.

<table>
<thead>
<tr>
<th>Participant Number</th>
<th>Participant Alias</th>
</tr>
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<tbody>
<tr>
<td>One</td>
<td>Jennifer</td>
</tr>
<tr>
<td>Two</td>
<td>Zoe</td>
</tr>
<tr>
<td>Three</td>
<td>Cerys</td>
</tr>
<tr>
<td>Four</td>
<td>Lily</td>
</tr>
<tr>
<td>Five</td>
<td>Aaron</td>
</tr>
<tr>
<td>Six</td>
<td>Olivia</td>
</tr>
</tbody>
</table>
2.3 Ethical considerations

This study was reviewed and given a favourable ethical opinion by the university, London – Camden and Kings Cross NHS Research Ethics Committee, and the Health Research Authority (HRA) (Appendix-A).

2.4 Interview

Interviews were completed in 2018 within hospital clinic rooms that were familiar to participants and provided confidentiality. Verbal consent to begin audio recording was first gained before the researcher checked participants had fully understood the participant information sheet (Appendix-B) and written consent (Appendix-C) was obtained from participants to take part. A broad, relatively unstructured interview schedule was developed (Appendix-D) with the support of the research supervisor’s expertise and in line with recommendations for interview development (Smith & Osborn, 2003) to help elicit narratives related to the research question. However, this was used flexibly to foster a collaborative balance of leading and following between the participant and the researcher (Smith, Flowers & Larkin, 2009). This schedule was shared with participants prior to the appointment via email. All interviews were audio-recorded and lasted between 56 and 100 minutes. These were then transcribed clean verbatim (including laughter and pauses) by either the researcher or a professional transcription agency. Transcripts were anonymized for confidentiality.

2.5 Service-user input

Essential consultation was provided by Surrey University’s Service-User and Carers Group and a service-user who had lived experience of being diagnosed with BPD. This feedback helped narrow the focus of the project and the construction of the participant information sheet, interview schedule and consent form.

2.6 Data analysis

Data collected within the interviews was analysed using IPA processes described by Smith, Flowers and Larkin (2009; see Appendix-E for more details). Transcripts were read and re-
read with their accompanying audio-recording to immerse the researcher. Single-case analysis was completed, producing subordinate and superordinate themes for each transcript before doing the same across the group in cross-case analysis. In line with the core aim of IPA to gain a comprehensive understanding of an individual’s experience, attention was paid to the nuances of each account and these were woven together to produce rich themes for the group. This was an iterative process at all stages of analysis, with meaning-making being checked and re-checked continually with transcripts to ensure themes were a true reflection of the language and perspectives of participants. Quotes were chosen to support the credibility of themes.

**2.7 Quality assurance**

The researcher followed Yardley’s (2000) framework (Appendix-F) as recommended for IPA research (Smith, Flowers & Larkin, 2009). In addition to this, the researcher used supervision, IPA workshops and a reflexive journal from the conception of this project to develop their awareness of potential assumptions and expectations they held. This was further supported by the researcher’s clinical training which encourages and requires self-reflexivity. The aim of understanding and being transparent about assumptions is to clarify the role these play in data collection and interpretation (Finlay & Gough, 2008). Therefore, the researcher has provided examples of credibility checks and self-reflexivity (Appendix-G-I). However, eliminating bias is not possible nor an aim of IPA. Analysis involved dual interpretation (double hermeneutic process) where meaning was co-constructed between the participants and researcher (Smith, 2008). The focus of IPA and this study is to provide a plausible interpretation of the data and not a single truth (Larkin & Griffiths, 2002).
3. Results

This narrative account explores and interprets themes that emerged from the analytic process (Table 2). Interview extracts\(^1\) are provided to help illustrate and support the credibility of themes. Participants used BPD and EUPD interchangeably. For simplicity and in keeping with current literature, the term BPD is consistently used.

3.1. Making sense of a BPD diagnosis

This superordinate theme captures how service-users made sense of BPD in response to the diagnostic process. That is, how they attempted to fit this new information into their understanding of themselves and their difficulties, how they evaluated themselves in light of this new information and how this was or was not supported by professionals. The data indicated that most participants accepted BPD as an explanation for their difficulties and that this helped them understand themselves (i.e. their behaviour and painful past experiences) in a way that, for some, reduced shame and empowered them to have more agency in their recovery. A lack of clarity about BPD, especially within generic services, appeared to prevent this process. Furthermore, acceptance of BPD appeared to be influenced by participants’ personal acceptance of medicalised language as a way of explaining their experiences and by effective specialist treatment.

\(^1\) Extracts have been chosen and edited to protect participants’ anonymity. ‘[]’ indicates missing material ‘…’ indicates a pause in the participant’s parlance ‘[word]’ indicates added material to clarify what a participant is referring to
Table 2. Themes that emerged from analysis and example quotes as evidence

<table>
<thead>
<tr>
<th>Superordinate Themes</th>
<th>Subordinate Themes</th>
<th>Quote Exemplars</th>
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<tbody>
<tr>
<td>Making sense of a BPD diagnosis</td>
<td>A process of acceptance: A label that fits best and has a specialised treatment that worked for me</td>
<td>“I was like, ‘Oh, my God, this is all just -- this is basically describing me.’” (Lily)</td>
</tr>
<tr>
<td></td>
<td>Understanding BPD has helped me make sense of myself and my past</td>
<td>“It’s helping me accept who I am…what I’ve done and what’s happened.” (Jennifer, page 34)</td>
</tr>
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<td></td>
<td>Lack of clarity: they didn’t help me understand what BPD meant for me</td>
<td>“So I’ve been drip fed it [information about BPD] really” (Cerys)</td>
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<td></td>
<td>Needing to be at crisis point to get the specialist help I need</td>
<td>“To me it seems that you have to reach crisis point um, for them to assess you” (Zoe)</td>
</tr>
<tr>
<td>Struggling to get what I need from services</td>
<td>Complex Needs is a last resort service</td>
<td>“I went a whole month with nothing except overdoses and cutting myself, and all of that. Um, and then after I got the new nurse she was saying, ‘Okay, we'll put you through for the Complex Needs Service...’” (Lily)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“Where else do you go if you've got depression, anxiety, self-harm? It’s like, ‘We'll throw you altogether and, uh, we'll offer you this' but thank God they are. Cause they weren't 5, 10 years ago.” (Jennifer)</td>
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<td>“I was failing all the time because I was trying really hard to engage with...and I did engage with services. I always you know turned up for appointments. I always did the therapy and engaged in the homework and did all those things and nothing I did was working.” (Cerys)</td>
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3.1.1. A process of acceptance: A label that fits best and has a specialised treatment that worked for me

All participants received multiple diagnoses before being diagnosed with BPD. Most shared that they felt BPD, and its criteria, fitted for them more than previous diagnoses. For some, acceptance of the diagnosis came through having access to treatment that worked for them, thus confirming it was the “right” diagnosis. For those still awaiting treatment, one person willingly accepted the diagnosis because they were ‘used’ to receiving stigmatising labels. Whereas for another person, the judgements of others and having received conflicting diagnoses from services prevented her from embracing BPD.

Despite having received different diagnoses since childhood, Olivia felt BPD fitted best with her experiences.

Olivia: I’ve been in services for like, 12 years or something, so there’s lots of sort of, "you might have this, you might have this, we think it's depression, da da da". Um, and um, when it was initially mentioned about BPD, I think I was kind of like, "Oh, this seems like it fits much better with what I've been experiencing".

However, Olivia explained how her acceptance of the diagnosis developed over time and following specialist treatment for BPD.

Olivia: I think a lot more sort of at peace with the fact that I have BPD or did have BPD, so I don't think I meet the criteria anymore but I think I accepted that that what was going on.

Her use of the words “at peace with” suggest that BPD was something difficult to accept previously. She then corrects herself to explain that although she accepted she had BPD at assessment, she no longer believes she fits the criteria post-treatment. It is possible that it was easier for her to accept BPD once she felt she had overcome it.
Cerys was explicit about how her acceptance of BPD related to having a thorough diagnosis and specialist treatment that worked for her.

*Cerys:* *since I’ve been properly diagnosed and I’ve received ummm I’ve been on the DBT programme, that has really worked and made sense to me completely so I feel like it is the right diagnosis because the treatment has really been you know been really life changes...*

As illustrated in this extract, for Cerys, an official diagnosis was the springboard for her making sense of her difficulties and receiving support that changed her life. It was this diagnostic process with the CNS and subsequent successful treatment that allowed her to accept BPD as the “right” diagnosis.

Slightly different to other participants, Jennifer, who was yet to receive specialist treatment, expressed a willingness to accept BPD because she was used to “labels”. She received her first diagnosis of conduct disorder at the age of 8, during a time that she reported difficult events at home.

*Jennifer:* *I was a junkie. I'm not ashamed of that. So I don't have a problem with these kinds of- labels. I'm not gonna pretend that I'm something that- that am not. Or that I do.* [chuckles]

In this extract Jennifer is comparing BPD to the label of “junkie”. Explaining that she is not ashamed by this label suggests that she believes that both BPD and “Junkie” are labels that society considers shameful. She says that she is not going to “pretend” that she is something that she is not and then links this to her behaviour. This perhaps suggests that Jennifer had internalised these labels and viewed herself and her behaviour as shameful.

Contrary to Jennifer, Zoe expressed doubt about BPD due to the numerous diagnoses she had received and this prevented her from fully embracing the diagnosis. This was complicated by
the fact she had received two diagnoses from different specialist services who contradicted one another.

Zoe: Um, so I’ve always been, um, known to the mental health services, and I think it’s a bit about labels as well. It’s almost like I have loads of different labels put on me.

Her use of the words “put on me” suggests that labels are something others have decided about her without her consent. Zoe expressed how she was afraid that using the diagnosis of BPD might lead to others thinking she was making excuses for her behaviour.

3.1.2. Understanding BPD has helped me make sense of myself and painful past experiences

This theme captures how diagnosis offered an opportunity for participants to feel understood by others and to make sense of themselves. All participants described facing much adversity throughout their lives, including childhood trauma. Although not discussed here as it has been captured in past research, everyone shared experiences of being judged by others for their mental health (including by professionals). This shaped how participants viewed themselves and their mental health, with some expressing shame. For two people, BPD provided a medical explanation which was internalised as a “reason” for their behavioural responses to distress. Most accounts described how it made sense of the links between childhood adversity, painful past experiences and current difficulties managing emotions. Relationships and information were viewed as important in using the diagnosis to change or reframe how participants understood their identity.

Aaron understood that his current mental health difficulties stemmed from childhood abuse.

Aaron: Um, in a way, it was good to know what was causing me to feel like that and what it actually was. I knew what had led up to it in the past but I didn't have that diagnosis. […] I've
got PTSD as well from things that happened in my childhood and it’s sort of stemmed from what's happened in my childhood.

Despite already knowing that these experiences had influenced his mental health, Aaron expressed relief as BPD appeared to add further explanation for his emotional dysregulation. However, he struggled to verbalise how BPD was “causing” him to “feel like that”. This perhaps suggests an internalisation of medicalised language as a sufficient explanation of the link between abuse and his difficulties.

The diagnosis itself was also important for Lily and Jennifer. After years of dismissal from others, BPD helped them feel understood and acknowledged as having ‘problems’ that were real.

**Lily:** There's a reason why I feel the way I feel. It's not just me being an attention-seeker, or, yeah, crazy. I have -- there is something...

In this extract, Lily is explaining how BPD is the “reason” for how she feels. It is as if the diagnosis gives her legitimacy to challenge the labels that others have put on her, and that she has internalised.

**Jennifer:** Um, you know, it has impacted who...You know, 'cause, uh, if I actually look back now, the eating disorder was part of the personality disorder. The drug use was part of the personality disorder. And all my life I've just been, uh, you know, a “junkie” […] Someone's acknowledged that actually this is, uh, this is a real problem. Although, it doesn't feel real sometimes. But someone's acknowledged me as a person, not a junkie, not a prostitute, not a failed mother...

When Jennifer starts to say, “it has impacted who [I am]”, this is a powerful communication of how repeated experiences of being labelled by others had influenced her own self-image. She describes how BPD had helped her make sense of her behaviour and why she had difficulties
with eating and substance use. Furthermore, Jennifer experienced the diagnostic process as someone taking time to acknowledge her as “a person” that was struggling with a “real problem”, rather than just a pejorative label that describes her behaviour. For both Jennifer and Lily, the diagnosis seemed to give them a sense of belonging and being accepted by others that they had not had before.

Cerys shared how diagnostic explanations in CNS including the role of genetics and childhood experiences, helped her accept herself and her past behaviour.

Cerys: So research about some of it being part of your makeup and the way you are and some of it being umm about your experience, early experience and childhood or trauma [...] so there was nothing that I did or didn’t do that made me who I am. [...] It’s just a massive relief. [...] There is a lot shame involved in having depression, having post-natal depression and trauma you know, childhood abuse and stuff. [...] So the failure to be a good mum, the failure to bond with your child. Lots of failing to deal with childhood abuse at the time, so stored up all those kind of feelings.

Here Cerys explains how she had felt ashamed of her own responses to childhood abuse and to the birth of her child. Like Jennifer, she described herself as a failure. Her use of past tense to describe “stored up” feelings of shame and her present tense in the phrase “It’s just a massive relief”, suggest that explanations she was provided with reduced her feelings of shame and changed how she understood her behaviour. Furthermore, when she says, “there’s nothing that I did or didn’t do that made me who I am”, she is suggesting that she no longer blames herself for becoming the person that she is. Her use of the phrase “who I am” may suggest that she continued to negatively evaluate herself, but she had internalised BPD as an explanation for this.
For Olivia, who also shared positive experiences of her diagnostic assessment, it was her therapist’s approach that enabled her to reframe her self-concepts and acknowledge her own resilience.

**Olivia:** Because I think for me resilience didn't look like still self-harming. [...] Resilience was like, "A-okay." Like, "Peak good mental health." [...] I don't think until that point I sort of was like, "I have had quite a tough time of it, but I haven't had a great upbringing." There's been a lot of stuff that hasn't been ideal. [...] And she seemed to be very calm and she knew her stuff and so I believed her so when she said, "You're doing well."

Olivia recollected how previous assessments had focused on how BPD was negatively affecting her. This extract shows how Olivia’s narrative about resilience was forced to change when someone she trusted helped her reflect on how she had coped with difficult experiences. In Olivia’s explanation, her perception that her therapist was calm and an expert in working with BPD, was what engendered this trust and led to her self-discovery rather than the diagnosis itself.

For Zoe, it was her own self-directed research that allowed her to use Attachment Theory (Bowlby, 1969) to understand the links between BPD, her experiences of childhood abuse and difficulties managing emotions.

**Zoe:** I'm trying to make a link because as my - my childhood, from the time I was born to 14 years of age, my childhood was horrendous. So now I'm thinking, I have BPD. [...] those precious years where I should have been nurtured, I should have been loved, and I should have had help to manage my emotions. That should have been in place, but I had none of it. So it's inevitable that me now, and throughout my life, I have had trouble with managing emotions.

Zoe’s use of the phrase “so now I’m thinking, I have BPD” indicates that BPD offered an opportunity to understand how her early environment prevented her from learning skills to
manage her emotions. Zoe explained how this understanding had not come through the diagnostic process but through her own research, pre-treatment groups and discussions with her daughter. Like Olivia, this highlights the importance of relationships (with family and other service-users) in supporting self-discovery.

3.1.3. Lack of clarity: They didn’t help me understand what BPD meant for me

The diagnostic process in BPD was not a clear or concise path for participants. They had heard of BPD or been informally diagnosed with BPD or “traits” of BPD within generic services before receiving an official diagnosis within CNS. Not all participants were sure they had been diagnosed after assessment and many described not knowing what BPD meant for them or their future (for example, treatment options). Some expressed how their diagnostic assessment in CNS had been crucial in developing an understanding of what BPD meant.

Cerys explained how she had experienced two assessments within CNS, 6 years apart. In the first instance she was not directly told she had BPD by the CNS, but a letter was sent to her community psychiatrist who dismissed this diagnosis in favour of PTSD. She was then diagnosed with “traits” of BPD and re-referred to CNS years later. The first assessment in CNS left her confused and mistrustful of services:

Cerys: *I think confusing, very confusing and you kind of, who do you trust?*

Whereas her account of her second assessment, spoke of a regained trust in professionals, a deeper understanding of what BPD meant for her, feeling responsible for her own recovery and hopeful that one day she might not need the support of services to cope.

Similarly, Olivia had tentatively been diagnosed with BPD as a teenager which was confirmed in her twenties within CNS. She described not being given information about BPD or treatment
options, instead being given medication without a full rationale. She viewed this process to negatively impact on her self-image and her prospects for the future:

**Olivia:** I just felt really bad about myself, to be honest. I was like, I don't know- I don't know what this is, really. They haven't really given me any information. Why have they not given me any information? Is it because there's nothing they can do? Like, is it because it's just like this big, you know, or is it because I'm just like a lost cause, or something?

Olivia expressed how she would have liked an open conversation initially about BPD and why this diagnosis is not given to adolescents. Like Cerys, she explained how the assessment process within CNS had allowed her to make sense of what BPD meant to her.

Lily and Aaron both explained how hearing the accounts of others within groups or on online blogs, had helped them to understand and relate to BPD.

**Lily:** And I think going on that really helped ‘cause I don't think I fully understood it until I went to that course.

**Aaron:** When I first got the diagnosis I'd never heard of it. So I did some research online. And there was actually a former service user that had created like a blog. So it was quite useful. That I could relate to that so it helped me to understand BPD a bit better.

This may either suggest that they were not given enough information to understand BPD during their assessments or that hearing information from other people with the diagnosis was more powerful.

Zoe explained that she did not know that she was being assessed for BPD when she came for her appointment at CNS. She only understood that she had been diagnosed when she received a letter from the service.
**Zoe:** Because sometimes you need it spelt out to you, you need somebody to say, this is what happened and I've just done, you know, in my medical opinion, you have, that didn't happen. It was all very complicated all, very vague.

This extract highlights Zoe’s desire to have clear face-to-face communication with professionals about what they were assessing and what they concluded. She called this a “trust-wide problem with clarity”. Zoe’s description of her diagnostic assessment as complicated and vague places her in the unknowing position about her own mental health whilst professionals hold the powerful position of knowing but not sharing this knowledge.

**3.2. Struggling to get what I need from services**

This superordinate theme captures how participants’ long journeys to accessing specialist assessment and treatment for BPD influenced their understanding of themselves and their mental health. The data highlighted how participants did not view the diagnostic process as a discrete event within CNS, having had significant contact with services before being “officially” diagnosed in CNS. Participants described how repetitive interactions with services, where professionals did not meet their needs, left them feeling abandoned, dependent, helpless and as though they were not understood. As described in the previous themes, for most, the chance to be understood came through receiving a diagnosis and treatment within specialist services. However, participants’ shared beliefs that this support was only offered once their distress and functioning had become severe and they had exhausted all other services and treatment options.

**3.2.1. Needing to be at crisis point to get the specialist help I needed**

Participants shared experiences of feeling simultaneously dependent on support from services whilst feeling abandoned and unsatisfied with their care. All participants described reaching
crisis point (i.e. overdoses, self-harm and violence towards others), and often numerous crises, before being referred to CNS and being supported to understand their mental health.

Jennifer used a physical health metaphor to describe her experiences of accessing mental health services and being accepted into CNS.

**Jennifer:** *if you have a pain in your leg, or your back, and you keep going backwards and forwards to the doctors for years, for years, for years. And they say, "Alright. I have this tablet, have that tablet." And then finally you go when you're in agony and you can't walk anymore. And they say, "Oh, we'll send you for an MRI scan." And then finally you find out what the hell's the matter with you. It's the same kind of thing.*

Through this metaphor Jennifer describes a long pattern of perseverance with services to seek support and to understand her “pain”. There is a sense of services not knowing how to support her and perhaps being dismissive of her distress by offering medication. She speaks of being in agony and unable to walk and how it is at this point that a thorough assessment occurs. Here she is expressing how her distress became intolerable before she was referred to CNS and supported to find a diagnosis that helped make sense of her difficulties.

Cerys described feeling dependent on her community nurse to keep her safe and “disempowered” by her interactions with services. It was her diagnostic assessment and treatment in CNS that allowed her to take responsibility for her recovery. The extract below illustrates Cerys’ suspicion that a serious overdose led to her referral to CNS.

