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# **Exploring Neurodevelopmental Profiles of Young People with Borderline Personality Disorder: A Feasibility Study**

## **And Clinical Research Portfolio**

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Submitted in partial fulfilment of the requirements for the degree of Doctorate in Clinical Psychology

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# **Experiences of Stigma and Discrimination in Borderline Personality Disorder: A Qualitative Meta-Synthesis**

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#### **Abstract**

**Background:** Borderline personality disorder (BPD) is a complex mental health problem and is the most common of personality disorders in clinical practice. Evidence suggests that individuals with BPD may experience discrimination and resulting stigmatisation by both the public and health care professionals; stigma may lead to delayed input from health care services, low treatment effect of interventions, and higher relapse rates. To date, a systematic review of stigma and discrimination experienced by individuals as a result of, and living with a diagnosis of BPD has not been conducted. **Objectives:** To examine and synthesise qualitative studies exploring experiences of stigma and discrimination in individuals with a diagnosis of BPD. Method: Systematic searches of Embase, Medline, Cochrane Library, PsycINFO, and Cinhal were conducted in January 2018. Reference lists and Google Scholar were hand searched. Meta-ethnography was used to synthesise the studies. Results: Seven articles were identified for inclusion and their quality assessed. All included articles were deemed to be of high or moderate quality. Seven themes were constructed, five of which were included in the final synthesis: impact on self-image/esteem; hopelessness and BPD as a permanent diagnosis; resistance from clinicians to explain BPD diagnosis and withholding information; discrimination; and feeling like a burden. Conclusion: Participants in this review experienced stigma and discrimination as a result of a diagnosis of BPD. This review highlighted a need for improved understanding across healthcare services of both the symptomology and long-term prognosis of BPD. Introduction of a standardised pathway of care across health services following diagnosis is discussed.

**Key words:** Borderline personality disorder; Emotionally unstable personality disorder; Stigma; Discrimination; Qualitative

Borderline personality disorder (BPD) is a complex mental health problem, characterised by a pervasive pattern of instability in affect regulation, impulse control, interpersonal relationships, and self-image (Lieb et al. 2004). Whilst it affects approximately 1.4% of the general population, it is the most common of personality disorders in clinical practice (The British Psychological Society, 2009), affecting up to 10% of psychiatric outpatients and 20% of inpatients (Lieb et al. 2004). Evidence suggests that BPD is often viewed negatively by both the public and health care professionals (Biskin, 2015) and may result in greater stigma as compared to other mental illnesses (Aviram, Brodsky, & Stanley, 2006).

A preliminary review of the literature pertaining to stigma and BPD reveals a number of studies focused on health care professionals' attitudes. Current literature indicates that health care professionals often view BPD more negatively as compared to other mental health problems, such as depression or anxiety (Bourke & Grenyer, 2010), experience negative reactions and attitudes towards individuals with BPD (Black et al. 2011; Deans & Meocevic, 2006) and are less optimistic about recovery for BPD as compared to other personality disorders, such as schizophrenia (Markham, 2003). With regards to BPD and stigma, Nehls (1998) outlined the different depreciatory terms used by clinicians including: "not sick," "manipulative," and "hateful", with Hersh (2008) arguing that the use of stigmatising and discriminatory terminology reflects a lack of empathy towards individuals with BPD.

To establish a shared understanding, Link and Phelan (2001) conceptualise stigma in four parts: labelling; stereotyping; separating 'us vs. them'; and status loss, with discrimination resulting as a consequence of the four previous components. Gabel, Zaske, and Baumann (2006) have expanded these concepts further by suggesting that labelling highlights a difference in an individuals' personality or behaviour, stereotyping associates these differences with negative stereotypes, and separating 'us vs. them' is classifying

negatively labelled persons as different from those who do not share this label. Evidence indicates that stigma is a contributing factor to preventing or delaying individuals with mental ill health from seeking input from health care professionals (Schomerus & Angermeyer, 2008). For a more detailed review on help-seeking behaviour and mental illness, see Clement et al. (2015). Stigma may lead to a vicious cycle of delayed input from health care services, low treatment effect of interventions, and higher relapse rates, which may reinforce negative attitudes from others and contribute to self-stigmatisation (Sartorius, 2007).

To the author's knowledge a systematic review of stigma and discrimination encountered by individuals as a result of, and living with, a diagnosis of BPD has not been conducted. Evidence suggests that stigma can reduce the likelihood of an individual seeking out support and accessing health services (Clement et al., 2015). A greater understanding of the experiences of stigma and discrimination for people with BPD may help in supporting clinical guideline development or address variation in practice approaches to individuals with BPD.