**Cerys:** *so things had to get a lot worse before I was referred back to the complex needs team. It felt like things had to, it felt to me that that only way I was going to get referred back was when I was at complete crisis point.*
Zoe shared a similar pattern with services where she felt abandoned and unsatisfied with her support. Below she describes a cycle where she would seek support for depression, self-harm and suicidal thoughts, receive a short piece of therapeutic work, be discharged and then inevitably relapse (crisis) once support had been removed. These interactions appeared to leave Zoe feeling isolated and helpless.

**Zoe:** But as soon as you know the protocol is done and I’m no longer able to have that kind of help anymore—there was no prevention [...] so it was inevitable with all these um, issues that I have that I was going to relapse.

Olivia, who had several A&E admissions before being referred to CNS, suggested that crisis was an implicit criterion for accessing not just CNS, but most mental health services.

**Olivia:** Because a lot of health mental services, you do have to be that bad, bad enough to to get the help that you need if it’s like a grey area again. So then in the middle is like, “Well, I’m not-- I’m still functioning but not as well as I could” then you don’t yeah.

Olivia shared beliefs that people’s functioning needs to be “bad enough” to access support from CNS and described fears that being in the “grey area” of functioning (i.e. maintaining education and employment) would affect her access to “gold standard” treatment she needed. Olivia described specialist treatment as a ‘long time coming’ and shared disappointment at having to go through crises to get treatment. Both Olivia and Jennifer reflected on how NHS services did not have the resources that service-users wanted or need and that this influenced their journey.

### 3.2.2. Complex Needs is a last resort service

This theme captures participants’ perceptions that CNS could only be accessed as a last resort after all other treatment options were exhausted. This led to self-beliefs that participants were “too complex” for generic services, that they had failed at other treatments, and that CNS was
their last hope for recovery. Conversations with clinicians and multiple unsuccessful interventions including cognitive behaviour therapy (CBT), appeared to influence participants’ expectations of CNS. Participants expressed hopelessness and fear about their future because of this and their assessment with CNS appeared to challenge this.

Zoe and Olivia both shared beliefs that CNS was a service for people who had experienced multiple treatment failures and relapses.

**Zoe:** I know this is really bad, but I thought the complex needs team is for people who are at their last resort. That’s what I thought. Where they’ve tried CBT, they’ve tried this therapy, they’ve tried that therapy, and nothings worked.

Zoe’s perception that no interventions had worked for her, led to her believing that CNS was a final option (a “last resort” service). This was influenced by conversations with clinicians who told her she could only access CNS once she had exhausted other options. This left her feeling alone and fearful for her future when treatments were ineffective. Her use of the words “that’s what I thought” suggest that her assessment and diagnosis within CNS may have challenged this perspective.

Similarly, as a result of assessments in generic services, Olivia believed that she was only able to access CNS because she had unsuccessful treatments of CBT and was ‘too complex’ for Improving Access to Psychological Therapy (IAPT).

**Olivia:** eventually I think I got referred for like psychiatric assessment and they said, “Okay, you’re too complex for IAPT. You’ve done CBT twice,” then they put a referral into complex needs.

However, Cerys and Jennifer both described how access to services had improved over time i.e. clinicians understanding PD better, the development of specialist outpatient services, and
greater service-user involvement. Nonetheless, both were explicit about CNS being their last hope.

**Cerys:** And it felt like the last stop [laughs]. That apart from another hospital admittance I’d been through all their— I’d been through CBT, I’d tried trauma focused work with the recovery support team.

From this extract, Cerys appears to have endured and been compliant with interventions. She described ineffective treatments as personal failures which appeared to impact on her hopes for CNS, viewing it as her ‘last stop’ from which she either began to recover or was hospitalised. Her laughter indicated her discomfort with the hopelessness she felt prior to her diagnosis and treatment in CNS.

**Jennifer:** I think it's kind of, um, God’s waiting, isn't it? Really. It's like last hope, complex needs service and MBT is-- [sighs and whispers] That's all there is. That's all there is.

Jennifer expressed gratitude for being offered CNS, explaining how PD services had not existed 20 years ago when she had needed them. Here you get a sense of how her long journey through services impacted on her views of CNS as her last hope. She appears to compare CNS and MBT (Bateman & Fonagy, 2016) to “God’s waiting” room. For Jennifer, this comparison seems to express a sense of waiting for a final judgement on whether life will improve for her or not. Her repetitive use of the words “that’s all there is” provides a strong message that the service is the only thing left to help her.

4. Discussion

4.1. Summary of findings, theory and existing literature

It transpired from participants’ narratives that diagnosis was not a discrete event within CNS. Instead this was viewed as the official confirmation of BPD, having received a previous diagnosis (or BPD “traits”) and other diagnoses in generic community or inpatient services.
These findings highlight service-users’ dissatisfaction with this process and shows how their diagnostic journey influenced how they made sense of BPD and themselves. This illustrates the strengths of IPA as an exploratory approach that allows for serendipitous findings within the nuances of individuals’ experiences (Smith, Michie, Stephenson & Quarrell, 2002; Turner, Barlow & Ilbury, 2002).

4.1.1. Making sense of a BPD diagnosis

There was a general acceptance of BPD for most participants, however this was not a straightforward process within the diagnostic assessment. In line with previous literature (Horn, Johnstone & Brooke, 2007; Nehls, 1999), most participants felt they fitted the criteria and two thirds of the group felt it made more sense than previous diagnoses. This reflects arguments about the value of BPD in explaining the co-occurrence of multiple affective, cognitive and behavioural symptoms (Paris, 2007a). However, some have critiqued the breadth of this construct which leads to a heterogeneous group being identified (Tyler, 1999), who potentially have different needs.

Despite challenges to the validity and utility of the construct, BPD has been highly researched which has led to the development of specialist services and effective treatments (Paris, 2007b). In fact, in the current study, for those receiving specialist treatment within CNS, the diagnosis felt “right” when the treatment was effective. This is an example of the fundamental aim of the medical model being achieved i.e. a medical explanation for symptoms led to people being directed to an appropriate treatment (Cuthbert & Insel, 2013). In terms of Identity Process Theory (IPT), these findings may suggest that service-users are motivated to accept a diagnosis of BPD, especially following effective treatment, because this offers a pathway (meaning; Vignoles et al., 2002) for recovery which provides a sense of self-efficacy and control (Breakwell, 1986).
There was a general acceptance of medical terminology, including BPD, to describe experiences. This was despite the group reporting significant stigma and discrimination, like many service-users represented in qualitative research (Nehls, 1999; Stalker, Ferguson & Barclay 2005; Veysey, 2014). Mirroring the findings of Haigh (2002), the diagnosis provided legitimacy for two participants’ responses to distress, helping them feel acknowledged and understood. This may be an example of the motivation to belong in IPT theory (Vignoles et al., 2002) where absorption of BPD into identity helped participants feel understood and accepted by others. Furthermore, this acceptance may have occurred because it fitted with the content and value of existing components of identity (Breakwell, 1986). For example, one person linked their acceptance of BPD to having received multiple diagnoses since childhood and having to make sense of themselves in this way. This might highlight the lack of alternative frameworks that can help individuals understand and seek support for mental distress.

Epidemiological research has highlighted high rates of childhood abuse and neglect in people diagnosed with BPD (Zanarini et al., 1997). In keeping with this, participants’ narratives were laced with challenging life events from childhood. This appeared to influence people’s sense of self, with participants self-identifying as “wrong” or a “failure” and having “built up” feelings of shame. This is in line with studies that indicate childhood physical (Gross & Keller, 1993) and sexual abuse (Maniglio, 2009) are associated with low self-esteem and an impaired sense of self in adulthood. Most participants described how their “official” diagnosis or assessment within CNS enabled them to make sense of themselves, linking their past experiences (including their responses to difficult situations) with their current difficulties regulating emotions and managing relationships. Aligned with past research, perceptions that therapists could be trusted and were experts (Horn, Johnstone & Brooke, 2007), in addition to them providing thorough explanations of BPD (Bilderbeck, Saunders, Price & Goodwin, 2014; Morris, Smith & Alwin, 2014; Richardson & Tracy, 2015), were seen to support the reframing
of self-perceptions. Participants were specific about the helpfulness of exploring the role of genetics and childhood trauma in reducing self-blame. In terms of IPT, it is possible that these explanations make BPD less threatening to identity and therefore easier to accommodate into what they understand about themselves. These findings partly mirror the Consensus Statement (Lamb, Sibbald, & Stirzaker, 2018), which highlights the importance of trauma-informed and formulation-driven approaches to the care of people diagnosed with PD. All participants highlighted the importance of access to peer support (within groups or via service-user blogs) in understanding the diagnosis and helping to challenge internalised stigma about mental distress. This suggests services are supporting service-users to access peer support in accordance with NIMH(E) (2003) and NICE guidance (2009).

Most participants shared positive experiences of the diagnostic process within CNS, in line with NICE guidance (2009), i.e. instilling hope, building a trusting relationship, clearly explaining the process of assessment and the use and meaning of the term BPD. However, this was not a global experience, with one participant only understanding she had been diagnosed after she requested a letter for welfare support. In line with past research (Fromene & Guerin, 2014; Horn, Johnstone & Brooke, 2007; Morris, Smith & Alwin, 2014; Nehls, 1999; Lawn & Mahon, 2015), service-users’ narratives included a lack of clarity about BPD whilst in secondary care, having to complete self-directed research to understand what BPD meant. Furthermore, two participants reported experiences of diagnostic disagreements between services (i.e. generic mental health versus CNS and CNS versus neurodevelopmental team). These experiences were reported to cause anxiety and confusion about whether participants were on the correct path to recovery and impacted on some people’s access to treatment. This finding suggests that, at least for this sample, the cohort of people currently being diagnosed feel they receive inadequate information during the diagnostic process, particularly within secondary care, and sometimes within CNS. This may suggest that NICE guidance (2009) is
not routinely followed. Sulzer et al. (2016) argues that this lack of clarity reduces service-users’ agency in their own care. As will be discussed next, these experiences highlight how the structure and performance of organisations influence how service-users understand BPD and themselves, build trust with professionals and access effective treatment.

4.1.2. Struggling to get what I need from services

Participants’ narratives described the challenges they had faced in getting what they needed from services in order to understand themselves, their difficulties and potential pathways to recovery. All participants had experienced several crises before being referred to CNS. This included taking active steps to end their own life. This supports the conclusions of the recent Consensus Statement (Lamb, Sibbald, & Stirzaker, 2018) that services do not respond to service-users’ needs before they reach crisis. Although this is not suggestive of an “exclusion” from services (NIMH(E), 2003; Nehls, 1999), accessing specialist support for BPD was seen as an unnecessarily long journey. Participants had to be compliant and persevere with services despite having cyclical and unsatisfying interactions with them. Previous research used to develop NICE (2009) guidance, highlighted the need for early intervention prior to a crisis (Haigh, 2002). Over a decade since these views were captured in research, and years after the implementation of these guidelines, service-users within this sample had numerous experiences of being responded to once they were in crisis rather than preventative action being taken by services. Furthermore, participants shared their fears at assessment of not being “bad enough” to access the specialist treatment they believed would help them.

As this study is the first to explore service-users’ specific experiences of the diagnostic process in specialist community PD services, a unique finding was that CNS was viewed by participants as a “last resort” service. Participants shared beliefs that they were only referred to CNS because their needs were “too complex” for generic services such as IAPT and other treatments had been ineffective. This somewhat reflects current care pathways in England
(NICE, 2009), where service-users are first referred to secondary care for diagnostic assessments and treatment, and access to specialist services only occurs when risk is “high” and greater diagnostic and treatment input is required. However, for some, this process led to service-users believing CNS to be their “last stop” where they either recovered from their mental health difficulties or did not. These findings suggest that service-users’ long histories of accessing services and experiences of unsuccessful treatment, impact on beliefs about themselves, their recovery and their expectations once they are referred to CNS. This supports past research that highlights how interactions with services influence how hopeful service-users feel (Morris, Smith & Alwin, 2014).

Some participants in the sample reflected on the current resources of mental health services and how things had changed over their years of accessing services. One participant highlighted how services such as CNS had not existed 20 years ago. Someone else shared that services had become more collaborative and better able to support their needs. However, there was a sense that inadequate resources had impacted on participants’ ability to access specialist services and treatment for BPD. These accounts may have captured how organisational and provisional changes outlined in NIMH(E) (2003) have impacted on those accessing services. That is, whilst a greater service is being provided to those diagnosed with BPD, resources within the NHS continue to impact service-users’ journeys through services and their access to specialist treatment.

4.2. Clinical implications and directions for future research

Study findings highlighted the potential of the diagnostic process to influence identity and empower or disempower service-users. Therefore, careful consideration needs to be taken when providing a diagnosis of BPD. In line with the recent Consensus Statement (Lamb, Sibbald & Stirzaker, 2018), this study suggests that service-users value a formulation-driven approach within the diagnostic process. In CNS, diagnosis provided a meaningful opportunity
to support service-users to make sense of the impact of attachment and challenging experiences, such as trauma, and reduce feelings of shame and rejection. However, diagnosis does not appear to be a one-off event within one service. Diagnostic discussions also occur within generic services before people are referred to specialist PD services. It is therefore important that clinicians within secondary care follow NICE (2009) guidance and provide time and space to explore what BPD means for the person being diagnosed. Follow-up 1:1 sessions, signposting to further information and groups are necessary for understanding this diagnosis and fitting it into identity. This clarity would help service-users feel fully informed and enable them to have more agency in their care (Sulzer et al. 2016), for example when deciding on treatments or advocating for themselves within the system.

It is interesting that for most people, it was formulation of their difficulties as opposed to the diagnosis that led to greater understanding and reduced internalised stigma. These experiences may support arguments for a shift in mental health to move from diagnosis, which struggles with validity and reliability, to formulation frameworks such as the “Power Threat Meaning Framework” (Johnstone, 2018). It would be interesting to explore service-users’ views of this framework. However, it is worth noting that for some participants, the diagnosis itself held power too, highlighting the importance of service-user choice when it comes to diagnosis.

Although findings are only representative of a small sample, they may reflect problems within current care pathways in England and about how NICE (2009) and NIMH(E) (2003) guidance has been implemented. In line with past research, participants described a lack of clarity around the diagnosis and treatment, particularly within generic services. There was a continued sense of being excluded or delayed from accessing specialist support for BPD, only being provided access as a last resort or once participants’ difficulties had reached crisis point. This may suggest that clinicians within secondary care services are not feeling skilled or resourced enough to provide a thorough diagnosis and follow-up support. However, this may also reflect
pressures on specialist services in terms of capacity to take on referrals and to provide specialist training to generic mental health services as stipulated by NICE (2009). Clinicians and researchers have already suggested how the organisation of care supporting this group, rather than the actual psychosocial intervention itself, is the key to positive outcomes (Bateman & Fonagy, 2013). Further research could explore the experiences of service-users who remain in secondary care for diagnosis and treatment, to understand whether their experiences of the diagnostic process differ from those who go on to access specialist services.

4.3. Limitations of methodology and considerations for future research

IPA assumes that a person’s experiences can be assessed through language. This relies on the participant’s ability to convey their experience through words and for the researcher to understand and convey this meaning to the reader (Willig, 2013). Therefore, a possible criticism of IPA and this study, is that participants might not have the communication skills to put their experiences into words. This may be particularly true of participants experiencing distress within the context of severe mental health difficulties, as this is known to impact on cognitive functioning (Green, 2002; Rock, Rosier, Riedel & Blackwell, 2014). However, this criticism of IPA has been rebuffed on the grounds of elitism, that is, suggesting that “only those having access to the right level of fluency are allowed to describe their experiences” (Page 4; Tuffour, 2017). Nonetheless, to ensure rich and exhaustive data was collected, the researcher used their clinical training to support participants’ expression: providing time to respond; reframing questions to get further elaboration; asking participants to expand on their meaning and checking that they had understood participants correctly throughout the interviews. Being led by participants in this way, also reduced the possible mismatch between the meaning that the participants were wishing to convey and how this was interpreted.

Nevertheless, objectivity is not possible nor an aim in IPA. All data was collected, analysed and presented through the researcher's own lens. The researcher attempted to address the
potential impact of assumptions at all stages using the following procedures: seeking support from service-users and experts in IPA to formulate questions and adhere to the framework; following Yardley's (2000) guidelines to improve validity and reliability; maintaining a reflexive account; and completing credibility checks (Appendix-F-I). Extracts were provided for the reader to assess the plausibility and credibility of themes and to be transparent about the analytic process.

A further criticism of IPA, particularly at a doctoral level, is that it is not performed in a standardised way and is descriptive rather than interpretative (Giorgi, 2010). The researcher though not new to qualitative research, was a novice in IPA. To keep true to the methodology and interpretative stance, the researcher undertook specialist training in IPA, received supervision from an IPA expert and followed the standardised procedures (Smith, Flowers & Larkin, 2009). Interpretation occurred at multiple levels of analysis, however, this was most obvious at the group analysis stage where the narratives of each participant were woven together to make sense of and illuminate the experiences across the group. In the case-level analysis, following recommendations from an expert in IPA, the researcher was careful to stay close to the language used by participants, so their voices were present within themes. Whilst this may appear descriptive, theme titles at this level were carefully chosen to reflect a narrative expressed within quote evidence and within the context of a whole transcript, and was in this way interpretative (Smith, Flowers & Larkin, 2009).

The findings represent the experiences of six participants accessing CNS in London, and so caution was taken by the researcher when discussing implications and generalisability. However, small samples are a pre-requisite for IPA to ensure a rich analysis of individuals’ experiences, therefore allowing for the discovery of original ideas. The project relied on service-users volunteering their time and service leads selecting potential participants, both of which could have introduced bias. Although not specified in terms of recruiting a homogenous
sample, all participants were white British. It was unclear why this had occurred, but it may reflect who is accessing specialist PD services in these localities. Systematic reviews have highlighted that black ethnic groups have more complex pathways to specialist services in the UK (Bhui et al., 2003), in addition to greater rates of compulsory admissions compared to white service-users (Atkinson, 2001). Black, minority and ethnic populations (BME) are under-represented in qualitative research exploring service-user perspectives of receiving PD diagnosis (Ingram, 2018). Given that there is an established variation in access to mental health services between different ethnic groups within the literature, this presents an important gap in our current knowledge to be rectified by further research.

Another possible limitation of the sample was that it transpired there were significant differences between the approaches adopted by each recruitment site in terms of diagnostic assessment and delivery. For one service, diagnosis was embedded within the assessment using a diagnostic tool which was discussed with the client. Whereas the other service worked trans-diagnostically, did not require a PD diagnosis, and discussed BPD within a pre-treatment group setting rather than at assessment. Although this could be considered a limitation in terms of the homogeneity of the sample, it highlights the nuances in the participant’s experiences of the diagnostic process in BPD and something important about the significant differences between how specialist services operate across localities.

4.4. Conclusions

Despite the increase in provision across mental health trusts in England and the evidence demonstrating cost-effective specialist interventions, there continues to be inconsistency in service availability for people with a diagnosis of PD (Evans et al., 2017). This is the first project to have successfully captured a group of service-users’ diagnostic journeys across services, following the implementation of NIMH(E) (2003) guidance, and explored the impact this has on identity and understanding of mental health. Participants’ narratives highlighted
how the diagnostic process, particularly within CNS, helped them make sense of themselves and challenging past experiences, and to better understand their mental health. However, this process and the pathway to specialist treatment was viewed as unnecessarily long and unclear. Participants felt they had to “jump through hoops” and that their difficulties had to get much worse before they could access the support they needed. These findings contribute to the limited research exploring service-users’ experiences of psychiatric diagnosis. Despite the potential challenges of recruiting service-users who experience high levels of distress to discuss sensitive topics (McCosker, Barnard & Gerber, 2001), this study highlights the importance of gaining a comprehensive understanding of service-users’ unique experiences and perspectives on accessing services. The is in line with the aims of NIMH(E) guidelines which emphasise the importance of service-user contribution to the development and functioning of services.
5. References:


Haigh, R. (2002) *Services for people with personality disorder: the thoughts of service users.* Retrieved from: 


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Appendix A - Favourable ethical approval

A.1: HRA approval

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Ms. Niamh Ingram
School of Psychology
AD Building University of Surrey
Guildford
GU2 7XH

20 June 2017

Dear Ms Ingram,

[Letter of HRA Approval]

Study title: Service-User Experiences of the Process of Receiving a Diagnosis of Borderline Personality Disorder within Outpatient Specialist Personality Disorder Services: How is the Diagnostic Process Perceived to Influence Service-User Understanding of this Diagnosis and Themselves

IRAS project ID: 217472
REC reference: 17/LO/0832
Sponsor: Surrey University

I am pleased to confirm that HRA Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. Please read Appendix B carefully, in particular the following sections:

- Participating NHS organisations in England – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities.
- Confirmation of capacity and capability - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria) - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

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Page 1 of 8
It is critical that you involve both the research management function (e.g., R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from www.hra.nhs.uk/hra-approval.

Appendices
The HRA Approval letter contains the following appendices:
- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

After HRA Approval
The 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.

In addition to the guidance in the above, please note the following:
- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the After Ethical Review document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the HRA website, and emailed to hra.amendments@nhs.net.
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the HRA website.

Scope
HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hec-ld-review/.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.
User Feedback
The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/.

HRA Training
We are pleased to welcome researchers and research management staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

Your IRAS project ID is 217472. Please quote this on all correspondence.

Yours sincerely

Alex Thorpe
Senior Assessor

Email: hra.approval@nhs.net

Copy to: Mr Ali Alshukry, Sponsor's Representative
A.2 – Research and Ethics Committee

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval.

20 June 2017

Ms Niamh Ingram
School of Psychology
AD Building University of Surrey
Guildford
GU2 7XH

Dear Ms Ingram,

Study title: Service-User Experiences of the Process of Receiving a Diagnosis of Borderline Personality Disorder within Outpatient Specialist Personality Disorder Services: How is the Diagnostic Process Perceived to Influence Service-User Understanding of this Diagnosis and Themselves

REC reference: 17/LO/0832
IRAS project ID: 217472

Thank you for your letter of 12th June, responding to the Committee’s request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact hra.studyregistration@nhs.net outlining the reasons for your request.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.
Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).


Where a NHS organisation’s role in the study is limited to identifying and referring potential participants to research sites (“participant identification centre”), guidance should be sought from the REU office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publicly accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g., when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non-registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHSHSC R&D office prior to the start of the study (see
"Conditions of the favourable opinion" below).

**Approved documents**

The final list of documents reviewed and approved by the Committee is as follows:

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<td>Version 5</td>
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<td>Summary CV for supervisor (student research) [Supervisor CV Dr. Kate Gleeson]</td>
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**Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

**After ethical review**

**Reporting requirements**

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

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

**User Feedback**

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:

http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/
HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

17/LO/0832 Please quote this number on all correspondence

With the Committee’s best wishes for the success of this project.

Yours sincerely

[Signature]

Mrs Rosie Glazebrook
Chair

Email: rcscommittee.london-camdenandkingscross@nhs.net

Enclosures: “After ethical review – guidance for researchers”

Copy to: Mr Ali Alshukry, University of Surrey
A.3 - University Sponsorship

[Niamh Ingram]
School of Psychology
Faculty of Health and Medical Sciences

22 June 2017

Confirmation of sponsorship by the University of Surrey

Dear Niamh,

Study title: Service-User Experiences of the Process of Receiving a Diagnosis of Borderline Personality Disorder within Outpatient Specialist Personality Disorder Services: How is the Diagnostic Process Perceived to Influence Service-User Understanding of this Diagnosis and themselves.

University of Surrey reference: SPON/2017/006/FHMS
IRAS Number: 217472
REC Reference: 27/LO/0892

I am writing to confirm that the above study has satisfied the requirements of the University of Surrey Research Integrity and Governance Office. We are pleased to confirm that the University of Surrey, as a recognised Sponsor under the Department of Health’s Research Governance Framework for Health and Social Care, agrees to act as a Sponsor for your study on the basis of the documentation listed below:

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<td>15 December 2016</td>
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<td>Research protocol or project proposal [Research Protocol Version 4, 04/05/2017, 217472]</td>
<td>4</td>
<td>04 May 2017</td>
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</table>
Once you have obtained Confirmation of capacity and capability from the participating trust you have permission from the University of Surrey to commence recruitment. Should the existing protocol undergo any changes you must complete the self-assessment form to determine whether the requirement for ethical review will change.

Please also ensure that you and your supervisors are familiar and act in accordance with the University of Surrey’s Code on Good Research Practice and the Ethical Principles and Procedures for Teaching and Research.

Yours sincerely,

Andrew McClave
Clinical Research and Governance Officer

Copy to: Dr Kate Gleeson
Appendix B - Participant information sheet

Participant Information Sheet

Service-User Views: Receiving a BPD Diagnosis in Specialist Services
(IRAS Project Number: 217472, Sponsor Reference: SPON 2017 06 FHMS)

Thank you for considering taking part in this study. Before you make a decision, please read through this important information describing the purpose of the study and what will be involved should you choose to take part. You can also take time to talk this over with friends, family or health professionals to come to a decision.

Participating in this research is completely voluntary. You do not have to take part. Whether or not you choose to take part in this study, your decision will not affect the care you receive from the NHS. You can also withdraw yourself from this study at any time.

If you have any questions, please do not hesitate to get in contact with the researcher, Niamh Ingram, whose contact details can be found at the bottom of this information sheet.

What is the study about?
I am a researcher working in the psychology department at the University of Surrey, in partnership with NHS Trust. As part of this project, I am interested in exploring individual’s experiences of receiving a diagnosis of Borderline Personality Disorder. Previous research suggests that service-users with a diagnosis of borderline personality disorder (BPD) have a mixed response to receiving this diagnosis, with some left feeling relieved and hopeful and others feeling hopeless and rejecting of the diagnosis. There is a small amount research that indicates that the way in which this diagnosis is given influences how a person understands BPD and how they feel about the diagnosis and themselves.

The current study aims to explore through interviews with service-users people’s experiences of a receiving this diagnosis within specialist personality disorder services. The research is particularly interested in how service-users came to understand this diagnosis, what it means to them and how they experienced the process of being diagnosed. In conducting this study, the I hope to contribute to a body of evidence that places service-users’ voices at the centre of evaluating and improving clinical practice.

Why have I been invited to take part?
The research is specifically interested in the perspectives of adults who have received a diagnosis of Borderline Personality Disorder within specialist personality disorder services after 2010. You have been invited to participate in this research because you have been identified as someone who might meet this criteria. If you have not received this diagnosis within a specialist personality disorder service, then unfortunately you are not eligible for this study.

What would taking part involve?
In agreeing to take part in the study, you will be invited to an interview with the researcher. The location of this interview will be decided upon by you and the researcher. Unfortunately, the researcher will be unable to interview you at home. Reasonable travel expenses will be reimbursed on receiving travel receipts (maximum of £10).
In order to make sure all your views are captured and no important information is lost, it is essential that the researcher audio records the entire interview. At the beginning of the interview the researcher will ask you verbally whether you consent to the interview being recorded, at which point the recorder will be switched on. Following this, the researcher will answer any questions you have and ask for your written consent to take part in the study. You can withdraw this consent at any point and end the interview without providing a reason. Withdrawing will have no effect on the care you currently receive.

In this interview you will be asked about your experiences of receiving a diagnosis of BPD and how this process and the diagnosis itself have impacted on the way you understand yourself and your mental health. This style of interview is unstructured and open, much more like a discussion than an interview. This is so that the researcher can grasp the complexities of your experiences and discover original ideas not yet captured in previous research. The interview itself will probably take 1-2 hours depending on each individual and how much they have to say on this topic. It is also possible to split this interview over two dates.

**Will my taking part in the study be kept confidential?**

What you and the researcher discuss in the interview becomes the data for this research study. This means that what you say will be interpreted to produce findings that will later be published and shared with others. For this reason, it is important to protect your identity.

If you agree to take part in this study, only you, the researcher and your care team will be aware of this. Your care team will not be informed of anything that you discuss within the interview. The only exception to this, is if you disclose something that suggests to the researcher that you or someone else is at risk of harm. If this occurs, the researcher will be bound by a duty of care to inform your care team of this risk. Where possible, the researcher will discuss this with you before contacting those involved in your care.

The only person who will be able to match you with any audio recordings, interview transcriptions, written pieces of work or publications, will be the researcher. However, in order to ensure that your data is used accurately to produce high quality research, other individuals may review audio-recordings, transcriptions and written pieces of work. These contributors will all be subject to a confidentiality contract to protect your identity and where possible only anonymised data will be shared with others. Although it is most likely that only the researcher will listen to any audio recordings of the interview, the researcher’s supervisor or a hired transcriber may listen to recordings in order to assist with parts of the research. Transcriptions will be anonymised before being shared with anyone else, so that you cannot be identified from what you have discussed.

All project data (e.g. consent forms) will be held for at least 6 years and all research data (anonymised transcriptions) for at least 10 years in accordance with the University of Surrey policy. Audio recordings may be kept for up to 3 years. Your personal data is held and processed in the strictest confidence, and in accordance with the Data Protection Act. All information gathered will be held on password-locked computers and secure Surrey University servers. Hard files will be locked inside cabinets within University or NHS sites. No identifiable data will be accessed by anyone other than researcher and authorised personnel from the University and regulatory authorities for monitoring purposes.

**How do I take part?**

If you agree to take part in the study, you can let your care team or the researcher know that you are happy to be contacted by the researcher to book an interview appointment. Your Care team may ask you...
In person whether you would be happy to be contacted by the researcher. The researcher will then call or email you to answer any questions and book a time, date and location for an interview.

What happens after the study finishes?
This piece of research is due to be completed by September 2018. Once data has been collected and analysed, the researcher may publish their findings in journals and present them at conferences. This is so the research can make an impact on the world and other researchers and practitioners can learn from the findings. Should you wish to be sent copies of the final study or of any published articles, the researcher can take your email address to forward these on to you. Your name or any other identifiable information will not be used in the write up of any findings.

Information about the researcher:
The researcher, Niamh Ingram, is a researcher within the Psychology Department at the University of Surrey. She holds Graduate degree in Psychology and is currently completing a Doctoral degree in Clinical Psychology. In addition to this, she has over 5 years of experience working in mental health. This research will contribute to her doctoral training programme and is funded by the University of Surrey.

Has the research been approved by any committees?
The study has been reviewed and given a favourable ethical opinion by the Faculty of Health and Medical Sciences at the University of Surrey, the London – Camden and Kings Cross NHS Research Ethics Committee, and the Health Research Authority (HRA). Funding for this project comes from the University of Surrey.

What are the possible benefits of taking part?
By participating in this study you are contributing to research that evaluates current practice within NHS services. This has the potential to improve the quality of care that people receive during the diagnostic process and puts service-user experience and feedback at the heart of clinical practice.

What are the possible disadvantages and risks of taking part?
Due to the nature of unstructured interviews, it is difficult to predict what issues might come up for those who participate. It may be that the interview makes you think about past events that you haven’t thought about in some time. It is also possible that we may discuss experiences that have been quite painful in your life. Although the researcher may have a few questions they would like to ask you, this interview is led by you and you can talk as little or as much as feels comfortable. You can choose not to answer questions or end the interview at any time. The researcher will also provide services that you can contact should you need to talk to someone after the interview.

Withdrawing from the study
You can choose to withdraw yourself from the study at any point during the research, even within the interview, without having to give a reason. As the analysis of data collected during this study begins soon after your interview ends and the data is quickly anonymised, should you wish to withdraw your data, you will only be able to do so up to 24 hours after the interview. Anonymised data cannot be withdrawn from the study. For this reason, it is recommended that you think carefully about participating in the study before agreeing to take part.

What if there is a problem?
The University has in force the relevant insurance policies which apply to this study. In addition, the Sponsor has made arrangements, in the event of harm where no legal liability arises, for “non-negligent
harm” claims. If you wish to complain, or have any concerns about any aspect of the way you have been
treated during the course of this study, then you can contact the study supervisor, Dr Kate Gleeson. Her
contact details can be found at the end of this sheet. You can also contact Mary John, Programme Director
of Clinical Psychology: Email: m.john@surrey.ac.uk, Phone: 01483 68 9267. Otherwise, you can contact the
National Health Service Patient Advice and Liaison Service (NHS-PALS), details of local PALS offices can be
found at http://www.nhs.uk/Service-Support/Patient-advice-and-liaison-services-(PALS)/LocationSearch/353

Thank you for taking time to read this information.

Researcher Details: Research Supervisor Details:
Niamh Ingram Dr Kate Gleeson
Trainee Clinical Psychologist Research Director on Clinical
Psychology Department, Psychology Doctoral Programme
University of Surrey, Psychology Department,
Guildford, University of Surrey,
GU2 7XH, Guildford, GU2 7XH
niamh.ingram@nhs.net kate.gleeson@surrey.ac.uk
Appendix C- Participant consent form

Participant Consent Form

Service-User Views: Receiving a BPD Diagnosis in Specialist Services

[IRAS Project Number: 217472, Sponsor Reference: SPON 2017 06 FHMS]

Researcher – Niamh Ingram, University of Surrey

I have read and understood the Information Sheet (Participant Information Sheet Version 2, February 2017). I have been given a full explanation by the researcher explaining what the project is about, where and why it is being done, and how long it is likely to take.

Please initial or tick each box

I have been given information by the researcher of what I will be expected to do. I have been told about any possible distress which taking part in the project may cause me and have been offered support should this happen.

I have been given the opportunity to ask questions about the research and have understood the advice and information given as a result.

I understand that my decision to take part in this project is entirely voluntary. I understand that whether I decide to take part in the research or not will have no affect on any treatment, support, etc, that I may be receiving from my care team.

I understand that should I share anything with the researcher that leads them to think that I or other people are at risk of harm, they will be obliged to inform my care team.

I agree to comply with the requirements of the study as outlined to me to the best of my abilities. I will inform the researchers immediately if I become upset or worried during or if I have any concerns afterwards.

I agree for my [anonymised] data to be used for this study that will have received all relevant legal, professional and ethical approvals.

I agree to my interviews being recorded and understand that this is necessary for this project and is therefore not optional.

I understand that all project data will be held for at least 6 years and research data will be held for at least 10 years, in accordance with University policy and that my personal data is held and processed in the strictest confidence, and in accordance with the Data Protection Act [1998].

I agree for the researchers to contact me to provide me with a study results summary or future publications using this research (optional).

I understand that all data collected during the study, may be looked at for monitoring and auditing purposes by authorised individuals from the University where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.

I understand that I can withdraw myself from the study at any time without having to give a reason, and my care and treatment will not be affected.

Version 4, May 2017
I understand that I can withdraw my data from the study up to 24 hours after my interview. This is because data is quickly anonymized to protect your confidentiality and begin analysis.

I understand that transcriptions of interviews and written pieces of work will be anonymized.

I agree for the researchers to use anonymized direct quotes from my interview in written pieces of work, publications and presentations, as evidence of the researcher’s findings.

I understand that researchers will also reimburse reasonable travel expenses.

I confirm that I have read and understood all the above and freely consent to participate in this study.

Participant please write your name here in block capitals:

Signed
Date

Name of researcher in block capitals:

Signed
Date

Version 4, May 2017
Appendix D - Semi-structured interview schedule

Interview Schedule:

Could you tell me what it means to have BPD? What is this like for you?

Can you tell me how you came to understand what your diagnosis was?

Could you explain to me the process of receiving your diagnosis?

How did you feel after receiving your diagnosis?

What was it like to tell other people about your diagnosis?

Note: this schedule is subject to change during the interview process and under feedback from service-users.
Appendix E- Analytic process for IPA as outlined by Smith, Flowers & Larkin (2009)

Single-case analysis

The first interview was read multiple times in depth whilst listening to the audio recording, and initial notes were made by the researcher on the transcript. Emergent themes that captured the content of the participant’s narrative were also noted during this process. This was then repeated for subsequent interviews. Following this, the emergent themes for the first participant were listed chronologically to observe any patterns across them. These themes were then collapsed and renamed if they described the same theme and reordered and clustered together in hierarchies of similar themes. This was translated into superordinate themes and subordinate themes for the participant. Again, this process was repeated with subsequent interviews so that each interview had its own set of superordinate and subordinate themes. Important themes that could not be initially clustered within this process, were placed in a miscellaneous category so as not lost in cross-case analysis.

Cross-case analysis

It was at this point that the researcher looked across themes for each interview to see if there were patterns across and discrepancies between participants’ narratives. Themes within a case were used to help illuminate what was said by another participant to develop a conceptual framework of superordinate and subordinate themes for the group. Extracts from transcripts were provided to exemplify themes. Supervision and peer support was essential during this process to enrich the analysis, synthesise and structure themes for the group, and check the credibility of findings.
Appendix F - Demonstrating the study’s quality and validity, Yardley (2000)

Sensitivity to Context

Throughout this project I have shown sensitivity to the context of the research in several ways. Initially this was through a literature survey and then more focused and thorough literature review to decipher gaps in our current understanding of people's experiences of the influence of the diagnostic process on identity and service-users' understanding of their mental health. This enabled me to develop a project that would contribute to our current understanding and be relevant to clinical practice. As outlined in my introduction and discussion, I immersed myself in the wider literature including policy papers, NICE guidance and position papers, such as feminist literature and the Power Threat Meaning Framework (Johnstone et al. 2018). In addition to this I read relevant newspaper and journal articles that enriched my understanding of the wider context of psychodiagnosis and borderline personality disorder (BPD). Due to my clinical training, I was also sensitive to participants' experiences within interviews (as discussed in my reflexive account, Appendix), considering the power dynamic and what I might represent to them as a professional within the NHS. This sensitivity allowed me to adapt my approach and questioning to make sure the voices of participants were heard, and the data reflected their perspectives on the research question.

Commitment to Rigor

To ensure that I was rigorous in my approach throughout this process, as mentioned above, I made sure that I was immersed in literature relevant to the topic including articles that would not be included in my literature review or empirical paper. I also drew on my previous experience of having worked with this client group and sought the support of service-users with this diagnosis to help me develop the project and to produce information sheets, consent forms and a draft schedule that fitted participants potential needs. I gathered background information about recruitment sites and how they operate prior to recruitment to understand this context by speaking to service leads and visiting one of the services to experience the group in which BPD was discussed with service-users. During the analysis process I read and re-read transcripts with the accompanying audio recording to immerse myself in the data and to pay attention to non-verbal cues within the interviews that may support analysis. I also made sure to write in my reflexive account following each interview to document my initial thoughts and reaction which I later compared with my analysis. Though I was not new to qualitative research, I was a novice in interpretative phenomenological analysis (IPA). To overcome this and remain committed to rigor I accessed all workshops (compulsory and specialist) provided on my training, utilised the expertise of my research supervisor and qualitative peer group, I also read a range of relevant books outlining the process of IPA to support my work. Within workshops I practiced through role-plays my interview technique and stance as a researcher and developed my interview schedule. This is also where I developed my analytic skills, on both my own work and others, and received feedback from an expert in the field and my peers. In addition to this, a peer researcher reviewed one full transcript with emergent themes (16.7% of data) to check the credibility of my superordinate and subordinate themes for this case and against the group themes. In response to this and my supervisor's feedback, I adjusted the language of my themes to better reflect the voices of participants (i.e. using less jargon), moved or replaced quotes/extracts to better reflect the theme (this can be found in Appendix-J).
Transparency and Coherence

Teaching on IPA, supervision, reading on this approach and around the topic and about IPA, helped my stay in line with IPA's theoretical assumptions throughout the project. I was also transparent with service-users about the aims of the project in order to provide fully informed consent and aid their own story telling within the interview. I have also shared an account of my self-reflexivity in an attempt to be transparent about my own biases and assumptions and how I recognised and planned for the potential impact on the project. I have also shared an audit trail to provide examples of how my analysis changed over time and with the input of others. Within my method section I have described clearly my analytic process so that others can understand how I developed themes.

Impact and importance

Within my introduction, discussion and conclusions I have explored the relevance of the project to our current knowledge and the potential impact of the findings on practice and policy.
Appendix G- Self-Reflexivity

I am a 27-year-old white British cis-woman currently undertaking my training to become a clinical psychologist. As a result of my training, I have experience using formulation to make sense of and contextualise the experiences of people with complex mental health problems, including borderline personality disorder. Within my clinical role it has be imperative that I reflect on my own context (i.e. privileges, power, beliefs, values, family structure, cultural background etc.) and the impact that this might have on my therapeutic relationships. I had some experience of qualitative research prior to my doctoral thesis but was new to IPA. As I will discuss, it has been difficult at times for me to switch from my role as a clinician, which is where I feel most comfortable, to my role as a researcher, particularly given that my sample was current service-users. However, the transferable skills that I have developed as a clinician, i.e. formulation, self-reflexivity, and analytical, communication and active listening skills, have fitted well with the framework and assumptions of IPA, and have allowed me to use this new approach to understand the experiences of people accessing services. Throughout this project I have kept a reflexive journal and the used supervision (both peer and expert) to openly reflect and plan for assumptions I have noticed in myself. Below I share my reflexive experiences at different stages of the project.