#### **Aims**

This review aims to systematically examine and synthesise studies exploring stigma and/or discrimination as experienced by individuals as a result of, and living with, a diagnosis of BPD. The systematic review aims to answer the following:

- 1. What are the experiences of stigma and discrimination encountered by individuals both receiving, and living with a diagnosis BPD?
- 2. What, if any, are the potential implications of understanding lived experiences of stigma and discrimination in individuals with BPD for supporting future clinical guideline development?

#### Methods

#### **Search Strategy**

A systematic search of published studies related to experiences of stigma and/or discrimination in individuals with a diagnosis of BPD or Emotionally Unstable Personality Disorder (EUPD) was performed in January 2018 using the following databases: Embase (Ovid), Medline (Ovid), Cochrane Library, PsycINFO (EBSCO), and Cinhal (EBSCO). Boolean operators (OR and AND) were used to combine search strings, an example of the terms used for PsycINFO (EBSCO) is included below. Subject heading and keyword searches using the following terms were run:

S1. (DE "Borderline Personality Disorder" OR (DE "Borderline States")

S2. TI (borderline personalit\* OR BPD OR emotionally unstable personali\*) OR AB (borderline personalit\* OR BPD OR emotionally unstable personali\*) OR KW (borderline personalit\* OR BPD OR emotionally unstable personali\*)

S3. S1 OR S2

S4. (((DE "Stigma") OR (DE "Labelling" OR DE "Stereotyped Attitudes")) OR (DE "Attitudes")) OR (DE "Social Acceptance" OR DE "Social Discrimination")

S5. TI ( stigma\* OR label\* OR stereotyp\* OR attitude\* OR discriminat\* ) OR AB ( stigma\* OR label\* OR stereotyp\* OR attitude\* OR discriminat\* ) OR KW ( stigma\* OR label\* OR stereotyp\* OR attitude\* OR discriminat\* )

S6. S4 OR S5

S7. S3 AND S6

S8. S3 AND S6 – limited to English language only and excluding dissertations.

Key words and terms from the search strategy were also entered in Google Scholar to search for additional papers, and reference lists of included studies were hand searched.

#### **Inclusion and Exclusion Criteria**

#### Inclusion Criteria

- Peer reviewed journal publications using qualitative methods and analysis to explore experiences of stigma and/or discrimination in individuals with a diagnosis of either BPD or EUPD
- Studies published in English language

#### **Exclusion Criteria**

- Studies using quantitative methods
- Studies describing experiences of stigma and/or discrimination in non-BPD or EUPD populations.
- Studies not published in English language
- Unpublished research
- Studies that have not undergone a peer-review process
- Studies that fail to provide illustrative quotations

# **Methodological Review of Studies**

There is some debate in the field of qualitative research with regards to quality assessment; specifically, whether poorer quality studies should be included or not, which

appraisal criteria to use, and whether quality criteria should be used at all given the varying methodologies often employed (Atkins et al., 2008). The Swedish Agency for Health Technology Assessment and Assessment of Social Services (SBU, 2016) have developed a quality assessment checklist for qualitative research studies and this was selected as the quality rating tool because it is specific to patients' and clients' perspectives (see Appendix 1.2), in line with the main research question of this synthesis. It was possible to obtain an overall assessment of study quality, which could be categorised as either high, moderate, or low (see Appendix 1.3). Studies were assessed by the author and a second independent researcher.

### **Data Synthesis**

Meta-ethnography was chosen for this systematic review as it facilitates the synthesis of research studies that use a variety of qualitative methods (Ring, Ritchie, Mandara, & Jepson, 2011) and is a well-developed method for synthesising qualitative data (Britten et al. 2002). Meta-ethnography involves choosing studies to synthesise that are intended to answer a specific research question, reading them a number of times, and recording key ideas from these original studies. These main concepts and interpretations then become the raw data for the synthesis (Britten et al. 2002). Noblit and Hare (1988) (pp. 26-29) described a seven-step process for carrying out a meta-ethnography (see Appendix 1.4). In line with the meta-ethnographic approach, summaries of original findings using the authors' terms and ideas, were gathered for each of the studies. These concepts were compared across studies, and after all key concepts were identified, a search was completed to ascertain whether or not these were present in the articles to be synthesised.

#### **Results**

The search strategy yielded 767 citations. Citations were screened for duplicates and 33 were removed. The title or abstract of the remaining 734 articles were screened and 713 were excluded. It was evident from the title or abstracts that these articles were: not related to the target population (e.g. other mental health illnesses, non-psychiatric conditions); not related to stigma or discrimination; or were not qualitative studies (e.g. reviews, feasibility studies, questionnaire studies). Of the remaining 21 articles, the full-texts were read and assessed for eligibility, and 14 were excluded. Excluded articles were: quantitative studies; not related to the target population; or not related to stigma or discrimination. References of the final seven articles were screened but no new articles emerged. A PRISMA flow diagram of this process is provided in Figure 1. Table 1 provides details on the seven articles included in this systematic review.

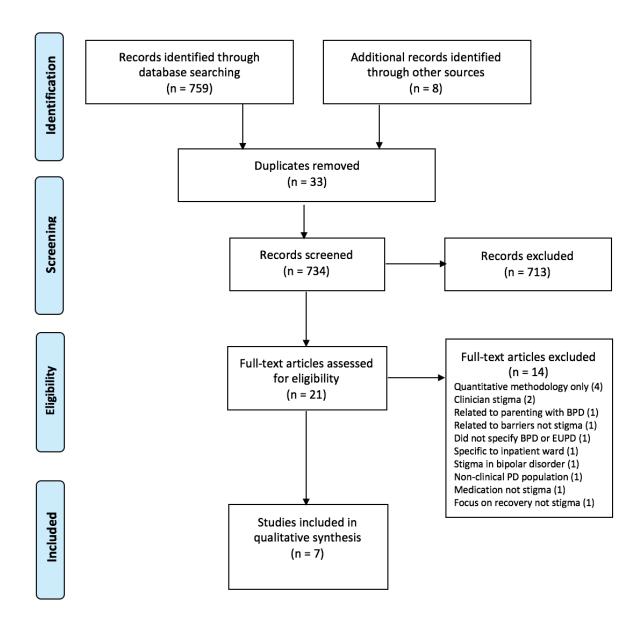


Figure 1. PRISMA flow diagram of systematic review search process and study selection

Table 1. Qualitative research studies exploring experiences of stigma and/or discrimination in people with a diagnosis of Borderline Personality Disorder (BPD)

Authors	Country	Aim	Participants	Design	Key Findings	
Bonnington & Rose (2014)	United Kingdom	To explore experiences of stigma and discrimination amongst people diagnosed with bipolar disorder or borderline personality disorder	22 BPD (n = 17 Focus Groups female; n = 5 male) Interview 24 BD Thematic Analysis		Four themes of participants' (BPD) experiences of stigma & discrimination: cultural imperialism; powerlessness; marginalisation; & violence	
Fromene & Guerin (2014)	Australia	To understand the contextual factors underlying the diagnosis of BPD; experiences of identity; understanding their diagnosis	5 BPD (n = 4 female; n = 1 male)	Interview Thematic Analysis	Themes identified: identity; culture; racism; stereotypes; trauma; family; underlying stigma as a result	
Veysey (2014)	New Zealand	To understand experiences of people with a diagnosis of BPD who self-identified as encountering discriminatory experiences	8 BPD (n = 7 female; n=1 male)	Interview Interpretative Phenomenological Analysis (IPA)	Two thematic areas identified: the impact of the participants' experiences, both helpful and discriminatory, and the relationship between stigma and the complaints process	
Horn, Johnstone, & Brooke (2007)	United Kingdom	To explore user experiences and understandings of being given the diagnosis of BPD	5 BPD (n = 4 female; n = 1 male)	Semi-structured interview IPA	Identified 5 super-ordinate themes: knowledge as power, uncertainty about what the diagnosis meant; diagnosis as rejection; diagnosis is about not fitting; hope and the possibility of change	
Fallon (2003)	United Kingdom	To analyze the lived experiences of the participants' contact with psychiatric services.	7 BPD (n = 4 female; n=3 male)	Interview Grounded theory thematic analysis	Four categories emerged: living with BPD; the service response; relationships; and travelling through the system	
Nehls (1999)	USA	To generate knowledge about the experience of living with the diagnosis of BPD	30 BPD (n=30 female)	Interview IPA	Three themes identified: living with the label; living with self-destructive behaviour perceived as manipulation; and living with limited access to care	

#### **Quality Appraisal**

Of the seven studies reviewed, five met criteria for "high" quality, and two met criteria for "moderate". It was agreed *a priori* that the analysis would indicate which papers contributed to each theme in addition to identifying their level of quality (see Table 2). All seven studies were considered eligible for synthesis based on their quality rating, and those in the "moderate" category would be further considered within the context of limitations. Interrater reliability was excellent, with five of the seven articles receiving the same rating from the independent accessor. Discrepancies regarding the sixth and seventh occurred because of varying interpretations of some of the appraisal questions; through discussion, this was resolved and ratings were agreed. It does not appear that the quality appraisals made a significant difference on the findings of the meta-ethnography as themes were similar across the studies, regardless of the quality of the paper. Meta-synthesis started with the five methodologically strongest papers before the remaining two studies were incorporated into the synthesis; this was to assess for data satiety and to examine any additional data that confirmed or disconfirmed initial interpretations.