Conception of the project:
Prior to training I had significant experience working with adults who had received an official or unofficial diagnosis of personality disorder within forensic inpatient and community complex needs services. Within these roles I had developed a specific research interest in people's experiences accessing services and went on to publish a service evaluation with my colleagues of service-users' experiences within ward rounds. I also have family members who had experiences of receiving this diagnosis and accessing mental health services. It was these experiences that led me to be curious about service-user experiences of accessing specialist services and receiving a personality disorder diagnosis, specifically borderline personality. It also made me aware of the stigma attached to the diagnosis and the potential difficulties people might have in accessing treatment which, as I will discuss later, is something that came explicitly through in participants' narratives. For me it was interesting that there were significant differences between how the people felt towards the diagnosis and services. I noticed that at the beginning of the project I also had ambivalent thoughts and feelings towards the diagnosis myself. To me it felt like a reductionist and pejorative way of understanding someone’s current difficulties managing emotions and relationships which was often related to childhood trauma and subsequent traumatic experiences. However, some-what paradoxically, I had also seen how helpful some people had found the diagnosis in normalising and validating their current difficulties, reducing the impact of stigma and providing a clear treatment pathway. In my first supervision, I reflected on my ambivalent feelings towards the diagnostic system and how I positioned myself within services that use this dominant framework. Here I owned my own beliefs and considered my own motives for undertaking the project, that is my beliefs that the medical model is flawed and my motivation to undertake a project that was both personally meaningful and explored the perspectives of those accessing services and being diagnosed.

Reflecting on these beliefs from the start of this project helped me think about how they might shape the study and the actions that I could take to reduce this bias. This began with doing an initial survey of the literature, to understand what our current knowledge was about people’s experiences of being diagnosed with a personality disorder, and then a more thorough literature review to focus on the influence of the diagnostic process itself on identity. This process helped me think more broadly and beyond my initial motivations to consider the gaps in our current
understanding, the possible impact of such a study and to create a sound rationale for a project that adds to our current understanding.

Interviews:
Within interviews, I was aware of the power that I had as a researcher to follow leads of enquiry and close down others. I reflected in supervision how this might lead me to attend to areas that answer my research question, but potentially reduce the likelihood of spontaneous findings. I was initially uncomfortable with this power and this position as researcher instead of therapist. I was both eager to answer my research question and uncomfortable with shutting down lines of conversation that might be beneficial for participants to talk about. In supervision we discussed the following and leading stance of the researcher in IPA, and how the tangents the participants may go on, may still be relevant to answering the question following analysis. I was able to practice this stance during workshops for IPA prior to interviews. Overtime I became more mindful of my responses to participants and why I was asking particular questions, finding it easier to strike the balance between giving space to participants and validating their experiences whilst asking questions that illuminated the research question.

I also considered who I might represent to service-users and the influence of the location of the interview within complex needs services. As participants knew I was a clinician and that I was in contact with their care team, I wondered whether this would impact how open people would be with me about their experiences of services. I found it helpful to clarify my relationships with the services, what confidentiality meant within this context and how I would maintain anonymity in anything I published. I also found that my skills as a clinician in being empathic, attentive and validating in response to people’s experiences helped me build a relationship in which people felt comfortable to share dissatisfaction with services and explore sensitive issues, such as the impact the diagnosis had on their identity.

Analysis:
When reading through transcripts for the first time, I noticed my attention being drawn to parts of the text that reflected findings currently present in the literature and my own personal experiences of working with people with this diagnosis e.g. not knowing what the term BPD meant or feeling judged or having this diagnosis. To reduce the impact of this attention and my own assumptions on the work, I read and re-read scripts with the audio-recording to immerse myself in the data. I also completed an initial line-by-line analysis for each transcript so that I did not attend to one part of the transcript over another. This helped be direct my attention evenly and helped my draw out interpretations and findings I would have otherwise missed. As I undertook individual case analysis for each transcript, I noticed myself worrying about how seemingly contrasting data and experiences would fit together. However, as I began to group emerging themes for participants and then looking across the group, I observed how this process allowed for the capturing of rich and nuanced themes. This lead to themes that felt authentic, and not reductionist, of participants’ experiences and narratives, which lead to original clinical implications of the research.

Writing:
The writing process was reiterative, with me attending to the data and themes to help me best represent the voices of participants. During this process I appreciated the richness of the data and the potential of it to answer several of the other research questions. At times I feared I was failing to capture important findings because they did not answer the research question. However, this emphasized for me the need for future exploratory research in this area.
Appendix H – Credibility check: Audit trail

Here I provide an audit trail of two different participants to illustrate how my themes developed over the process of my analysis. That is, from exploratory comments and emergent themes for a participant, to group subordinate and superordinate themes. As discussed in my credibility check, supervision was important in the transformation of themes to check that they were a plausible and true reflection of the data and participants' language.

Table 3 - Extract from Jennifer’s Interview

<table>
<thead>
<tr>
<th>Exploratory comments</th>
<th>Interview Extract</th>
<th>Emergent Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Experience of being seen more clearly</td>
<td><strong>Interviewee</strong>: And that, for actually for someone to unpick me a little bit more than that, think outside the box, it's not rocket science. Cause I knew 15 years ago about this thing I saw it on tellie.</td>
<td>Not feeling understood by professionals</td>
</tr>
<tr>
<td>Looking past labels and other diagnoses</td>
<td><strong>Interviewer</strong>: Mmhhh.</td>
<td></td>
</tr>
<tr>
<td>Frustration of professionals not knowing</td>
<td><strong>Interviewee</strong>: Um, but yes. So for me it's, kind of -- I mean I- I'm in the service now and it's my last- it's my first chance and it's the only hope kind of thing. And it, kind of, feels like, [sighs] um, someone's acknowledged that. Someone's acknowledged that actually this is, uh, this is a a real problem. Although, it doesn't feel real sometimes. But someone's acknowledged me as a person, not a junkie not a prostitute not a failed mother, not -- or anything, but just as a person. And gone, &quot;Okay. You do have difficulties with one, two, three, four, five. And then, to put that in a little bracket-</td>
<td></td>
</tr>
<tr>
<td>Seen BPD in media</td>
<td><strong>Interviewer</strong>: Mm-hmm.</td>
<td></td>
</tr>
<tr>
<td>Last chance but also first proper chance? Viewing the service as only hope of recovery/change? Feeling acknowledged as having a real difficulty At times feeling that she doesn’t have a real problem Experiences of being labelled in the past Feeling acknowledged as a person-seen as a whole rather than a label? Having difficulties made sense of Diagnosis makes difficulties easier to understand, cope with.</td>
<td><strong>Interviewee</strong>: -in a little box and say that's what you've</td>
<td>Diagnosis is an acknowledgement that I have a real problem</td>
</tr>
<tr>
<td>Not knowing what is wrong makes difficulties hard to cope with</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Transformed, I can deal with that a bit better than being off key out there with not knowing, or understanding what the hell is going on with me really.

BPD has helped me understand what’s happening

Transformation of theme across analytic process

1. Emergent theme: *Diagnosis is an acknowledgement that I have a real problem*

2. Initial subordinate theme: *Accepting BPD into my identity*

3. Revised subordinate theme: *Understanding BPD has helped me makes sense of myself and painful past experiences*

4. Developed superordinate theme: *Making sense of a BPD diagnosis*

In supervision, my supervisor challenged me to use the language of participants rather than using psychological constructs such as ‘normalising’ and ‘identity’. This led to me using first person in my themes. She also highlighted how themes appeared to link together and suggested that I organise them under two superordinate themes. This led to me developing superordinate themes to organise and illuminate the data.

Table 4-Extract from Zoe’s interview

<table>
<thead>
<tr>
<th>Exploratory comments</th>
<th>Interview Extract</th>
<th>Emergent Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not the first time CNS been considered, though not explained about BPD</td>
<td><strong>Interviewee</strong>: Um by a do-uh, um, a consultant, and she knew about my ongoing problems. And she always said, well, she said to me at one assessment, um, try CBT, and if you don’t get on with CBT there are our other options here. And I’m like, “But what other options are here.” And I’m like, “But what other options are there?” And she mentioned the complex needs team, but she said it’s a long way off for you to be able to access help from there.</td>
<td>Lack of transparency about treatment options</td>
</tr>
<tr>
<td>Professionals having ideas about what treatment might be suitable</td>
<td></td>
<td>Not ‘getting on’ with CBT leads to CNS referral</td>
</tr>
<tr>
<td>Lacking explanation</td>
<td></td>
<td>Having to wait for complex needs</td>
</tr>
<tr>
<td>Powerlessness</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
| Having someone onside-pushing for referral | Interviewer: Hmm.  
Interviewee: She was saying years.  
Interviewer: And was it years?  
Interviewee: I think my CBT therapist managed to pull a few strings. I don’t know.  
Interviewer: Hmm.  
Interviewee: maybe in about a couple years.  
Interviewer: Hmm.  
Interviewee: So I knew about this team, um, but when she said that the psychiatrist said, "Years." I’m thinking, "Oh, my gosh." And then CBT didn’t work, and I’m thinking, "Oh, my gosh. What’s gonna happen to me?" | Needing someone to push for the referral to CNS  
Not knowing what will happen to me |
<table>
<thead>
<tr>
<th></th>
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<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowing about CNS before referral</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Scared- not knowing what the future will hold |  
Lack of control |
Appendix I - Credibility check: Use of supervision, workshops and peer review

I completed several credibility checks with my supervisor and research peers throughout this project to ensure I was providing a plausible explanation of the data. This process of explaining my interpretations and having my work reviewed by others influenced the language that I used to describe themes that emerged and led to amendments of my findings. This in turn helped me produce credible and valid findings that best represented the data.

**IPA supervision**
I received monthly supervision from an expert in IPA from the conception of this project. This helped steer the study at all stages and make sure that the work and the stance of the researcher was in line with the core aims and assumptions of IPA. This supervision was more intense over the period of analysis. At this time, I used supervision to present my themes first at a single-case and then cross-case level. During this process I was challenged on how I had linked emergent themes within each account and then across accounts, being careful not to simply group but to think about what the underlying shared meaning was between themes. This led to discussions about the language I was using to describe a theme, making sure that this captured the meaning that linked these experiences. This process felt like a collaborative discussion, where I held the in-depth knowledge of the data and my supervisor guided me to a plausible IPA explanation of this data. These conversations also showed me how important it was to be immersed in the data as this allowed me to respond to my supervisor’s questions and defend my work. My in-depth knowledge of each transcript and the interview (e.g. non-verbal cues and the tone with which participants described their narratives) supported my interpretations when participants’ meaning was more ambiguous. This also helped me identify and cut extracts to best illustrates these themes. For me this whole process was an example of the hermeneutic circle in IPA described by Smith, Flowers & Larkin (2009), where you can only understand a given extract by examining the whole transcript, and you can only understand the whole transcript by looking at its parts.

**IPA workshops**
During this workshop I was able to practice my analytic technique on other transcripts and compare these with other people’s findings. I also used these workshops to begin line-by-line analysis of my transcripts at the initial stage of analysis and receive feedback from an expert in IPA and my peers. The process of line-by-line analysis helped me pay attention to the whole transcript, so as not to cherry-pick data that was interesting to me based on my own knowledge and assumptions. I was encouraged at this stage to remain very close to the data, not adding too much interpretation (e.g. using psychological terminology) and using participants’ own language. This was to safeguard me from putting a theoretical interpretation at this early stage of analysis which could prevent the discovery of novel ideas.

**Peer review of transcript with themes**
A qualitative researcher peer reviewed one full transcript (16.7% of data), which was randomly selected, alongside my single-case analysis and superordinate and subordinate themes for the whole group (cross-case analysis). The aim of this was for her to give feedback on how my themes had developed from the initial transcript to emergent themes and then to themes for the whole group. Through this process she was able to see how I had come to my superordinate and subordinate themes for the group. She also scrutinised whether quotes provided suitable evidence for these themes at single and cross-case analysis. This led to me replacing or extending extracts so that they were better able to capture a theme. Finally, she explored the language I had used, in order to help me produce theme titles that best exemplified participants’ narratives and were impactful for the reader.
Part Two: Literature Review

How does the diagnostic process in Personality Disorder influence how service-users understand their identity and mental health?
Abstract

Background: Psychiatric diagnoses such as personality disorders (PD) have been questioned in terms of their utility for service users, the validity of the construct and the reliability with which they are diagnosed. Furthermore, some service-users and mental health organisations have reported that the term is offensive and stigmatising, and needs to change.

Aims: This literature review aims to establish what the current literature can tell us about the influence of the diagnostic process in PD on how service-users understand themselves and their mental health difficulties.

Method: A systematic search of the literature pertaining to service-users’ experiences of the diagnostic process in PD was undertaken, specifically focusing on self-concept and service-users’ understanding of their mental health. Thirteen papers that met the inclusion criteria were reviewed thoroughly. As most literature used qualitative methods, themes were the most common findings. The researcher looked for common themes across articles whilst assessing their quality and therefore contribution to our current knowledge.

Results: The review highlighted that no studies exist that focus specifically on service-users’ experiences of the diagnostic process in PD. However, themes relating to the research question emerged from exploring service-users’ lived experiences of the label and of accessing services. This included: the impact of a stigmatising label on self-concept; diagnosis leading to participants believing they are untreatable; clinicians withholding the diagnosis; the potential of the diagnosis to explain longstanding difficulties; dismissal of service-user accounts at diagnosis; limited information provided about PD at diagnosis; and struggling to understand one’s identity following diagnosis.

Conclusions: Limitations and methodological differences influenced the strength of conclusions that could be drawn. Further research is needed to explore the current experiences of service-users undergoing the diagnostic process in PD.
1. Introduction

1.1. Study Purpose

A limited number of studies have explored service-users’ perspectives on the impact of receiving a diagnosis of personality disorder (PD). Diversity of focus and methodology within these studies make it difficult to synthesise findings to gather an understanding of how service-users experience the diagnosis. The aim of this narrative literature review is to clarify what current research can offer to our knowledge of the influence of the diagnostic process in PD on service-users’ understanding of their own identity and mental health. Most research best able to answer this research question is qualitative and underpinned by a social constructionist epistemological position (not always explicit). This means that data is analysed from a perspective where knowledge or meaning-making is jointly constructed by people through language in a specific social context and time period (Lock & Strong, 2010). It is therefore essential in this review to first provide a brief outline of the social context in which psychiatric diagnosis, the term PD and the research were constructed.

1.2. Background

1.2.1. Psychiatric diagnosis

A psychiatric diagnosis is a process whereby clinical judgements are made about an individual’s thoughts, feelings and behaviour to determine whether they are ‘abnormal’ and cause them distress (Johnstone, 2014). The fundamental aim of diagnosis, although not always achieved, is to provide a medical (biological) explanation for these symptoms to direct people towards appropriate treatment (Cuthbert & Insel, 2013). However, it is worth noting that recent updates of diagnostic manuals avoid focusing on biological causation, instead providing a descriptive account of diagnoses (Spitzer, 2001). Other purposes of using diagnoses are to provide the following: explanations that remove fault from service-users and their families; predictions about prognosis; a language for clinicians to communicate; a definition to begin research; information about aetiology based on research findings; and to help service-users and
their families to access services (Johnstone, 2014). However, there are significant political and philosophical debates over the reliability, validity and utility of psychiatric diagnoses and the potential impact they have on service-users (Johnstone, 2014; Kinderman, 2005). This has sparked a search for alternative models for understanding mental distress. This includes the work of Anne Cook and Peter Kinderman who provide a psychological understanding of schizophrenia (Cook & Kinderman, 2017) and the work of Lucy Johnstone and colleagues in the development of “Power, Threat, Meaning Framework” for understanding mental distress more broadly (Johnstone et al. 2018).

1.2.2. Reliability and validity of diagnosis in psychiatry

Despite a great deal of research, the majority of psychiatric disorders have no consistent biological cause (Cuthbert & Insel, 2013; Frances & Widiger, 2011; Johnstone, 2014; Krystal & State, 2014). There are limited measures that can reliably delineate psychopathology and biomarkers from ‘normal’ states and that distinguish one disorder from another (Krystal & State, 2014). As a result, psychiatrists have to rely on clinical experience and diagnostic manuals. However, some studies have questioned the accuracy and reliability of these judgements (e.g. Aboraya, Rankin, France, El-Missiry & John, 2006; Goodman, Rahav, Popper, Ginath & Pearl, 1984; Kirk & Kutchens, 1997; Kitamura, Shima, Sakio & Kato, 1989). Diagnostic criteria are developed within culturally specific values and concepts of what is ‘normal’ within Western medicine. Thus, diagnoses may be personal and social judgements rather than ‘scientific’ conclusions.

Arguments have also been raised against the validity of constructs outlined in diagnostic manuals such as The Diagnostic and Statistical Manual of Mental Disorders (5th ed.; DSM–5; American Psychiatric Association, 2013) and the International Statistical Classification of Diseases and Related Health Problems (10th Revision; ICD-10; World Health Organisation, 1992). These diagnostic systems have been described as atheoretical, as they are not based on causality and empiricism but on expert consensus (Sarkar & Duggan, 2010). Though this may
improve agreement between professionals and the reliability with which mental disorders are diagnosed, arguably, this does not improve our understanding of the nature of mental distress. Although medication and psychosocial interventions have been found to reduce distressing symptoms, treatments work across broad diagnostic classes (Cuthbert & Insel, 2013). Therefore, interventions are not precise in treating a specific category of ‘illness’. This leads to the question of whether the diagnostic categories being applied to service-users are accurate constructs. As newer editions of diagnostic manuals have been published, diagnostic categories have increased in number and criteria have become less stringent, which, particularly in America, has led to an inflation in rates of diagnoses (Frances & Widiger, 2011). The ethics of providing such diagnoses, or using a diagnostic system at all, has also been questioned (Johnstone, 2008; Johnstone, 2014; Timimi, 2014).

Service-users are at the centre of this debate, whilst diagnoses are provided by professionals who vary in their comfort of using or disclosing diagnoses (e.g. Sulzer, Muenchow, Potvin, Harris & Gigot, 2016). It is argued below that the specific diagnosis of PD provides an excellent exemplar through which to explore this controversy.

1.2.3. Controversy surrounding ‘Personality Disorder’

According to the DSM–5 (American Psychiatric Association, 2013), PD is an umbrella term describing pathological personality traits alongside a disruption in interpersonal functioning (empathy and intimacy) and the self (identity and self-direction), that are relatively stable across time and not better understood in terms of substance misuse, other general medical conditions, developmental stage or socio-cultural environment. However, diagnostic criteria, and the term PD, have created great controversy.

Sarkark and Duggan (2010) highlighted that there is significant overlap between PD and other diagnoses such as depression, and a lack of understanding of the pathology of maladaptive personality traits. Furthermore, they argued that there is no convincing evidence that PDs are
singular, discernible constructs with a biological underpinning which can be treated. The empirical basis for recent changes to criteria of PD in the DSM 5 has also been heavily criticised (Widiger, 2011; Zimmerman, 2011). This raises questions about the scientific validity of delineating different PD diagnoses. Therapist factors (such as clinical experience and specialist training) and client factors (such as gender) have also been found to impact on the accuracy of diagnosis (Liebman & Burnette, 2013). Being diagnosed with PD does not necessarily lead to specific treatment pathways, which fails to meet the primary purpose of assessing and classifying psychiatric disorders (Sarkark & Duggan, 2010). Finally, both service-users and health professionals have described the term PD as offensive and stigmatising (Stalker, Ferguson & Barclay, 2005). The recent Consensus Statement for ‘People with Complex Mental Health Difficulties who are diagnosed with a Personality Disorder: “Shining lights in dark corners of people’s lives”’ (Lamb, Sibbald & Stirzaker, 2018), claims that the diagnosis is ‘broken’ and needs replacing.