# **Synthesis**

Table 2 provides an overview of five key themes that emerged from the synthesis, in addition to which papers contributed to each theme; these were:

- 1. Impact on Self-Image/Esteem
- 2. Hopelessness; BPD as a chronic, permanent diagnosis
- 3. Resistance from clinicians to explain BPD diagnosis and/or withholding information
- 4. Discrimination
  - i. From Clinicians/Healthcare Professionals
  - ii. From others

# 5. Feeling like a burden

For the purpose of this synthesis, only themes found in four or more of the selected articles, i.e., more than 50%, would be included in the body of this review. The themes were not excluded due to the quality of the papers as all seven papers were of either 'high' or 'moderate' quality. Two additional themes found in three articles were noted: individuals with BPD perceived to have control over their actions, and diagnosis as either helpful or unhelpful. The analysis of these can be found in Appendix 1.5.

Table 2. Emerging themes from synthesis of selected papers, categorised by quality rating

New Themes from	Papers (Quality Rating: High)				Papers (Quality Rating: Moderate)		
Analysis	Bonnington & Rose (2014)	Veysey (2014)	Horn, Johnstone, & Brooke (2007)	Fallon (2003)	Nehls (1999)	Fromene & Guerin (2014)	Miller (1994)
Impact on Self-Image/Esteem		<b>√</b>	<b>√</b>	<b>√</b>	<b>√</b>	<b>~</b>	<
Hopelessness/BPD as a chronic, permanent diagnosis	<b>√</b>	<b>√</b>	<b>√</b>		<b>√</b>		<b>✓</b>
Resistance from Clinicians to explain diagnosis/withhold information	<b>√</b>		<b>√</b>	<b>√</b>	<b>√</b>	<b>√</b>	
Discrimination  Clinicians/Healthcare  Professionals	<b>√</b>	✓	<b>√</b>	<b>√</b>			<b>√</b>
Others	<b>√</b>				<b>√</b>	<	<
Feeling like a burden			<b>√</b>		✓	✓	✓

### Theme 1: Impact on Self-Image/Esteem

Six of the included seven studies addressed the impact having a diagnosis of BPD had on their self-image and/or self-esteem. For some, diagnosis had led to discriminatory experiences thereby negatively impacting how they viewed themselves: "not as human, as others" (Veysey, 2014, p. 26); others' self-harm led to feelings of guilt and embarrassment, "which both reinforced low self-esteem and increased feelings of isolation" (Fallon, 2003, p. 399); and for some diagnosis led to a reinforcement of both implicit and explicit self-judgement:

You're this...you're a sod, you're a slimey. I was already in the mindset where I was a bit of a failure...a freak...because I had no explanation...my nature is that I do internalise, sort of, my problems...And you know, you're this, you're a sod (Horn, Johnstone, & Brooke, 2007, p. 261).

Some individuals felt the diagnosis meant they would now be labelled as a difficult client (Horn et al. 2007), which inadvertently reinforced their own self-beliefs: "I had no self-respect...I'm a reject" (p. 262).

As Miller (1994) outlined, participants often held a view of themselves as estranged from others and "inadequate in the face of perceived social standards" (p. 1216), but also found that rather than having an impaired sense of self (DSM-5 BPD diagnostic criteria, American Psychiatric Association, 2013) participants instead identified their sense of self as intact, but recognised they may have impairments in their behaviours. Alongside difficulties resulting from the reinforcement of self-judgements was the impact on the participants' experience of self, which Fromene and Guerin (2014) argued was affected by being forced to integrate both positive and negative notions of self.

#### Theme 2: Hopelessness/BPD as a chronic, permanent diagnosis

A sense of hopelessness and permanency following a diagnosis of BPD was evident across five papers. Participants recounted their feelings on the permanency of the diagnosis, not believing things could change for them: "The best we [BPD clients] can do is the least amount of damage to ourselves as possible and this is going to be our lives" (Veysey, 2014, p. 26). This was echoed by Nehls (1999) through a participant's description of diagnosis as something "you can never get rid of..." (p. 288), whilst other participants explicitly stated their sense of the word 'disorder' implied permanency (Horn et al. 2007, p. 263). Others described diagnosis as the "killing of hope...it almost feels like, well, your hands are tired, your cards laid and your fate set" (p. 262).

But to have a diagnosis means you are just screwed. Once you have that on a piece of paper in a medical file, it's over. It's just over. No one will touch me with a ten-foot pole. It's like you got the plague (Nehls, 1999, p. 287).

Another participant within the Horn et al. (2007) cohort appeared to be resigned to the fact that there was nothing they could change about their diagnosis, stating: "Well, okay, that's what I've got. Y'know? There's nothing I can do about it. Got to accept it" (p. 263). Another stated: "I didn't have a positive outlook of my future for quite a number of years." (p. 262). Miller (1994) stressed a sense of estrangement that followed diagnosis, highlighting that a number of the participants felt unable to meet society's standards, which lead to feelings of inadequacy and despair. This was echoed by Nehls (1999) who quoted participants as feeling blamed and undeserving of treatment (p. 288).

Theme 3: Resistance from Clinicians to explain diagnosis and withholding of information

A sense of reluctance on the part of healthcare professionals to give a diagnosis of BPD or explain it in greater detail was highlighted across a number of the articles. Fallon (2003) described this as most evident for participants when first entering the mental health system via their general practitioner, highlighting variability across explanations that were given by various mental health professionals. It is unclear whether this was for those who had already received a diagnosis of BPD, but the author felt that despite the participants' distress and concern, "some received no explanations concerning the roles of the individuals they were seeing, or of their function" (p. 398). Bonnington and Rose (2014) described participants' experiences of healthcare as one that left the individuals in a "disempowered limbo for long periods" whereby: a) their diagnosis and treatment was withheld or b) they were given the diagnosis but told no treatment was locally available (p. 13). They further noted a sense of BPD patients feeling as if they were "being held at arm's length" (p. 13) which often led to disengagement from mental health services. Horn et al. (2007) highlighted the same sentiment, stating "that all participants reported that initially they were given little information or explanation about the diagnosis" (p. 260). The authors explained that a participant described "how many questions were met with "No, this is definitely what you have. We are 100% sure" (p. 261). That sense of expertise or the 'expert-role' was further highlighted by Fromene and Guerin (2014) whose participant stated:

I didn't really know anything about it [BPD]. I would have liked a lot more information. She just gave it to me and said "you have got BPD." And I said, "Okay what is that?" and she said "Ah, well, that is what you have got" (p. 575).

A number of participants explicitly stated they had to engage in their own research in order to find out further information about BPD: "He wouldn't explain it or anything. He said

'You have a personality disorder. You have a character disorder' I had to go and research what that meant. I had no idea what he was talking about..." (Nehls, 1999, p. 287). Another participant explained: "[I had] to try and find out more about it...it was almost as though I had to be quite challenging to professionals, by being persistent and for quite a large part of the response in that I was..." (Horn et al. 2007, p. 261). Fromene and Guerin (2014) stated that all individuals in their study had wanted more information about BPD and potential treatments: "I still feel that it needs to be explained to me more...If I've got a better understanding of it, I might be able to change it and became a better person..." (p. 575) with three out of five individuals stating they had not been given any information about BPD.

#### Theme 4: Discrimination

From Clinicians/Healthcare Professionals

Five of the seven papers described participants perceiving negative attitudes and discrimination from clinicians/health care professionals in relation to their diagnosis of BPD. Participants described themselves being perceived by healthcare professionals as "liars, attention-seeking, unreasonable/difficult, manipulative, and taking resources from other patients" (Veysey, 2014, p. 26); another was told she was "undeserving of inpatient care" (Fallon, 2003, p. 397). Attention-seeking was highlighted on numerous occasions (Bonnington & Rose, 2014; Veysey, 2014; Nehls, 1999) with one participant stating: "Well of course I'm seeking attention. I need help; I'm terribly depressed...[but] I've done dozens of mutilations and not told anyone" (Nehls, 1999, p. 289). Another participant explained: "you walk into the emergency room, and they don't want to treat you because you did this to yourself...they think it's just attention seeking. But that's not what is about" (p. 287). Nehls argued that by viewing manipulation as being an inherent part of a borderline disorder, health care providers were responding negatively to the individual with BPD.

Some individuals felt diagnosis was an opportunity for clinicians and healthcare professionals to discriminate by rejecting them from services: "I think to be honest they were glad to be shot of me" (Horn et al. 2007, p. 261). Bonnington and Rose (2014) affirm this, stating "the use of it [diagnosis] to the doctors was that it meant they no longer had to bother to make an effort because "she's one of those we can't help" (p. 13). Nehls (1999) outlined one participant's perception that clinicians think "no matter what we do, it's not enough, therefore we'll just put an end to it [services]" (p. 290) with another stating "we're not going to get anywhere with her anyway" (p. 288).