1.2.4. Impact of diagnosis on service-users

Despite the potency of diagnosis in the West, there has been limited research into the impact of providing a diagnosis to service-users (Johnstone, 2014). As one of the fundamental purposes of providing a diagnosis is to provide an explanation of symptoms, the first aim of this literature review is to explore what is already known about the impact of the diagnostic process in PD on service-users’ understanding of their mental health. Receiving a diagnosis of a severe mental health problem, such as schizophrenia, is believed to have an impact on identity (Hayne, 2003; Yanos, Roe & Lysaker, 2010). Therefore, a secondary aim of this current review is to assess what is known about the impact of the diagnostic process in PD on identity. According to Identity Process Theory (IPT; Breakwell, 1986, 1988, 1992, 1993, 2001; Vignoles et al., 2002a), identity is structured in terms of its content and the value of identity components. When a person is faced with new information that may relate to their identity, processes of assimilation/accommodation and evaluation occur in order to make room for and
make sense of this new understanding. Diagnosis is a significant event which requires service-users to re-evaluate their identity (Jaspal & Breakwell, 2014). Therefore, this review aims to address the following research question: how does the diagnostic process in PD influence how service-users understand their identity and mental health?

2. Method

2.1. Sampling

A systematic search of the literature was completed in May 2017 within Psychology Cross Search to draw all relevant literature from the following databases: Medline, PsychInfo and Psychology and Behavioural Science collection. An initial survey of the literature identified a paucity in relevant articles and highlighted difficulties identifying articles through searches. Therefore, initial search terms to explore the research questions were trialled in different combinations within the databases, to ascertain which of these gathered the most relevant literature. The keywords that yielded the highest number of relevant hits were: “impact” OR “effect” OR “influence” OR “experience” OR “consequence” AND “diagnosis” OR “diagnostic process” OR “receiving diagnosis” OR “diagnosis delivery” AND “personality disorder” OR ‘complex needs” OR “borderline personality disorder” OR “emotionally unstable personality disorder” AND “identity” or “self concept” or “understanding”. Additional studies were found by performing a fingertip search of references in articles initially found and through an additional search on Google Scholar. No specific time scales or methodological requirements were applied to searches in order to capture all relevant research. To ensure a baseline level of quality, only peer-reviewed and published papers were included in this review.

2 Start dates/ coverage of databases: Medline (1966), PsychInfo (coverage 1597–present, with comprehensive coverage from the 1880s), Psychology and Behavioural Science collection (coverage from 1930s)
2.1.1 Screening process

This search generated a large number of hits (741). Titles and abstracts of studies were reviewed by the researcher (see Fig.1. for the screening, eligibility and inclusion process undertaken by the researcher). During this initial screening, papers were excluded if they were considered to be unrelated to the topic, duplicates, reviews of articles or books, were not written
in English or were inaccessible within an hour’s search. The remaining 43 articles were then reviewed in full. The inclusion criteria for this review was the following: there was a focus on the impact of PD diagnoses or the diagnostic process of PD and findings related to identity or a person’s understanding of their mental health. Studies were excluded at this stage for the following reasons: the sample did not include participants who had experienced being diagnosed with PD and there was a lack of focus on the diagnostic process in PD, identity or understanding of mental health. This left 13 records that met the inclusion criteria.

2.2. Data extraction and analysis

All included articles were read thoroughly by the researcher in order to gain familiarity with the literature. For each study, the following data was collected and summarised in Table 1: authors’ names, year of publication, location of recruitment/ cultural context, sample description, aim, methodology/ analysis employed, summary of main findings. This allowed for easy comparisons of the data. Summaries of findings were then read in depth to identify themes (the most commonly reported finding) across the literature and were considered in light of the limitations of the study from which they came. Note that only findings relating to the research question were included into the analysis.

2.3. Quality evaluation

The researcher used a quality checklist adapted from Spencer, Ritchie, Lewis and Dillon (2003) to evaluate qualitative research. Each paper was evaluated using the checklist as a guide to criteria for evaluation. A table comparing studies against this framework can be found in the appendix. The checklist directed the researcher to consider: clarity of background, rationale, sampling, methodology, data collection and analysis of findings that displays rigour and credibility and allows evaluation of the study; evidence of self-reflexivity and discussion of study limitations and ethical considerations; the use of quotes as evidence and clear delineation of findings; and the quality and flow of writing style. The Critical Appraisal Skills Programme
for cohort studies (2018), was used to identify key strengths and weaknesses of quantitative studies. A rating system was not adopted because of the challenges of the comparing the quality of quantitative, qualitative and mixed method designs. Key strengths and weaknesses from each study have been summarised in Table 2.

Studies were not eliminated as a result of this process, the emphasis was upon evaluating the credibility of each study, the methodology and the contribution made to our understanding of the topic. This process also helped identify potential gaps in our current knowledge of the experiences of those being diagnosed with a personality disorder.

3. Results

3.1. Description of the studies

3.1.1. Methodologies

Thirteen studies were included into the analysis. The majority of these utilised different qualitative methods (unspecified qualitative analysis, thematic analysis, interpretative phenomenological analysis) to explore lived experiences of service-users (N=10). These were not specifically focused on experiences of the diagnostic process but did provide findings that are relevant to understanding the experience of diagnosis and its impact. Two papers used quantitative analysis (an online survey that reported descriptive statistics and self-administered Likert Scale questionnaires), and one used mixed methods to evaluate both qualitative and quantitative information.

3.1.2. Participants

As 11 of these studies used qualitative methods, this literature review will not focus on sample size other than for the quantitative studies included. The rationale for this is that the nature of explorative research, generally speaking, is to gather a comprehensive understanding of a phenomenon from a small number of participants. However, for a brief overview, the total number of service-users interviewed across the qualitative studies included was 119 (91
female). The total number of participants included in the quantitative studies was 176 (147 female) and in the mixed method study was 50 (30 female). Therefore, data from a total of 345 (268 female) participants is explored within this review. Research investigating whether there are sex differences between rates of PD are inconsistent, with some studies indicating no differences and others reporting specific differences between PD diagnoses (Gawda & Czubak, 2017). However, rates in the UK are estimated to be equal in a recent screening survey (McManus, Bebbington, Jenkins & Brugha, 2016). Eight of the studies included were conducted in the UK whilst the other five were carried out in other Western countries (Australia, USA and Canada). The majority of samples included only individuals with a diagnosis of PD or who identified as such (n=12), predominantly those diagnosed with BPD (n=9), and one study looked more broadly at individuals with clinical disorders that involve emotion dysregulation including personality disorders. Eleven studies recruited service-users from health services. One of these also recruited from voluntary sector organisations and another used online/published written personal accounts of individuals diagnosed with BPD. The final two studies recruited from mental health consumer networks and/or voluntary sector organisations. Ten of the studies were published between 2013 and 2016 (Median date=2014; seven in the UK), and three were published before this between 1999 and 2007. Further demographic information such as age and ethnicity were not supplied by all articles and so cannot be summarised here.
<table>
<thead>
<tr>
<th>Authors</th>
<th>Origin</th>
<th>Sample</th>
<th>Method and Analysis</th>
<th>Main Relevant Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bilderbeck, Saunders, Price &amp; Goodwin (2014)</td>
<td>UK</td>
<td>N=28 diagnosed with mood instability disorders (18 female, 10 male, age range 20-58 years, 24 White British, only 5 participants with PD: 3, BPD; 2, PD not specified). CMHTs, a specialist mood disorders clinic and Complex Needs Service.</td>
<td>Unstructured interviews with questions that were developed with each interview. Observed 79% of assessments prior to interview. Used thematic analysis (framework technique) using software to explore frequency of themes.</td>
<td>Diagnosis provides containment, validation, recognition of difficulties, removes blame and personal responsibility for previously harmful behaviours. Difficulty communicating difficulties within time pressure, and in response to ambiguous questions. Participants felt clinicians focused too much on abuse history. Mostly not feeling informed (about stigma) or involved in treatment decisions. Professionals discredited personal accounts of participants. PD as a dismissive diagnosis with little utility. Diagnosis being concealed from participants.</td>
</tr>
<tr>
<td>Black, Thornicroft &amp; Murray (2013)</td>
<td>UK</td>
<td>N=10 service-users diagnosed with PD (2 female, 8 male) Secure (forensic) services</td>
<td>IPA- unstructured interviews</td>
<td>Personality causes people with PD to commit crimes. PD diagnosis reinforces that a person is ‘bad/ fundamentally wrong’, even from the wording.</td>
</tr>
<tr>
<td>Courtney &amp; Makinen (2016)</td>
<td>Canada</td>
<td>N=23 adolescents diagnosed with BPD (18 female, 5 male, mean age 16) Acute (inpatient) adolescent mental health services.</td>
<td>Likert questionnaire about aspects of receiving a diagnosis.</td>
<td>Mixed response to question asking whether participants were confused following BPD diagnosis. Responses indicated that service-users did not feel ‘better about themselves’ after receiving a diagnostic explanation.</td>
</tr>
<tr>
<td>Fromene &amp; Guerin (2014)</td>
<td>Australia</td>
<td>N=5 indigenous Australian people diagnosed with BPD (4 female, 1 male, age range 27-47 years). Adult Mental Health services.</td>
<td>Yarning- unstructured, informal and in-depth conversations. Analytic method not named.</td>
<td>A wish for more information about the diagnosis. Service-user expressed a wish to reject the label as not fitting with own experience. Diagnosis helpful: connect with others, not alone, know what is wrong.</td>
</tr>
<tr>
<td>Gillard, Turner &amp; Neffgen (2015)</td>
<td>UK</td>
<td>N=6 service-users referred to Specialist PD Services and identified as having a PD (3 female, 3 male, age 26-65, 5 identified as White, 1 identified as ‘other’)</td>
<td>Semi-structured interviews, guided by interview schedule around recovery. Thematic and framework technique for analysis- conducted</td>
<td>Increased awareness and acceptance of self, in part supported by better understanding that can come with diagnosis and treatment. Ambivalence towards the diagnosis: aids understanding but isolates service-user from the outside world because of stigma. Feedback from professionals about diagnosis reduced service-users hopes for recovery.</td>
</tr>
</tbody>
</table>
by researcher, clinicians and trained researcher with lived experience

<table>
<thead>
<tr>
<th>Reference</th>
<th>Country</th>
<th>Sample Description</th>
<th>Methodology</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Horn, Johnstone &amp; Brooke (2007)</strong></td>
<td>UK</td>
<td>N=5 service-users diagnosed with BPD (4 female, 1 male, 23-44 years) Mental Health services</td>
<td>IPA- unstructured interviews</td>
<td>Knowledge as power- for some diagnosis provided containment (from expert knowledge), a path to follow, clarity. All provided with limited information or explanation initially and tended to be negative. Clinician as expert and service-user as not knowing. Uncertainty about what the diagnosis meant- simplistic and less useful for some. Little meaning and not matching service-user own experiences. Searched internet for more information and mainly negative. Perception of self as a ‘trouble maker’ ‘nutter’ as a result of diagnosis. Diagnosis as rejection- an implicit or explicit judgement about the person. Diagnosis about not fitting- not fitting into a clear category. Hope and the possibility of change- mixed feelings about hope.</td>
</tr>
<tr>
<td><strong>Lawn &amp; McMahon (2015)</strong></td>
<td>Australia</td>
<td>N= 153 people diagnosed with BPD (129 female, 18 male, 6 gender not provided, 18+) Mental Health consumer networks</td>
<td>Online survey exploring experiences of contact with services. Descriptive statistics and qualitative responses captured.</td>
<td>Significant association found between the length of time that participants had been diagnosed with BPD and the adequacy of the diagnostic explanation (i.e. information provided by clinicians met personal requirements for understanding BPD): ( \chi^2 (4, n = 106) = 9.54, P = .049 ). Descriptive statistics: 45% of service-users who received their diagnosis over 5 years ago reported an inadequate diagnostic explanation of BPD compared to 27.5% of those diagnosed within 1-5 years and 27.5% of those diagnosed within 1 year of data collection. 37.8% of the total sample reported having been given no explanation of BPD 19.3% reported that although they had received an explanation, they had not understood it.</td>
</tr>
<tr>
<td><strong>Lovell &amp; Hardy (2014)</strong></td>
<td>UK</td>
<td>N= 8 service-users diagnosed with BPD (all female, age range 24-55 years, predominantly White British, 1 White ‘other’ and 1 White and Black Caribbean (mixed)) Inpatient Secure (forensic)</td>
<td>IPA- unstructured interviews</td>
<td>Diagnosis given against their will- inescapable diagnosis. Impact on identity- BPD taking away part of identity, but also contributed to by secure environment. BPD is who I am- an explanation of own behaviour and experiences (3 people). Gratitude for making sense of them. Confusion around identity as a result of being given diagnosis.</td>
</tr>
<tr>
<td>Morris, Smith &amp; Alwin (2014)</td>
<td>UK-North west</td>
<td>N=9 service-users diagnosed with BPD with significant contact with services (7 female, 2 male, 31-47 years, all had other diagnoses, 8 White British, 1 British other) Voluntary sector (not specified)</td>
<td>Thematic analysis of data collected from semi-structured interviews, including open and closed questions regarding experiences of services.</td>
<td>The diagnostic process (how they were told) influences how service users feel about BPD. Being given diagnosis in insensitive manner with poor opportunity for discussion meant less positive about label. Limited understanding of the label due to poor information given. Valued all information given. Optimism about the effectiveness of treatment and likelihood of recovery found to impact on how service-users perceive the diagnosis. Being defined by the label- now seen as difficult rather than unwell.</td>
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<tr>
<td>Nehls (1999)</td>
<td>USA</td>
<td>N=30 service-users diagnosed with BPD (all female, low economic status) Community/ outpatient and inpatient unit.</td>
<td>IPA though unclear from methodology and sample size. Unstructured interviews.</td>
<td>Living with the label- being labelled not diagnosed. Clinicians have preconceived ideas and treat differently. Feeling like the criteria fits but not wanting the label because of subsequent treatment. No benefit of guiding treatment. Reluctant to disclose diagnosis to others.</td>
</tr>
<tr>
<td>Ramon, Castillo &amp; Morant (2001)</td>
<td>UK</td>
<td>N=50 service-users diagnosed with PD (30 female, 20 male, ages 18-74, 44 English, 1 Scottish, 1 Irish, 1 Romany, 1 Australian, 1 Pakistani, 1 Spanish) Inpatient unit, voluntary organisations and an advocacy group in Colchester</td>
<td>Mixed methods: semi-structured interviews with service-user researchers with the same diagnosis, demographic data and diagnostic information was also collected. Descriptive statistics and an unnamed qualitative analysis.</td>
<td>Not knowing what the label means, professionals not knowing what the label means, I have no identity. Conclusions- diagnosis has negative consequences for self-concept. - 26% didn’t know what the diagnosis label meant -18% labelled as bad -6% means I have no identity Different from own explanations of MH.</td>
</tr>
<tr>
<td>Richardson &amp; Tracy (2015)</td>
<td>UK</td>
<td>N= 8 service-users who had all self-diagnosed with Bipolar Affective Disorder before being diagnosed with BPD (White female, 27-56 years of age). Secondary Care unspecified</td>
<td>Semi-structured interviews explored the differences between the diagnoses in terms of service provisions and experiences. Qualitative analytic method unclear. Software used.</td>
<td>Delivery of diagnosis: not having enough time to discuss diagnosis, feeling abandoned, dismissed, judged, not leading to treatment, withholding diagnosis, staff lack of knowledge about the diagnosis. Potential for diagnosis to make sense and contextualise life-long difficulties and give sense of hope when given time to discuss what is was, why it occurs, differences between people and how it can be managed. Stigma and blame: personal fatalism, receiving diagnosis could help remove self-blame, not alone and lead to better self-understanding</td>
</tr>
<tr>
<td>Sulzer, Muenchow, Potvin, Harris, &amp; Gigot (2016).</td>
<td>USA</td>
<td>N=64 (N=22 primary written accounts from past or present service-users diagnosed with BPD, N=10 interviews with service-users, N= 32 interviews with health care professionals)</td>
<td>Semi-structured interviews with mental health care providers and experts were compared with patient interviews and triangulated with primary patient-written accounts. Grounded theory approach was used to explore causal pathways between clinical practice and service-users’ responses.</td>
<td>Clinicians reported a tendency to withhold diagnosis in favour of axis 1 disorder or euphemism due to concerns about stigma on participants. This matched many service-user experiences of being diagnosed i.e. finding out when changing provider or requesting medical notes. Service-users and accounts showed acceptance of the diagnosis. Some expressed a sense of understanding, relief and belonging following receiving their diagnosis. Service-users expressed wanting to receive their diagnosis and have stigma discussed with them. Strategies used by clinicians to avoid giving diagnosis created confusion in clients and limited their agency in their care and accessing treatment.</td>
</tr>
<tr>
<td>Authors</td>
<td>Key Strengths</td>
<td>Key Limitations</td>
<td></td>
<td></td>
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<td>-------------------------------</td>
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</tbody>
</table>
| Bilderbeck, Saunders, Price & Goodwin (2014) | - Detailed explanation of analysis  
- Quality control checks explained  
- Follow ups provided to take into account mood fluctuations of service-user's responses  
- Individually tailored interviews.  
- Some consideration of researcher’s assumptions on data (but not how these were managed) | - Due to the number of participants included and the different diagnoses given to service-users, it was unclear what themes were most relevant to those diagnosed with a personality disorder. This was despite efforts of the authors to provide quotes from all client groups to each theme.  
- Some participants had multiple diagnoses and it was unclear whether the interview was focused on diagnoses they had received throughout their lives or the most recent one.  
- Unclear about use of thematic software.  
- Epistemological position not named explicitly  
- Unclear when sample received their diagnoses. |
| Black, Thornicroft & Murray (2013) | - Drawing on relevant identity literature  
- Input from service user group Emergence to develop interview schedule  
- Sensitivity to participants’ experiences of the interview and covering sensitive issues. | - No evidence of self-reflexivity  
- Credibility checks not discussed thoroughly  
- Difficult to generalise outside of forensic setting  
- Unclear when sample received their diagnoses |
| Courtney & Makinen (2016) | - Sample and service context clearly defined | - Unclear what responses or significant findings meant because of ambiguous wording  
- Lack of qualitative data about experience  
- Not a standardised tool and questionable internal consistency  
- No control or comparison group  
- Large range in scores for each item of questionnaire  
- Ethical implications of diagnosing young people with BPD- not advised by diagnostic manuals due to effects of maturation  
- Small sample for quantitative study. |
| Fromene & Guerin (2014) | - In depth analysis that was culturally sensitive | - Small culturally specific sample that is difficult to generalise to other cultures/settings  
- Analysis unnamed and unclear how themes were derived  
- No evidence of self-reflexivity  
- Epistemological position not named  
- Unclear when sample received their diagnoses |
<table>
<thead>
<tr>
<th>Study</th>
<th>Strengths</th>
<th>Limitations</th>
</tr>
</thead>
</table>
| Gillard, Turner & Neffgen (2015) | - Service-user researcher involvement  
- Unusual but clearly explained methodology and analysis  
- Wider context provided around PD  
- Suitable quotes provided as evidence | - Unclear what the nuances were between participants as phenomenonological techniques were not used  
- Generalisability: small sample from one service so participants’ experiences likely reflect the organisation of the one service  
- Focuses more on recovery as opposed to the diagnostic process itself  
- Limited self-reflexivity around own assumptions and epistemological position not explicitly named  
- Unclear when sample received their diagnoses |
| Horn, Johnstone & Brooke (2007) | - Provides detailed context for research  
- Evidence of self-reflexivity- discussion of the role of the researcher and potential impact of own beliefs on research.  
- Names epistemological position  
- Credibility checks provided: participants’ feedback on themes and independent researcher analysing one transcript  
- Clear analytic process and references provided | - Unclear when sample received their diagnoses, though likely before provision and policy changes in the UK |
| Lawn & McMahon (2015) | - Clearly defined sample  
- Clear rationale for study provided | - Multiple comparisons performed without correction  
- Generalisability: relatively small sample for quantitative research, biased towards females  
- Volunteer bias: those that had strong views or negative experiences of services more likely to respond to the questionnaire  
- Service-users identified as having BPD, so unclear for sure whether they had received a diagnosis |
| Lovell & Hardy (2014) | - Clear rationale and background information  
- Sample clearly defined  
- Clear analysis  
- Credibility checks provided  
- Self-reflexivity demonstrated | - Difficult to generalise outside of forensic setting  
- Epistemological position not explicitly named  
- Unclear when sample received their diagnoses |
<p>| Morris, Smith &amp; Alwin (2014) | - Reflective diary kept during analysis and Yardley’s (2000) | - Not all of the sample were diagnosed following significant policy and provision changes in England |</p>
<table>
<thead>
<tr>
<th>Framework followed to ensure credibility</th>
<th>Not recruited from health services which means the context of services is not present in the analysis and findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Service-user input into themes after analysis.</td>
<td>Loss of nuances between participants’ experiences because of use of thematic analysis as opposed to IPA</td>
</tr>
<tr>
<td>Corroboration on two transcripts and negative case analysis.</td>
<td>Epistemological position named</td>
</tr>
<tr>
<td>Epistemological position named</td>
<td>Clear rationale and references for analysis</td>
</tr>
<tr>
<td>Clear quote evidence provided that gives service-user participants a voice throughout the findings.</td>
<td>Impossible to have a comprehensive understanding from 30 interviews within a publication. This is contrary to IPA methodology</td>
</tr>
<tr>
<td>Nehls (1999)</td>
<td>No evidence of nuances or contradictions between or within participants’ accounts</td>
</tr>
<tr>
<td>Credibility checks include feedback from other researchers and participants.</td>
<td>Limited self-reflexivity demonstrated</td>
</tr>
<tr>
<td>Clear quote evidence provided that gives service-user participants a voice throughout the findings.</td>
<td>No discussion of how the differing biases of researchers influenced findings</td>
</tr>
<tr>
<td>Ramon, Castillo &amp; Morant (2001)</td>
<td>No reflections on limitations</td>
</tr>
<tr>
<td>Service-user involvement in data collection and analysis of themes</td>
<td>Unclear how credibility checks impacted on final article</td>
</tr>
<tr>
<td>Highlighted the importance of service-user involvement and training to be involved in research.</td>
<td>Unclear when sample received their diagnoses, though this would have been before provision and policy changes in the UK</td>
</tr>
<tr>
<td>Demographic data considered in analysis</td>
<td>Data collection unclear i.e. who conducted the interview (author or member of research team)</td>
</tr>
<tr>
<td>Richardson &amp; Tracy (2015)</td>
<td>Analysis process unclear- i.e. how thematic analysis software was used.</td>
</tr>
<tr>
<td>Sample clearly defined</td>
<td>Participants had not all experienced a diagnosis of bipolar affective disorder but were self-diagnosed prior to receiving BPD diagnosis. Therefore, could be argued that they were not able to comment on the differences between these diagnoses.</td>
</tr>
</tbody>
</table>
| Useful clinical implications | No self-reflexivity: epistemological position not provided or potential impact of researcher’s assumptions on
Provided hypotheses for a qualitative approach which suggests the intention may not to have been exploratory. Unclear when sample received their diagnoses.