#### From Others

Bonnington and Rose (2014) stated many participants "anticipated/experienced stigma in public relating to visible signs of their distress, such as scars or 'challenging behaviour' which made them 'discredited'" (p. 14). Some individuals felt their mental health was dismissed by friends or family and others felt there was an absence of public awareness regarding accurate information about BPD. Others recounted experiences of physical and psychological violence as a result of their diagnosis, particularly when first entering into healthcare settings (p. 14). A participant from Nehls (1999) explained:

I've had a lot of negative experiences as a result of what I consider more of a label than a diagnosis. I've learned from experience not to give that diagnosis...because it just has a lot of negative ramifications. I mean, immediately it puts up a stop sign, like "oh here, you know she has borderline. She's going to be difficult to work with (p. 288).

Miller (1999) echoed a sense of participants feeling inadequate and estranged from others as a result of their diagnosis, particularly with regard to meeting perceived social standards.

### Theme 5: Feeling like a burden

Four of the seven included studies highlighted that a sense of burden was experienced by individuals with BPD, often describing feeling they were a "burden to everyone" (Horn et al. 2007, p. 261). Others were concerned with not "wanting to burden anyone" (Miller, 1994, p. 1218), in addition to a sense of fear that others would tire of hearing them repeat the same issues. As one participant explained:

I guess I can understand...they [healthcare professionals] hear from me quite often, and, I suppose, I'm the little boy that cries wolf, and they're kind of tired of it. But I'll call, and I'm legitimately having what I would consider a crisis (Nehls, 1999, p. 288).

Fromene and Guerin (2014) noted, one participant held a fear of becoming a burden to their children and was attempting to no longer be absent in their lives. Similarly, a participant in Nehls (1999) study felt that the impact of having BPD and subsequent pain she was experiencing as a consequence of the diagnosis was "so overwhelming that it overshadow[ed] [her] love for them [her children]" (p. 289).

#### **Discussion**

This systematic review synthesised qualitative studies exploring experiences of stigma and discrimination in individuals with a diagnosis of BPD to facilitate greater understanding of their views and experiences. Seven themes were identified through the meta-synthesis, five of which were included in the main body of this review: impact on self-image/esteem; hopelessness; resistance from clinicians to provide information or explain a BPD diagnosis; discrimination (from clinicians and from others); feeling like a burden. Control and diagnosis (as helpful or unhelpful) were additional synthesised themes not included in the main body of this review, but are noted in Appendix 1.5.

This review found that individuals with BPD felt the diagnosis had an impact on their self-esteem and self-image. This is consistent with previous research that examined the impact of having a mental illness diagnosis on self-image (Horn et al. 2007), with the label itself leading to an internalised and disempowered view of self (Knight, Wykes, & Hayward, 2003). It is important to consider that internalised stigma experienced by these individuals appears to be at least in some part, rooted in their experience of seeking help from services. Castillo (2000) has argued that there is a need to reconsider the label of personality disorder, as it has the potential to sustain an impaired sense of self in individuals with a personality disorder diagnosis, although this was in reference to individuals with a diagnosis of schizophrenia. Nonetheless, the broader label of personality disorder still applies to a population with BPD. This is consistent with the experiences described previously in this synthesis, by which some individuals experienced discrimination first-hand as a result of their diagnosis, leading to an impaired sense of self (Veysey, 2014), and others finding the diagnosis reinforcing both implicit and explicit self-judgement (Fallon, 2003).

This review found that individuals experienced feelings of hopelessness following their diagnosis of BPD, which was often influenced by their belief that the disorder was chronic and permanent. Hayne (2003) notes that clients who received a psychiatric diagnosis found the use of medical language as destructive, stating that clients' distress was due to "pure knowing; hearing a medical term that is taken as absolute and irrefutable fact" (p. 725). This sentiment was echoed across this review, with participants explicitly stating their sense of the word 'disorder' suggested permanency (Horn et al. 2007). Participants linked their sense of hopelessness to their perception of the permanency of a diagnosis, with little hope for their future (Veysey, 2014), a sense of all hope being taken away (Horn et al. 2007), and diagnosis increasing their sense of marginalisation and estrangement from society in general (Miller, 1994; Nehls, 1999).

A significant proportion of participants' hopelessness stemmed from their belief that BPD was a permanent diagnosis, with little understanding of the potential for change. However, there is evidence to indicate that BPD is not a life-long condition, with a reduction in symptoms over time (Biskin, 2015; Zanarini, Frankenburg, Reich, & Fitzmaurice, 2012). This links to participants' experiences of clinicians' explanations of BPD and perceived resistance to providing adequate information. It may be that clinicians are not aware of the long-term prognosis and longitudinal course of BPD and therefore are not able to provide this information to individuals when first diagnosed. This may have clinical implications for how individuals view themselves and how they engage with services going forward, in addition to potentially contributing to a sense of hopelessness, as evidenced by participants' experiences in this synthesis.