Sulzer, Muenchow, Potvin, Harris, & Gigot (2016)
- Shares both clinician and service-user perspectives
- Rationale for triangulation provided
- Saturation point clearly defined
- Unclear how accounts were ‘triangulated’ with service-user participant accounts
- Does not state epistemological position
- No self-reflexivity on researchers’ own assumptions and the impact
- Unclear when sample received their diagnoses

3.2. Synthesis of findings

A stigmatising diagnosis: a rejection and judgement of one’s personality that can reinforce negative self-concepts

Eight of the studies included in this review found that service-users experienced the effects of the stigma associated with being labelled or diagnosed as having a PD (Bilderbeck, Saunders, Price & Goodwin, 2014; Black, Thornicroft & Murray, 2013; Gillard, Turner & Neffgen, 2015; Horn, Johnstone & Brooke, 2007; Morris, Smith & Alwin, 2014; Nehls, 1999; Ramon, Castillo & Morant 2001; Richardson & Tracey, 2015). Furthermore, some of these studies reported that service-users perceived the diagnosis to reinforce existing negative self-concepts.

An early large scale qualitative study exploring people’s lived experience of BPD (Nehls, 1999) found that many service-users felt they were labelled rather than diagnosed. That is, although many believed they fitted the diagnostic criteria, they felt the label led to professionals having negative preconceptions and avoiding them rather than treating them. Researchers utilised interpretive phenomenological analysis (IPA) at a time when this was a relatively new methodology to explore data. As the aim of this type of analysis is to gain a comprehensive understanding.
understanding of the lived experiences of a small sample (N= 4-10; Smith, Flowers & Larkin, 2009), it is difficult to conceive how a rich analysis would have been possible with 30 participants. This is noticeable within the findings with little evidence of contradictions between participants’ narratives. Although the methodology is clearly described and analysis was cross-checked with other members of the research team for credibility, there is no evidence of self-reflexivity and consideration of the impact of the researchers’ values and motives. This is an essential element of qualitative research as it allows the reader to evaluate the credibility of data interpretations (Finlay & Gough, 2008). This is a limitation of many of the qualitative studies reviewed.

Ramon, Castillo & Morant (2001) undertook a mixed methods project jointly led by service-user researchers with lived experience of a PD diagnosis. They found that 18% of service-users reported feeling labelled as ‘bad’ as a result of the diagnosis. However, as methodology was not clearly described and an interview schedule was not provided, it was difficult to decipher how this figure was calculated i.e. whether this was a self-generated comment made by participants or an answer to a direct question from researchers. Many services-users shared negative self-concepts within interviews, including ideas of being ‘worthless’, ‘a burden’, ‘hopeless’ and ‘no good’ (pg. 9). The authors argue that diagnosis has negative consequences for identity, but it was unclear how data was collected or how these conclusions were derived. For example, it is possible that participants’ negative self-concepts predated the diagnosis.

In Horn, Johnstone & Brooke’s (2007) IPA study, service-users similarly reported ideas that the label of BPD meant that they were a ‘trouble-maker’. Furthermore, they perceived the diagnosis as a rejection of them; both an implicit and explicit judgement of them and their personality. Unlike Nehls (1999), this study showed strong evidence of self-reflexivity, with the researchers naming their epistemological position and a priori beliefs about BPD. The
authors also provided details about the wider context of BPD and how they had ensured credibility during their work.

In a recent thematic analysis performed by Morris, Smith and Alwin (2014), participants similarly described feeling defined by the label of BPD. The consequence of this was being viewed by others as difficult rather than unwell. This study had many strengths including: providing a clear rationale for the methodology, stating epistemological position, collaborating with service-users to develop the interview schedule and by completing several credibility checks. However, this was a relatively small sample for a thematic analysis of a semi-structured interview (N=9), which impacts on generalisability of findings. Despite being a recent publication, not all participants had received their diagnosis before 2009 and some potentially before 2003. This is an important factor as will be discussed, many changes have occurred to service provisions and policy following these time-periods, which may impact on service-user experiences of a PD diagnosis.

Gillard, Turner and Neffgen (2015), who recruited from a specialist PD service, found that service-users were ambivalent about receiving a diagnosis. They described feeling isolated from the outside world due to the stigma surrounding PD. However, some shared that it helped improve self-esteem. Although this was a small scale sample (n=6) recruited from one specific service, this study shows high rigour and credibility due to the clearly defined method and sample, service-user researcher involvement, some evidence of self-reflexivity (e.g. reflecting on how different researchers approached the data), and consideration of the wider context around PD.

Bilderbeck, Saunders Price and Goodwin (2014) performed a qualitative study exploring the experiences of those diagnosed with disorders characterised by emotional instability (including PD). Within this study some participants reported feeling ill-informed about the stigma
surrounding their diagnosis. The sample did not exclusively include those with a PD diagnosis (5 out of 28 participants) and those with PD also reported co-morbid diagnoses. It was therefore unclear how many participants diagnosed with PD specifically reported this experience and whether it related to their experiences of PD or another diagnosis.

In an interesting study, Richardson and Tracey (2015) explored the experiences of service-users who had self-diagnosed with Bipolar Affective disorder (BPAD) before later being diagnosed with BPD. Semi-structured interviews gathered service-users’ opinions on the similarities and differences between the two disorders in relation to a number of different factors including stigma and attitudes. Service-users understood BPAD to elicit sympathy, being viewed as uncontrollable as a result of the media helping to deconstruct stigma. In comparison, service-users described how stigma and blame about BPD were reinforced by staff attitudes, a lack of sympathy, a label that implies blame, a sense of being responsible for being unwell and lack of information about the diagnosis. Seven of the 8 participants felt that whereas those diagnosed with BPAD might be perceived as ‘victims’, people diagnosed with BPD were perceived as ‘perpetrators’ and responsible for their own problems. This was viewed to create shame and guilt and increase self-loathing. This indicates that other people’s perceptions and the way this diagnosis is explained to service-users impacts on the way they view themselves. Participants shared that when time and care was taken to explain BPD, this diagnosis could reduce self-blame and increase self-understanding. However, the analytic process using thematic analysis software was unclear making it difficult to understand how final themes were delineated. There was also no evidence of self-reflection, specifically around the choice of topic areas that structured the interview. Similar to other studies, this affects the reader’s ability to judge the plausibility of themes. Furthermore, participants did not actually have experiences of being diagnosed with BPAD and so it may have been challenging for them to compare these diagnostic processes.
Black, Thornicroft & Murray (2013) described findings whereby receiving a diagnosis of PD had a reinforcing impact on service-users’ ideas about themselves. These researchers interviewed service-users within forensic services which therefore had the added element of participants having received both a diagnosis of PD and having offending histories. Through IPA they identified a process whereby service-users redefined their identity based on the offences they committed and upon receiving a diagnosis of PD. Service-users reported internalising negative understandings of past offences and the diagnosis, often describing themselves as bad people. The term PD itself was viewed to reinforce this, suggesting something fundamentally wrong with personality. Furthermore, service-users described simultaneously having pre-existing negative self-conceptions (due to their offending histories) which were then reinforced by the term PD, whilst holding ideas that they committed offences because they had a PD, i.e. that the diagnosis of PD was an explanation for their offending behaviour. As with many other studies, there was a lack of detail regarding credibility checks and poor evidence of self-reflexivity. It may also be difficult to generalise these findings beyond forensic settings due to the added stigmatising factor of participants having offending histories.

_Hopes for recovery: an untreatable diagnosis_

Five studies indicated that service-users had understood from the diagnostic process that PD is a life-long condition with limited treatment available (Gillard, Turner & Neffgen, 2015; Horn, Johnstone & Brooke, 2007; Morris, Smith & Alwin, 2014; Nehls, 1999; Richardson & Tracey, 2015).

Service-users interviewed by Nehls (1999) felt the diagnosis did not guide treatment. Richardson and Tracey (2015) found that some service-users were told by professionals that there was nothing services could do to support them following their diagnosis. This finding was supported by Gillard, Turner and Neffgen (2015) who found that the feedback service-
users received about PD reduced their expectations for recovery. In Horn, Johnston and Brooke (2007), some service users explained how the label of BPD suggested that the difficulties they were experiencing were permanent and unamenable to change which reduced people’s hope for their future. Service users interviewed in Morris, Smith and Alwin (2014) similarly highlighted the importance of optimism within the diagnostic process. Whether service users were told there was hope for recovery impacted on how they felt about the diagnosis of BPD. Although this experience has been captured in several studies, it is possible that sampling may have impacted the strength of this finding. As these qualitative studies rely on service-users volunteering their time, it is possible, as with much research, that those who have views that they would like to share are more likely to volunteer. Therefore, it may be that those who had negative experiences of the diagnostic process volunteered and more neutral views are lost. In addition to this, it was unclear from all these articles when service users received their diagnosis.

*Withholding a diagnosis of personality disorder to protect service-users from a stigmatised label*

Three studies indicated that service-users had experienced their diagnosis being withheld or concealed from them (Bilderbeck, Saunders, Price & Goodwin, 2014; Richardson & Tracey, 2015; Sulzer, Muenchow, Potvin, Harris, & Gigot, 2016). Bilderbeck, Saunders, Price and Goodwin (2014) and Richardson and Tracey (2015) mentioned the frustration that one participant in each of the studies had experienced as a result of having their diagnosis withheld over many years. However, these are the reported experiences of two individuals which makes these findings difficult to generalise. Sulzer et al. (2016) carried out a qualitative study specifically exploring clinicians’ decisions to provide or withhold a diagnosis of BPD and the impact this has on service-users. Using a grounded theory approach in which interviews with service-users and clinicians, and public written personal
accounts of those diagnosed with BPD were triangulated, the researchers found that clinicians tended to prefer withholding a diagnosis of BPD in favour of euphemisms or Axis 1 conditions (DSM-5). Clinicians justified this approach because of concerns over service-users’ reactions to the diagnosis and wanting to protect them from stigma. Only 9% of clinicians reported that they always provide a diagnosis, indicating that this was important in terms of their professional duties and informed consent to treatments. In line with this, many service-user accounts (published and given within interviews) described how they had found out their diagnosis when they switched health providers or requested medical notes. Contrary to the beliefs of clinicians, service-users expressed a desire to receive this diagnosis and discuss stigma. The strategies used by clinicians to avoid providing a diagnosis led to service-users feeling confused. Sulzer et al. (2016) argued that withholding this diagnosis limited service-users’ self-agency in their care. Although Sulzer et al. (2016) were clear about their methodology and analysis, there was no evidence of self-reflexivity regarding the impact of their own status and values on analysis.

Knowledge of the diagnosis has the potential to empower, contain, validate and make sense of difficulties

In seven of the studies included in this review, findings arose relating to whether the diagnostic process presented an opportunity to provide an explanation for people’s difficulties and reduce self-blame (Bilderbeck, Saunders, Price & Goodwin, 2014; Courtney & Makinen, 2016; Gillard, Turner & Neffgen, 2015; Horn, Johnstone & Brooke, 2007; Lovell & Hardy, 2015; Morris, Smith & Alwin, 2014; Richardson & Tracey, 2015). Moreover, two of these studies stressed the importance of diagnosis delivery on the impact of the diagnosis on the service user (Morris, Smith & Alwin, 2014; Richardson & Tracey, 2015).

In Bilderbeck, Saunders, Price and Goodwin (2014), service-users found diagnosis validating and containing. It provided recognition of the person’s difficulties and helped remove blame
or personal responsibility for harmful behaviours. Although some of the evidence for this finding was from individuals diagnosed with PD, it was unclear whether this was a view held by all with this diagnosis within the sample. However, other smaller scale studies have reported the potential utility of the diagnosis. For example, native Australian subjects interviewed in Fromene and Guerin (2014) expressed how a diagnosis of BPD could be helpful in connecting with others, reducing feelings of isolation and providing an explanation for current difficulties. Although this is sample is small and culturally specific, these findings were reflected in other study’s themes. Gillard, Turner and Neffgen (2015) who collected data from service-users recruited from a specialist PD service, found that although many were ambivalent about receiving a diagnosis, people found information provided within the diagnostic process and by the diagnosis itself, helpful in explaining some of their experiences and in improving self-esteem. Similar concepts arose in Lovell and Hardy (2015) who found that some service-users interviewed in forensic services described how BPD had become an integral part of their identity as it helped explain some of their experiences. Although difficult to generalise these findings to other settings, this study showed high rigour through being transparent about the researchers’ own assumptions, detailing credibility checks. In Sulzer et al. (2016), contrary to the predictions of service providers, many service-users expressed relief upon hearing their diagnosis, viewing it as crucial to accessing treatment. Despite clinicians' concerns that service-users needed protecting from this diagnosis and the stigma associated, most service-users in this study found diagnosis useful.

In a quantitative study, Courtney and Makinen (2016) developed a Likert-style questionnaire to explore adolescent service-users’ views on having received a diagnosis of BPD one month after their diagnosis session. The researchers analysed responses to a series of statements to explore whether the mean response to each statement was significantly different from a neutral response (i.e. 4 on scales rated 1-7). Two significant findings indicated that service-users
believed that BPD was an accurate diagnosis and that there was not a better way to explain their symptoms. However, another significant finding indicated that the majority of service-users provided a negative response to the following statement: ‘Hearing my symptoms being described as part of “borderline personality disorder” has made me feel better about myself’. Contrary to other studies within this theme, these findings may suggest that while these adolescents felt that a diagnosis of BPD was an accurate explanation of their symptoms, it did not improve how they evaluated themselves. However, this was not a standardised measure and had questionable levels of internal consistency. Furthermore, the wording of some questionnaire items was ambiguous which could have led to different interpretations of the questions. The absence of control or comparison groups within the study does not allow us to distinguish whether these results reflect the impact of receiving a diagnosis in general or specifically BPD. There was a small sample recruited from one service and therefore it is difficult to generalise findings. There are also ethical implications, though discussed by the authors, of diagnosing people under the age of 25 with a personality disorder. For instance, behaviours seen in adolescence may reduce with maturation and therefore providing an early diagnosis may prove to be inaccurate. However, some argue that there is evidence of a subgroup of individuals for which these diagnostic traits remain stable across time (Miller, Muehlenkamp & Jacobson, 2008).

Horn, Johnstone and Brooke (2007) found mixed responses within their sample in response to receiving a diagnostic explanation. Some service-users expressed having more sense of control from understanding their diagnosis, that something chaotic had been made sense of by the diagnostic process. However, others interviewed within this study expressed that the diagnosis had little meaning to them and had not aided their understanding of their mental health difficulties or personality.
Morris, Smith and Alwin (2014) found that for all participants, the diagnostic process, specifically how service-users were informed of their diagnosis of BPD, impacted on how they felt about it. Those who were told in an ‘insensitive manner’ with poor opportunity for discussion were less positive about the label. This indicates how the usefulness of a diagnosis may hinge on the way in which it is provided. This was echoed in Richardson and Tracey’s study (2015) which found that all eight participants believed that when time was taken and sensitivity used to explain what a personality disorder was (i.e. potential causes, differences between people, and how to manage difficulties) then the diagnosis of BPD made sense. Most service-users expressed a sense of relief upon hearing the diagnosis as it helped contextualise a longstanding difficulty and helped them feel more proactive in their care. Furthermore, two participants felt so strongly about diagnosis delivery that they volunteered to help with professional training.

*Dismissal of personal accounts over expert knowledge and a mismatch between these perspectives*

Three of the studies included in the review highlighted a potential mismatch between service-user explanations for their current difficulties and the diagnosis, and how this could be experienced as being dismissive of service-user perspectives (Bilderbeck, Saunders, Price & Goodwin, 2014; Horn, Johnstone & Brooke, 2007; Ramon, Castillo & Morant, 2001)

Ramon, Castillo and Morant (2001) compared service-users’ own explanation of their mental health difficulties with the diagnostic criteria for different personality disorders. Their findings suggested a mismatch between how service-users would describe their current difficulties compared to the diagnostic criteria. Horn, Johnstone and Brooke (2007) reported the importance of the power of knowledge and how this can be held by professional groups, elevating them as an expert over the service-user’s own experiences. For some this experience was viewed as containing. However, others shared experiences of being placed in the ‘not-
knowing’ position. Similar to Ramon, Castillo and Morant (2001), some participants expressed how the term BPD had limited meaning to them and did not match their own understanding or experiences. Bilderbeck, Saunders, Price and Goodwin (2014) found that service-users reported having their personal accounts dismissed by professionals. Although service-users found it helpful to consider the impact of trauma on their current difficulties, they shared how this was difficult to talk about and clinicians overemphasised this at the expense of considering their more recent difficulties. Due to the lack of clarity in this analysis and the relevance of this finding to those with a diagnosis of PD within the sample, it is likely that further research is necessary to evaluate the credibility of these findings.

**Inadequate information and explanation of diagnosis initially leads to confusion**

Five studies found that service-users were provided with limited information when they were first diagnosed which impacted on their understanding of the diagnosis (Fromene & Guerin, 2014; Horn, Johnstone & Brooke, 2007; Morris, Smith & Alwin, 2014; Lawn & Mahon, 2015; Nehls, 1999;).

Morris, Smith and Alwin (2014) reported that the way in which a diagnosis was provided impacted on service-user understanding of their mental health and diagnosis. Within their sample, service-users explained that information provided about a diagnosis of BPD was helpful, but that many services had not provided this. Most service-users reported a limited understanding of their diagnosis due to not being provided with adequate information. Horn, Johnstone and Brooke, (2007) found that service users reported being provided with little information initially and that this was often negative. This was echoed in Nehls (1999) who found that service-users had been provided with limited information. Similarly, all indigenous Australian service-users interviewed in Fromene and Guerin’s (2014) study expressed a wish for more information within their interviews. One person reflected on how not having this
information during their diagnosis was a missed opportunity for them to redefine themself or think about themself in a different way.

In a quantitative study conducted by Lawn and McMahon (2015) through an online survey with Australian service-users with a diagnosis of BPD, a significant association ($\chi^2 (4, n = 106) = 9.54, P = .049$) was found between the length of time someone had been diagnosed and how adequate they perceived the explanation of their diagnosis to have been (i.e. whether the information given to them by clinicians met their personal requirements for understanding the diagnosis). Forty-five percent of service-users who reported that they had received an inadequate diagnostic explanation had received their diagnosis over five years ago compared to 27.5% who had been diagnosed within one to five years ago, and 27.5% who had been provided with a diagnosis within one year. Furthermore, 37.8% reported having been given no explanation of BPD, and 19.3% reported that although they had received an explanation, they had not understood it. The findings, albeit from a single relatively small scale study in Australia, suggest that a high percentage of those being diagnosed with BPD within this study at least, do not receive an adequate explanation of the diagnosis that allows them to understand the condition and their mental health. It may also imply that the level of information and the quality of explanation provided may have improved for those being diagnosed more recently. However, these findings must be interpreted with caution. Multiple comparisons were performed within this study (though not reported here) without correction and so it is possible that the association reported here may not have met significance if they had been more conservative. This was a relatively small sample online survey which may have biased data. It is possible that those that had strong views or negative experiences of services were more likely to respond to the questionnaire, and therefore more neutral perspectives were not gathered.
Struggling to understand one’s identity after receiving a personality disorder diagnosis

Two studies within the sampled records for this literature review, found that service-users’ understanding of their identity was impacted by the diagnosis (Ramon, Castillo & Morant, 2001; Lovell & Hardy, 2015).

Ramon, Castillo and Morant (2001) found that three participants believed that their diagnosis meant they had no identity. However, this is a small number of participants within the sample and as previously discussed, the process by which data was analysed is unclear. Within all the accounts of service-users interviewed by Lovell and Hardy (2015) in secure services, a theme of identity arose. For some, BPD had become an integral part of their identity that help make sense of their experiences. In contradiction, others expressed confusion about their identity as a result of receiving a diagnosis and struggled to integrate this into their understanding of themselves. Some described BPD as taking over their identity and removing something from them. The authors reflected on how the secure environment of forensic services was also a factor in removing something from service-users’ identities.

Therefore, while there is mention of the impact of the PD diagnosis on the understanding of identity in this literature, there is no strong evidence for this theme as only two papers report this and both studies have limitations. It is suggested that further research is required to explore the impact of the diagnostic process on identity.

4. Discussion

4.1. Summary of findings:

The findings reviewed here indicate that the diagnostic process can indeed influence how service-users understand their mental health and their identity. A strong theme that appeared across eight studies captured the impact of stigma and being judged by others for having a PD diagnosis. For some, this impacted on how willing they were to accept or disclose the diagnosis to others. Service-users expressed a sense of being labelled as ‘bad’, a perpetrator and ‘not ill’
in comparison to those diagnosed with other disorders. Some of the studies found that receiving a diagnosis of PD reinforced existing negative self-concepts. However, there were contradictions between participants, across and within studies, with some service-users describing an increase in self-esteem as a result of receiving the diagnosis. Furthermore, a subsequent theme apparent across seven studies captured how the diagnostic process had the potential to reduce self-blame, explain symptoms and contextualise long standing difficulties, but that this was not always achieved. Two of these studies (Morris, Smith & Alwin, 2014; Richardson & Tracey, 2015) highlighted diagnosis delivery as an important factor in how service-users felt about the diagnosis, themselves and their future.

Five studies found that the diagnostic process in PD and subsequent conversations with professionals regarding treatment, influenced their hopes for recovery. Most of these studies reported that participants were left feeling that PD was permanent and there was little professionals could do to help them. Conversely, one study (Morris, Smith & Alwin, 2014) reported one positive experience within a diagnostic assessment which instilled optimism. A consistent finding reported across five studies indicated that service-users were being provided with inadequate information at diagnosis and that this could often be negative. This led to many service-users feeling confused about their mental health or what the diagnosis meant. Furthermore, findings from one quantitative study conducted in Australia suggested that those who had experienced a more recent diagnosis were more likely to have received an adequate explanation of BPD that they could understand. This may suggest that clinicians and services (in Australia) are now providing greater information at diagnosis and more thorough explanations of BPD. However, there are some fundamental problems with this study that question the validity and generalisability of these findings outside of Australia.

A small number of studies (three) reported how service-users had experiences of having their diagnosis withheld from them, finding out many years later as a result of changes in their care. Service-users described feeling confused about their mental health and frustrated at having
their diagnosis withheld from them by professionals. Clinicians interviewed in one study expressed a wish to protect service-users from the stigmatised label of BPD. Contrary to this, service-users expressed a wish to receive their diagnosis and have the stigma explained to them. Sulzer et al. (2016) concluded that this tendency to withhold the diagnosis impacted on service-users’ ability to take agency in their own care.

Three studies highlighted a mismatch between the clinical diagnosis of PD and a person’s own understanding of their mental health and how this could be experienced as dismissive. For example, for some interviewed, the label of PD was not seen to hold meaning compared to their own understanding. Finally, there was a small amount of evidence from findings that service-users struggled to understand their identity after diagnosis. It is possible that this again could be related to diagnosis delivery, however this is likely to need further investigation.

Although these studies highlight aspects of the diagnostic process that influence service-user understanding of themselves and their mental health, it is unclear how long ago participants included in this review had an experience of being diagnosed with PD. This has significant implications for those diagnosed in England and across the UK, as there have been substantial provisional and policy changes to improve service-users’ access and experiences of services. This occurred in response to the National Institute for Mental Health in England (NIMH(E), 2003) guidance ‘Personality disorder: No longer a diagnosis of exclusion’ which highlighted a deficit in services being provided to those diagnosed with PD. Following the publication of some of the articles reviewed here (e.g. Horn, Johnstone & Brooke, 2007), the National Institute of Clinical Excellence (NICE, 2009) produced guidance for the assessment and treatment of BPD. Whilst many of the studies reviewed here were published following this guidance, only three studies define their sample in terms of when people received their diagnosis and only one of these was based in the UK (Morris, Smith & Alwin, 2014). Not all participants within this study had received a diagnosis before the implementation of the
guidelines and the focus of the research question was on the group’s broad experiences of accessing services. This presents a potential gap in our knowledge as there has been no research conducted in light of these changes to specifically gain a comprehensive understanding of service-users’ current experiences of the diagnostic process and how this may impact not only on people’s understanding of their mental health, but their identity.

4.2. Limitations:

4.2.1. Study Limitations

The main limitation of this literature review is the limited number of studies able to answer the research question and the quality of the studies included. A large number of search terms used in varying sequences was necessary to pool the relevant literature, and further than this, fingertip searches of key paper references and a Google Scholar search was required to make sure important articles were not missed. This was a reflection of the limited amount of research into the impact of the diagnostic process itself and that vast amount of terminology used interchangeably to describe similar constructs or phenomena.

4.2.2. Overarching Limitations of the Current Literature

In terms of sampling across the studies, a number of issues arose. A problem for all research relying on volunteer service-users is that data will be biased by the views of those willing to be involved. It is therefore possible that these views are not transferable to all groups of service users who have received a diagnosis of a PD. People may be less likely to be represented in the research if they are struggling with high levels of distress, find it difficult to meet up with strangers (e.g. the researcher), have mistrust in services or do not personally identify as having the diagnosis of PD. There is also limited research exploring the views of people from Black and Ethnic Minority backgrounds who receive the diagnosis. As the majority of the research approaches utilised small samples, e.g. IPA, it is not appropriate to generalise findings to a wider population receiving this diagnosis. However, due to the limited research currently
available to answer this research question and the problems with using experimental paradigms

to explore phenomena relating to experiences of this kind, it would be difficult to design and

perform larger scale studies from the current level of understanding of the impact of the
diagnostic process on service-user identity.

Furthermore, there are ethical implications of working with this group that make research
difficult to conduct. People given this diagnosis can experience high levels of distress which
not only presents difficulties in terms of recruitment, but also means that considerations need
to be taken when inviting people to be interviewed and when thinking about how they may be
supported afterwards. It is possible that this limits the quantity of research conducted with
current service-users and the number of people recruited within studies.

A problem observed early in the data collection process of this review, was that no studies
focused purely on the diagnostic process in terms of impact on identity and understanding of
mental health. Rather findings relating to this research question fell out of the exploration of
people’s lived experiences of having the diagnosis. Therefore, this review helped synthesise
findings across methodologies and the different aims of studies to help make sense of what is
already known about the research question. It is possible that the contradictions within and
across studies could be better understood by an interpretative approach aiming to gain a
comprehensive understanding of the influence of the diagnostic process itself.

Self-reflexivity was not evidenced by many studies within this review. Horn, Johnstone and
Brooke (2007) reflected on their epistemological position and provided context of the social
construction of BPD. Similarly, Gillard, Turner and Neffgen (2015) reflected on how different
researchers within the team would have different interpretations of the data and referenced the
wider context of personality disorder diagnoses. Only one article (Lovell & Hardy, 2014)
provided examples of analysis where self-reflexivity had been used to help the researcher
notice the impact of their own values or attitudes on the findings. Although this may have been
lost due to restrictive word counts, self-reflexivity is an essential element of qualitative research that allows for the evaluation of the credibility of findings.

4.3. Clinical implications and directions for future research

Although caution should be taken when generalising the findings presented here, this review highlights the diagnostic process in PD as a significant event that can influence how service-users feel about themselves and how they understand their mental health. Therefore, care must be taken when psychiatric diagnoses, such as PD, are provided to ensure this label is helpful, informative and leads to treatment. Service-users who have their diagnosis withheld or who are provided with limited information about what PD means, are likely to feel confused about their mental health and will feel unable to be fully informed and involved in making decisions about their own care. Clinicians providing a diagnosis should consider the impact that this might have on service-users, given the stigma surrounding mental health and the attitudes held about PD. It is therefore important to provide this diagnosis clearly, to offer space for questions and disagreement, and to consider with service-users the potential stigma they might have faced. Furthermore, the diagnosis should be discussed with optimism and in the context of treatment options. This fulfils the aim of diagnosis but also provides hope to service-users that their difficulties can not only be understood but supported to improve.

All studies reviewed here had different focuses and methodologies which made answering the research question somewhat challenging. In addition to this, as studies did not focus on the diagnostic process per se, data about when, where and how service-users received their diagnosis was not provided. There have been significant policy and service provision changes in England over the past 15 years, including the development of specific guidance for clinicians providing a PD diagnosis (e.g. NICE, 2009) and an increase in dedicated and specialist PD services. This occurred in response to (NIMH(E), 2003) guidance that highlighted a deficit in the services being provided to those with PD. Exploring the experiences of service-users in
light of these significant changes would be helpful in understanding the contemporary experience of service-users currently accessing services and receiving this diagnosis. As there is not a sound empirical basis on which to develop such a study and this review highlighted nuances in people’s experiences of the diagnosis, further research will have to be exploratory with a strong self-reflexive approach to gain a comprehensive understanding of people’s current experiences of the diagnostic process.

Although themes emerged from several studies that related to aspects of identity, this was not explored within a framework of theory relating to identity formation such as Identity Process Theory (Breakwell, 1986, 1988, 1992, 1993, 2001; Vignoles et al., 2002). This could perhaps be an avenue for future research where there is a specific focus on how someone understands their own identity in light of the diagnostic process in PD.
5. References


## Appendix: Table comparing studies against a quality checklist adapted from Spencer, Ritchie, Lewis and Dillon (2003)

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<tbody>
<tr>
<td>Introduction</td>
<td></td>
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</tr>
<tr>
<td>How well are the study focus and methods justified and explained in the context of an existing body of theoretical/empirical knowledge?</td>
<td>Not a great deal of background context given therefore introduction reads more like a summary than a section that sets the scene Lack of background research.</td>
<td>Attention paid to the context of PD and then more specifically with regard to provision and forensic services Review of the literature leads to aims and somewhat a rationale for methodology.</td>
<td>Attention paid to the context of the sample (Australian indigenous people) as opposed to PD. Clear justification for the study from reviewed literature.</td>
<td>Clear justification for study from the reviewed literature and context of recovery models in mainstream services.</td>
<td>Attention paid to the social context and discourse around PD in addition to policy in UK. Literature used to justify study.</td>
<td>Attention paid to the debates surrounding BPD. Clear justification for study from the reviewed literature.</td>
</tr>
<tr>
<td>Design</td>
<td>Rationale explained for methodology and broad research aims as exploratory study. Analysis looks for commonality and frequency so loses richness of data. Limitations of design discussed.</td>
<td>Rationale for choice of IPA not given. However, design fits broad and exploratory aims of the work. Limitations of design discussed.</td>
<td>Methodology culturally sensitive-informal talking. Method unnamed other than semi-structured interviews. Limitations of design discussed.</td>
<td>Involvement of service-user researcher to support experiential interpretations of research. Clearly described design to meet aims of study. Limitations of design discussed.</td>
<td>Clear rationale for study aims and methodology to explore lived experiences of participants. Limitations of design discussed.</td>
<td>Rationale for IPA clearly explained in relation to the research question. Limitations of the method not discussed.</td>
</tr>
<tr>
<td>Sampling</td>
<td>Demographic data collected and process of sampling clearly described. Only 5 participants with BPD diagnoses.</td>
<td>Sample necessary for answering the question. Recruitment clearly described. Some demographic data collected and</td>
<td>Sample and sampling procedure clearly defined. Sample appropriate for answering research question.</td>
<td>Sample and sampling procedure clearly defined. Sample appropriate for answering research question.</td>
<td>Recruitment process does not provide context in which participants were recruited. Limited</td>
<td>Recruitment clearly described in addition to the clinical context that participants were in. Sample well defined. Unclear when sample</td>
</tr>
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Table 3. Comparison of qualitative studies against quality checklist.
<table>
<thead>
<tr>
<th>Data collection</th>
<th>How well was the data collection carried out? (clarity of procedure, who was involved, interview schedule)</th>
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<tbody>
<tr>
<td>Sample well described?</td>
<td>Unclear when sample received their diagnoses.</td>
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<tr>
<td>Rationale around ethics and wishing participants to tell their own story as to why further information not collected. Unclear when sample received their diagnoses.</td>
<td>Unclear when sample received their diagnoses.</td>
</tr>
<tr>
<td>Interview process described clearly and who was involved. Clear how data was recorded. Topic schedule available as supplement to paper.</td>
<td>Interview process described clearly and who was involved. Clear how data was recorded. Interview schedule not provided or details of the questioning.</td>
</tr>
<tr>
<td>Clear data collection process including how all researchers contributed. Interview schedule described and provided. Clear how data was recorded.</td>
<td>Clear data collection process including how all researchers contributed. Interview schedule described and provided. Clear how data was recorded.</td>
</tr>
<tr>
<td>Interviews clearly described and brief guiding schedule provided. Clear how data was recorded.</td>
<td>Interview process clearly described including how participants engaged with this process (i.e. if they did not attend initial appointment). Schedule described.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Analysis</th>
<th>How well has the approach to, and the formulation of, the analysis been conveyed? (clarity of analysis and use of software, evidence of credibility checks during analytic process)</th>
</tr>
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<tbody>
<tr>
<td>Clearly described analysis process including how software was used and with references provided. Described how preconceptions were noticed and managed via note keeping during all stages of project. Credibility checks to ‘ground’ data in participants’ narrative not explained.</td>
<td>Analysis described though references not provided regarding IPA methodology was followed. May suggest a standardized procedure was not followed. No credibility checks explicitly named but co-authors supported the analysis process.</td>
</tr>
<tr>
<td>Analysis unnamed and unclear how themes were derived or by what procedure. No credibility checks described.</td>
<td>Analytic process clearly described, and references provided for procedure. No credibility checks described explicitly but use of university researcher to support the analysis process.</td>
</tr>
<tr>
<td>Analytic process clearly described with references. Credibility checks clearly described.</td>
<td>Clearly described analysis. Quality control (credibility checks) clearly outlined: follow-ups with participants to explore preliminary themes; peer audit of one full transcript; audit trail diary kept; and re-reading of transcripts following initial themes.</td>
</tr>
<tr>
<td>How well has context and diversity of perspective and content been explored?</td>
<td>Care taken to specify approximates about how many individuals shared a narrative. Some attention to drawing out diversity in experiences, though mainly looking for commonality.</td>
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<tr>
<td>How well has detail, depth and complexity (i.e. richness) of the data been conveyed?</td>
<td>Not a great deal of evidence of diversity of perspective - this may have been lost due to publication length. Query whether richness may have been possible with this large sample size.</td>
</tr>
<tr>
<td>Reporting</td>
<td>Plausible examples of themes though not all quotes were from individuals with PD. Some themes had more quote evidence than others.</td>
</tr>
<tr>
<td>Reflexivity</td>
<td>How clear are the main assumptions/values/theoretical perspectives which shaped the form and findings of the study? (consideration of epistemological position and impact of assumptions and how this was managed)</td>
</tr>
<tr>
<td>-------------</td>
<td>--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Evidence that assumptions were considered during all stages of project, although examples not provided about how this was managed using the named technique of a diary. Epistemological position not named explicitly nor assumptions.</td>
<td></td>
</tr>
<tr>
<td>Authors reflect on the distressing content of interviews. Epistemological position not named explicitly nor assumptions. No evidence of self-reflexivity on assumptions or how these were managed.</td>
<td></td>
</tr>
<tr>
<td>No evidence of self-reflexivity or management of assumptions on analytic process. Epistemological position not named.</td>
<td></td>
</tr>
<tr>
<td>Reflexivity around how each researcher approached the interviews and data e.g. clinician versus service-user researcher. Epistemological position not named. Not clear about how assumptions were managed.</td>
<td></td>
</tr>
<tr>
<td>Discussion of a priori assumptions of researchers and how this was managed- external readings of analysis and feedback from participants. Epistemological position of the researcher and analysis discussed.</td>
<td></td>
</tr>
<tr>
<td>Provided evidence of self-reflexivity i.e. provided information about the researcher to consider how this impacted on the work Quality control checks used to manage potential impact of researcher. Epistemological position not explicitly named.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Audibility</th>
<th>How adequately has the research process been documented? (discussion of limitations and strengths and documentation of changes to sampling/data collection/analysis or implications)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Authors open about limitation of study and impact on implications. Topic schedule changed as themes began emerging which then narrowed the questioning to look for commonality. Therefore, may have missed spontaneous findings and lost richness.</td>
<td></td>
</tr>
<tr>
<td>Authors open about limitation of study and impact on implications. Discussion of the diversity within the group that may have affected homogeneity and therefore the ease with which analysis could occur.</td>
<td></td>
</tr>
<tr>
<td>Does not share analytic method which makes the study difficult to evaluate. Limited exploration of limitations of the study.</td>
<td></td>
</tr>
<tr>
<td>Explained why one participant was interviewed twice. Consideration of strengths and weaknesses.</td>
<td></td>
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<tr>
<td>Strong consideration of strengths and weaknesses and how this relates to the methodology.</td>
<td></td>
</tr>
<tr>
<td>Authors clearly described how they discovered the group to be more heterogeneous than they had thought prior to interviews. This is considered as a limitation of the work, though literature is provided to consider how findings may continue to contribute to knowledge.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Ethics</th>
<th>What evidence is there of attention to ethical issues?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consideration to participants’ experiences of the interview and offers of follow up interviews to take into consideration fluctuating mood of data.</td>
<td></td>
</tr>
<tr>
<td>Sought support from service-user organization to consider how to sensitively discuss topics of self-harm. Consideration to paying participants and how they could</td>
<td></td>
</tr>
<tr>
<td>Consideration of clients’ mental health stability as part of inclusion/exclusion criteria.</td>
<td></td>
</tr>
<tr>
<td>Consideration of the importance of service-user researcher contribution to research exploring lived experiences of service-users.</td>
<td></td>
</tr>
<tr>
<td>Consideration of the ethics of using a diagnostic system is considered throughout the article.</td>
<td></td>
</tr>
<tr>
<td>Researchers clearly considered the high level of distress participants might be experiencing and how to manage this at all stages.</td>
<td></td>
</tr>
</tbody>
</table>
still withdraw following payment.