This review found that individuals with BPD felt that clinicians appeared resistant to providing adequate information regarding their diagnosis; others felt clinicians withheld information. It was noted that for some individuals, this was first experienced when moving into a mental health service via their general practitioner, with many individuals finding the explanations provided to be highly variable (Fallon, 2003). Participants consistently felt they were not provided adequate information and that they often had to conduct their own research to gather additional information, whilst others sensed they were being held at "arms-length," leading to their subsequent disengagement from services (Bonnington & Rose, 2014; Fromene & Guerin, 2014; Horn et al. 2007; Nehls, 1999). Given that mental health practitioners are the next point of contact after general practitioners, for individuals with BPD they may be the first people to diagnose BPD and by doing so are in a unique position to impact how an individual with BPD experiences the diagnosis and influence their understanding. As such, the clinician may inadvertently reinforce stereotypes or reinforce the individual's lack of self-esteem by withholding, or not providing, adequate information.

Evidence from this review has indicated that a number of participants who received a diagnosis of BPD found the information they were provided often instilled a sense of hopelessness; clinically this could have implications for how clinicians provide information or diagnosis. It may be that this could encourage a more standardised BPD-specific pathway to care that could stipulate a level of psychoeducation that must be provided to newly-diagnosed individuals when first entering mental health services.

There is research that highlights clinician and healthcare professionals' stigma towards individuals with BPD (see Dickens, Lamont, & Gray, 2016; Sansone & Sansone 2013, for reviews of the literature). This review substantiates those findings, with participants detailing their experiences of discrimination from clinicians and other healthcare providers. This discrimination is not exclusive to BPD and has been demonstrated towards mental health problems more broadly (Corrigan, 2005) but there is some evidence to indicate that BPD is discriminated against more so than others (Biskin, 2015). Biskin argues this may be in part due to many clinicians' view of BPD as an "untreatable" (p. 305) condition, and that clinicians often encounter individuals with BPD in crisis settings, which is not where they would receive treatment, resulting in a biased perspective of the clients. Some individuals felt diagnosis was an opportunity for clinicians to discriminate by rejecting them from services, and further research could be considered to explore whether individuals with other mental health illnesses similarly perceive receiving a diagnosis as a way for services to reject them.

Individuals with BPD described discrimination from others, but it was not necessarily due to the diagnosis itself but instead as a result of the *symptoms* of their diagnosis. That is, individuals with scars on their arms from self-harming or those engaged in behaviours deemed challenging felt discriminated against by the public due to their visibility and experiences they felt were not always entirely in their control. This highlights that stigma and

discrimination may not exclusively be linked to the internal label provided, but instead may be the result of the physical, external presentation of their mental illness.

This review highlighted that a number of individuals with BPD were concerned they were a burden on others, particularly their children (Horn et al. 2007; Nehls, 1999; Miller, 1994). Parental concern about their mental health being burdensome on their children is not exclusive to individuals with BPD alone but expands to mental illness more broadly; in their systematic review of the literature Wahl, Bruland, Bauer, Okan, & Lenz (2017) found that parents with mental ill-health had three primary concerns: the need for being a good parent; worries about the child's well-being; and the need for practical help. Additional research indicates variable findings with regard to the evidence around the impact of parental mental illness on children, however it would appear that providing psychoeducation and peer support to children of parents with mental illness may be well-indicated (Gladstone, Boydell, Seeman, & McKeever, 2011). This could contribute to a reduction in parents' concern about the burden they may be placing on their children, which may have a positive impact on their overall well-being.

#### **Strengths and Limitations**

Unpublished or grey literature studies were excluded and it may be that inclusion of these would have added to the range of studies. To counter this selection bias, the included studies were peer-reviewed which provided reinforcement to the overall quality of methodologies. A decision was made not to exclude papers on the basis of quality as there is no consensus on the application of quality criteria to qualitative research (Atkins et al., 2008). All papers were critically appraised prior to beginning the meta-synthesis and themes emerging from the two methodologically weaker studies were largely consistent with the five methodologically stronger studies.