<table>
<thead>
<tr>
<th>How credible are the findings? (reader can see how researcher arrived at conclusions)</th>
<th>Some themes lost in the discussed principal findings, but those mentioned link to data and analysis.</th>
<th>Not always clear how findings relate to implications as these links are not made explicit. Summary of findings is brief compared to richness of results.</th>
<th>Clear conclusions and implications from data situated in the cultural context of the sample. However, the credibility of findings is affected by unclear methodology.</th>
<th>Clear conclusions and implications from data. Conclusions situated within current debates around diagnosis and specific issues highlighted within the literature surrounding BPD.</th>
<th>Clear conclusions and implications from data. Conclusions and implications situated within current literature.</th>
</tr>
</thead>
<tbody>
<tr>
<td>How well does the study address the original aims?</td>
<td>Addresses broad aims of the exploratory study well.</td>
<td>Addresses broad aims of the exploratory study well.</td>
<td>Addresses aims, but richness may have been lost due to methodology.</td>
<td>Addresses broad aims of the exploratory study well.</td>
<td>Addresses broad aims of the exploratory study well.</td>
</tr>
<tr>
<td>Findings</td>
<td>First study to explore the experiences of service-users with mood instability undergoing psychiatric assessment. Past research described in discussion, but not earlier in the article which affects flow. Describes how this group fits with other groups’ experiences of assessment.</td>
<td>This study adds to the knowledge of individuals diagnosed with PD accessing forensic services. Also adds to our understanding of how service-users integrate PD into their identity. Pays attention to literature around recovery.</td>
<td>Study attempts to develop the evidence base to explore indigenous people’s experience of BPD diagnosis and consideration of different understanding of “symptoms”.</td>
<td>Study acknowledges similar studies exploring recovery published at the same time. Suggest that this complements this research to add further support for the conclusions.</td>
<td>The study places study findings in the context of debates around PD and provides potential alternatives to the BPD diagnosis and other clinical implications of the findings.</td>
</tr>
<tr>
<td>How has knowledge been extended by the research? (reference to how the findings sit in the literature)</td>
<td></td>
<td></td>
<td></td>
<td>The study places study findings in the context of debates around PD and provides potential alternatives to the BPD diagnosis and other clinical implications of the findings.</td>
<td></td>
</tr>
</tbody>
</table>
Table 3. Comparison of qualitative studies against quality checklist continued…

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<thead>
<tr>
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</thead>
<tbody>
<tr>
<td><strong>Introduction</strong></td>
<td>Attention paid to the context of PD and then more specifically with regard to provision changes in UK. This is used to provide a study rationale.</td>
<td>The need for the study well-argued: the paucity of literature exploring people’s lived experience at the time of publication.</td>
<td>The need for the study well-argued in terms of the debates around PD, lack of service-user involvement in research and need to hear the service-user perspective on PD diagnosis and meaning.</td>
<td>General setting of the scene with broad research. Rationale based somewhat on clinical experience of authors- this may reflect a paucity in the literature. Research question not described so rationale somewhat unclear.</td>
<td>Attention paid to context and debates around BPD. Rationale for study explained but limited literature reviewed. For example, they explain that there is limited research, but not what this is.</td>
</tr>
<tr>
<td><strong>Design</strong></td>
<td>Rationale for inductive thematic analysis provided which fits the aims of the study to explore participants’ experiences over several years. Researcher influences reflected on as limitation.</td>
<td>The research design is appropriate for answering the broad and exploratory research questions. However, the rationale for IPA and the large sample size, which is contrary to this approach, was not provided. No reflection on limitations of design.</td>
<td>Design rationale given for including service-user researchers and both quant and qual data. There is no discussion of the limitations of methodology. Design difficult to defend because parts of methodology unclear.</td>
<td>Rationale for semi-structured questionnaire given. Limitations of this methodology not discussed.</td>
<td>Clear rationale for exploratory study. Rationale for triangulation of data provided. Could have stated explicitly why grounded theory helped to answer question as opposed to other qual methods.</td>
</tr>
<tr>
<td><strong>Sampling</strong></td>
<td>Recruitment and sample clearly described. However, not all participants were diagnosed prior to NICE guidance (2009) and NIMH(E) guidance or potentially long enough</td>
<td>Large sample for an IPA study which meant that richness was lost from individual’s experiences. Sample clearly defined in terms of demographics and appropriate for answering the question.</td>
<td>Demographic data considered in the analysis (descriptive statistics) and sample well-defined. Unclear when sample received their diagnoses. Recruitment clearly described.</td>
<td>Sample clearly defined and suitable for the aims of the study. Unclear when sample received their diagnoses. Recruitment clearly described.</td>
<td>Sample clearly defined which is important given the triangulation of data. Unclear when sample received their diagnoses. Sampling process clearly described.</td>
</tr>
<tr>
<td>Data collection</td>
<td>How well was the data collection carried out? (clarity of procedure, who was involved, interview schedule)</td>
<td></td>
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<tr>
<td>Procedure clearly described. Service-user input into schedule described. Interview schedule provided.</td>
<td>Interview process clear and details of schedule and prompts explained.</td>
<td></td>
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</tr>
<tr>
<td>Interview procedure clearly described and who was involved. Interview schedule described, but not provided therefore unclear what the nature of the questions were. Similarly, questionnaire was not provided and the descriptions of this are vague.</td>
<td>Semi-structured interview described but not provided. As research question was not described it was difficult to link how the design of this schedule aimed to answer this. Hypotheses provided are at odds with qualitative methodology - suggests not exploratory.</td>
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<tr>
<td>Interview semi-structured but this is not fully described. Clear how clinicians and service-users were interviewed. Not clear how written accounts were collected i.e. no information on how the search was completed.</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Analysis</th>
<th>How well has the approach to, and the formulation of, the analysis been conveyed? (clarity of analysis and use of software, evidence of credibility checks during analytic process)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yardley’s framework used to ensure credibility of analysis/ findings and other stages of study. Reflective diary kept to document analytic process. Corroboration of two transcripts and negative case analysis.</td>
<td>Analysis procedure clearly explained, but unclear how many people were in the research team. The manuscript draft was read by the research team and two participants to give feedback which was incorporated. Unclear how these checks affected the analysis.</td>
</tr>
<tr>
<td>Analytic method not named and limited description provided about the interpretive process. No references for procedure provided. Credibility checks not stated.</td>
<td>Use of thematic analytic software not explained or how themes were derived. No credibility checks described or the process of interpretation.</td>
</tr>
<tr>
<td>Analytic process clearly described - references provided for grounded theory and how software was used. However, the triangulation of published written accounts was not clear.</td>
<td></td>
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</tbody>
</table>

<p>| How well has context and diversity of perspective and content been explored? (evidence of multiple perspectives, patterns as well as | Not a great deal of full supporting quotes, so difficult to consider the plausibility of findings. Consideration paid to divergence within the group and multiple perspectives present within the data. |
| It is difficult to see individuals within the text with their own context, in line with IPA. Instead the focus appears to be on convergence rather than divergence within the group. This is likely due to the size of the sample. | Multiple perspectives are not explored but stated. Limited exploration of nuances between people’s experiences despite the researchers stating they were looking for negative cases to themes. |
| Some attention paid to divergence and multiple perspective present. Limited quote evidence to give a sense of individual participants’ perspectives. | Multiple perspectives clearly presented with the data, within service-user and clinician samples. Divergence explored in line with aims of the study to explore different approaches to diagnosis. |</p>
<table>
<thead>
<tr>
<th>Context of participants discussed to some extent at mainly group level.</th>
<th>How well has detail, depth and complexity (i.e. richness) of the data been conveyed?</th>
<th>There is richness and depth in the narrative and the interpretations made.</th>
<th>Due to the number of participants involved richness and complexity is lost for commonality and description.</th>
<th>Not a particularly rich analysis of the data which appears descriptive rather than interpretative. However, this is more in line with the methodology.</th>
<th>Rich analysis of data and exploration of the complexity.</th>
</tr>
</thead>
<tbody>
<tr>
<td>How well has detail, depth and complexity (i.e. richness) of the data been conveyed?</td>
<td>Richness in the shared experience of the group. Due to methodology used there is a focus on commonality as opposed to the individual’s nuanced experience.</td>
<td>Clear narrative that links data to interpretations, though there are a limited number of full quotes for the reader to judge plausibility of these links.</td>
<td>It is unclear at times how findings were derived i.e. from semi-structured interviews or from the questionnaire. This was further complicated by the qualitative methodology not being named. Descriptive statistics (percentages) are used on seemingly qualitative data, but is unclear how this links to the interview questions asked.</td>
<td>Limited quotes provided and unclear which of the participants provided the quotes. Findings are linked to literature through narrative.</td>
<td>Clear how data (quotes and descriptions) link to interpretations and conclusions.</td>
</tr>
<tr>
<td>Reporting</td>
<td>Epistemological position named (critical realist) and how this fits with methodology. Quality checks used to manage researcher’s assumptions i.e. reflective journal.</td>
<td>Epistemological position described but not explicitly named. No explicit discussion of the researcher’s or research team’s assumptions prior and during the analysis and write-up or how these were managed.</td>
<td>Epistemological position not named. No evidence of self-reflexivity around different researchers’ assumptions or how these were managed.</td>
<td>Shared their hypotheses prior to the data collection, but did not consider how these might have impacted on study design or analysis.</td>
<td>No evidence of self-reflexivity around impact of researchers’ assumptions. Epistemological position not named.</td>
</tr>
<tr>
<td>Refllexivity</td>
<td>Epistemological position named (critical realist) and how this fits with methodology. Quality checks used to manage researcher’s assumptions i.e. reflective journal.</td>
<td>Epistemological position described but not explicitly named. No explicit discussion of the researcher’s or research team’s assumptions prior and during the analysis and write-up or how these were managed.</td>
<td>Epistemological position not named. No evidence of self-reflexivity around different researchers’ assumptions or how these were managed.</td>
<td>Shared their hypotheses prior to the data collection, but did not consider how these might have impacted on study design or analysis.</td>
<td>No evidence of self-reflexivity around impact of researchers’ assumptions. Epistemological position not named.</td>
</tr>
<tr>
<td>Audibility</td>
<td>Explained iterative process where participants contributed to the interview schedule. Discussion of strengths and limitations of the study.</td>
<td>There is no discussion of strengths and limitations. However, the experiences of service-user researchers were carefully described at all stages of the project to reflect on this design and any changes that occurred.</td>
<td>Limitations of the sample discussed, but not of the methodology.</td>
<td>Clear how sample were interviewed differently e.g. by phone or face to face.</td>
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<tr>
<td>Ethics</td>
<td>Ethical issues as a result of clinical implications but not of the study itself.</td>
<td>Discussion of the lack of consultation with service-users within research.</td>
<td>Ethical issues not discussed.</td>
<td>Ethics of withholding diagnoses explored within research aims.</td>
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</tr>
<tr>
<td>How credible are the findings? (reader can see how researcher arrived at conclusions)</td>
<td>Clear conclusions and implications drawn from data and situated in the current literature.</td>
<td>Clear conclusions and implications drawn from data and situated in the current literature.</td>
<td>Due to problems with methodology and how it is described, it is difficult to make connections between the findings and the data. Despite the researcher looking for themes in the analytic process—these themes are not named and therefore it reads poorly. However, the conclusions appear to link to reported findings.</td>
<td>Clear how data links to narrative and conclusions drawn. This is set within research relating to clinical context and the historical treatment of those diagnosed with BPD.</td>
<td></td>
</tr>
<tr>
<td>How well does the study address the original aims?</td>
<td>Addresses broad aims of the exploratory study well.</td>
<td>Addresses broad aims of the exploratory study well.</td>
<td>Methodological issues interfere with the ability of the study to address research aims.</td>
<td>Addresses broad aims of the exploratory study well.</td>
<td></td>
</tr>
<tr>
<td>Findings</td>
<td></td>
<td></td>
<td>The aims are not entirely clear i.e. is the study exploratory? The method is also unclear so it is</td>
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</tr>
<tr>
<td>How has knowledge been extended by the research? (reference to how the findings sit in the literature)</td>
<td>This study considers the lived experiences of people accessing services diagnosed with PD accessing services between 2006-2009. Although it did not focus on the diagnostic process, this emerged as a theme. However, issues with sampling impact the strength of this finding.</td>
<td>This was a seminal piece of work that led to a greater research focus on individuals’ lived experience of BPD.</td>
<td>This was an important contribution to a growing evidence base in involving service-users in research and capturing their experiences of the diagnosis.</td>
<td>First study to explore the interface of BPD and BPAD from clients’ perspective. Contributes ideas about the role of diagnosis delivery in client satisfaction and understanding.</td>
<td>An interesting study that highlights the impact of withholding a diagnosis on service-users, whilst considering the reasons why clinicians do so. Useful and clear clinical implications.</td>
</tr>
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</table>
Part Three: Summary of Clinical Experience

Year 1 (Adult): *Split placement across a Recovery Team and an Improving Access to Psychological Therapies (IAPT) service*

In my first year I worked with adults aged 18-65 years old, across two different placements. The focus of my work in IAPT was developing core skills in undertaking psychological assessments and delivering therapy based on Cognitive Behavioural Therapy (CBT) models for social anxiety, OCD and depression. Within this role I also developed my skills in routine evaluation and outcomes and how to make this meaningful for the service-users I worked with. Within the Recovery Team I worked with adults both in community residential settings and in a step-down inpatient unit. Service-users had complex trauma histories and had received diagnoses such as schizophrenia, bipolar affective disorder and major depression for which they were receiving medical treatment. Within my individual work, I supported people to learn ways of ‘tuning out’ voices that were critical or unhelpful to them and to develop self-compassion using a Compassion-Focused Therapy approach. I also co-facilitated a psychoeducation group with an occupational therapist and mental health volunteer to support service-users in self-care, improving quality of life and reducing stressors that could lead to a deterioration in their mental health. I undertook several cognitive assessments to understand the nature of service-users’ executive functioning difficulties (including memory difficulties, suspected dementia, and problem solving/decision making difficulties) and provided recommendations for the individual and those working with them to better support their needs.

Year 2: *Split Placement across Child and Adolescent Mental Health Service (CAMHS; Tier three) and Looked After Children CAMHS (LAC; Tier two)*

My role within Tier three CAMHS involved working with young people (aged 11-17) experiencing moderate to severe mental health and/or behavioural difficulties. Within
individual work I drew on a range of models including CBT, Interpersonal Therapy (IPT), Attachment, and Systemic-informed approaches. As part of this work I also undertook CHOICE assessments, undertook risk assessments, and administered cognitive functioning assessments including the WISC. This work also involved working within the systems around each child, including their families, schools and social care. Within LAC, I worked with foster parents, and new adoptive parents, using Mentalization Based Therapy (MBT) and empathic parenting strategies to support their parenting approach to separation anxiety, anger and challenging behaviour. Using a Dialectical Behaviour Therapy (DBT) approach I worked individually with young people who had experienced neglect, abuse, and loss associated with being removed from families. I also provided training in MBT and Adaptive Mentalization-Based Integrative Treatment (AMBIT) models to social workers to support them in their work.

**Older People’s Community Mental Health Service**

On this placement I worked across three different pathways or teams for older adults aged 65 and over. This included working within memory assessment service (MAS), administering and interpreting a battery of assessments to determine whether people were presenting with dementia and/or executive functioning difficulties of a psychological nature. I also supervised the work of an assistant psychologist who was delivering a psychoeducation group to individuals newly diagnosed with dementia. Alongside this, I worked within a team utilizing the Newcastle model (systemic approach) to support people diagnosed with dementia and displaying behaviours that challenge. This work was done predominantly through care teams and the service-users’ family, supporting them to formulate the function of challenging behaviours and the potential unmet needs the behaviour might be communicating e.g. pain, loneliness, hunger. Furthermore, I was able to develop an individually tailored training session on sexuality and sexual challenging behaviours in people with dementia. Within a separate care pathway for adults experiencing ‘functional’ difficulties, I delivered narrative trauma work,
CBT for anxiety, and individual and couples work for long-term medically unexplained symptoms. Throughout this placement I received group and individual systemic supervision. This helped develop my knowledge of systemic models and considered the influence of my own background on service-users and vice-versa.

**Year 3: Community Learning Disability Health Team**

On this placement I worked within a joint mental health and physical health team supporting adults (18+) diagnosed with a learning disability. I worked in a systemically-informed way within a PBS framework to support residential care teams to better meet the needs of service-users displaying low mood or challenging behaviors. I also delivered adapted CBT to clients experiencing anxiety. A large part of this work was undertaking specialist assessments including: sexual knowledge and capacity; eligibility for LD services; dementia and ASD assessments. I also worked within a reflective team for systemic family consultation.

**Specialist Placement: Adolescent Outreach Team**

Within this placement I supported adolescents (12-17 years of age) at risk of being admitted to hospital due to risks of harm to themselves or others. This involved developing collaborative safety plans with young people and their families to manage risk; establishing and communicating within the network (including social care, CAMHS and schools); delivering integrative psychological interventions; and supporting the MDT in psychological formulation. This placement involved a great deal of multi-agency working, providing consultation and containment to the network in order to support the management or risk and improve young people’s quality of life. Within individual work I drew on a range of models (Narrative therapy, Systemic therapy, DBT and CBT) to support young to understand and manage painful emotions that increased their risk of self-harm and suicide. As part of this work I also co-facilitated a DBT skills group, provided supervision for a support worker’s CBT intervention.
# Part Four: Table of Assessments Completed During Training

## PSYCHD CLINICAL PROGRAMME
### TABLE OF ASSESSMENTS COMPLETED DURING TRAINING

#### Year I Assessments

<table>
<thead>
<tr>
<th>ASSESSMENT</th>
<th>TITLE</th>
</tr>
</thead>
<tbody>
<tr>
<td>WAIS</td>
<td>WAIS Interpretation (online assessment)</td>
</tr>
<tr>
<td>Practice Report of Clinical Activity</td>
<td>Case report of an integrative assessment and formulation of a young woman experiencing distress in response to critical voices</td>
</tr>
<tr>
<td>Audio Recording of Clinical Activity with Critical Appraisal</td>
<td>Audio recording and critical appraisal of a cognitive behaviour therapy session for social anxiety</td>
</tr>
<tr>
<td>Report of Clinical Activity N=1</td>
<td>Cognitive behavioural therapy with a young woman experiencing social anxiety and low mood</td>
</tr>
<tr>
<td>Major Research Project Literature Survey</td>
<td>How do individuals diagnosed with Borderline Personality Disorder experience being given their diagnosis?</td>
</tr>
<tr>
<td>Major Research Project Proposal</td>
<td>How do individuals with a Borderline Personality Disorder diagnosis perceive the delivery of their diagnosis to impact on their understanding of themselves and their mental health?</td>
</tr>
<tr>
<td>Service-Related Project</td>
<td>Training and supervision needs analysis of staff supporting individuals with enduring mental health conditions in 24-Hour supported housing</td>
</tr>
</tbody>
</table>

#### Year II Assessments

<table>
<thead>
<tr>
<th>ASSESSMENT</th>
<th>TITLE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Report of Clinical Activity/Report of Clinical Activity – Formal Assessment</td>
<td>An extended psychological assessment of a girl in her late teens to assess the specific nature of her learning difficulties and needs</td>
</tr>
<tr>
<td>PPLD Process Account</td>
<td>Reflecting on my experiences of personal and professional development groups on clinical psychology training</td>
</tr>
</tbody>
</table>

#### Year III Assessments

<table>
<thead>
<tr>
<th>ASSESSMENT</th>
<th>TITLE</th>
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</thead>
<tbody>
<tr>
<td>Presentation of Clinical Activity</td>
<td>Reshaping a problem landscape: Using a narrative and structural approach with a couple in their late 70’s</td>
</tr>
<tr>
<td>Major Research Project Literature Review</td>
<td>How does the diagnostic process in Personality Disorder influence how service-users understand their identity and mental health?</td>
</tr>
<tr>
<td>Major Research Project Empirical Paper</td>
<td>&quot;Too complex for IAPT&quot;: Service-user experiences of accessing specialist services and the process of being diagnosed with borderline personality disorder</td>
</tr>
<tr>
<td>------------------------------------------------------------------------</td>
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</tr>
<tr>
<td>Final Reflective Account</td>
<td>On becoming a clinical psychologist: A retrospective, developmental, reflective account of the experience of training</td>
</tr>
</tbody>
</table>