A limitation of this review is that sampling bias may have impacted on the findings, as the participants who chose to take part in the research may have been motivated to share their experiences, whereas those who chose not to take part may not have experienced stigma and/or discrimination. The articles selected for this review were conducted in Europe, United States of America, Australia, or New Zealand; therefore, the results of the review may not fully reflect the experiences of participants from alternative geographical locations or cultural backgrounds. It is important to consider that different healthcare services may also have had an impact on the findings. Limiting the search to studies published in English language meant that studies in different cultural contexts may have been missed. Qualitative research is rarely published in high ranking journals (Gagliardi & Dobrow, 2011); this finding combined with the exclusion of unpublished research from this review may have limited our understanding of the topic area. More qualitative studies in this field could allow for additional analysis to be carried out which may capture further details about the experiences of stigma and/or discrimination in individuals with a diagnosis of BPD. In light of these limitations, it is important to acknowledge that the results of the current review may not be entirely conclusive.

### Reflexivity

The synthesis and interpretation of the findings may have been influenced by the author's experience of working with young adults with a diagnosis of BPD as part of their major research project. To maintain reflexivity as much as possible, the author looked at the data and its interpretation for competing conclusions.

#### **Clinical and Research Implications**

This review has highlighted a need for improved understanding in healthcare providers and services of both the symptomology of BPD and longer-term outcomes

following diagnosis. One of the main findings of this review was that individuals felt they were not provided with adequate information regarding their diagnosis. It may be that a standardised pathway of care following diagnosis could be introduced across health services, that would indicate mandatory psychoeducation be provided. Given that participants in this review felt a sense a hopelessness as a result of their belief in the permanency of a BPD diagnosis, clearer psychoeducation could encourage a sense of empowerment in patients and lead to a reduction in hopelessness, which in turn may improve their overall wellbeing. This review also recognises that clinicians may not have access to current research on BPD and therefore they may not feel confident when providing information regarding the diagnosis. Given that BPD is the most common of personality disorders in clinical practice (BPS, 2009) mental health practitioners should have access to current research on BPD. Further research on how best to make this information more accessible to mental health providers is warranted. Additionally, further research could investigate the two themes not included in the final analysis of this review, in particular, the view of diagnosis seen as both helpful and unhelpful in individuals with BPD.

This review has highlighted a need for mental health professionals and services alike to consider the validity of a diagnosis of BPD and whether the perceived benefit outweighs cost, as experienced by individuals in this study. Current DSM-5 diagnostic criteria for BPD includes a pervasive pattern of instability of self-image (APA, 2013) and Miller (1994) summarised clinicians' understanding and descriptions of BPD as including identity disturbance and an impaired sense of self. However, this review found that patients with BPD described themselves as having a cohesive identity; rather than having an *impaired* sense of self, they had *a sense of an impaired self*. It is important to recognise that this is not applicable to all individuals with a diagnosis of BPD but it does highlight that further

research may be warranted to investigate the real-life validity of these criteria for a diagnosis that can in fact show a reduction in symptoms over time (Biskin, 2015).

#### Conclusion

To the author's knowledge this is the first qualitative meta-synthesis of experiences of stigma and discrimination in individuals as a result of, and living with, a diagnosis of BPD. This review has provided an opportunity to gain a greater understanding of their experiences and highlights that individuals report experiencing stigma and discrimination as a direct result of receiving a diagnosis of BPD. This review has highlighted areas for further research that may contribute to a reduction in stigmatisation and discrimination of individuals with BPD and improve healthcare providers' understanding of the longer-term prognosis following diagnosis.

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# **Exploring Neurodevelopmental Profiles of Young People with Borderline Personality Disorder: A Feasibility Study**

Chapter word count: 6,593

Prepared in accordance with *Journal of Personality Disorders* (Author submission instructions Appendix 2.1)

## **Plain English Summary**

**Title:** Exploring Neurodevelopmental Profiles of Young People with Borderline Personality Disorder: A Feasibility Study

**Background:** Borderline personality disorder (BPD) is a complex diagnosis describing difficulties regulating emotions, problems with relationships, and self-image. BPD has been associated with Adverse Childhood Experiences (ACEs) such as breakdown in important childhood relationships, and sexual or physical abuse. It has been suggested that there may be an overlap between BPD and Neurodevelopmental Disorders (NDDs) such as Autism Spectrum Disorder (ASD) or Attention Deficit Hyperactivity Disorder (ADHD). It may be that NDDs go unrecognised and it is therefore important to identify the extent to which these problems may contribute to the problems associated with BPD.

# **Aims and Questions**

The primary aim of this research was to explore the feasibility of recruitment of young people with BPD to investigate the prevalence of NDDs using a screening tool. This study further aimed to investigate profiles of young people with BPD with regards to NDDs, difficulties in emotion regulation, attachment, and ACEs.

# 1. Feasibility

- a. Is it feasible to recruit young people meeting criteria for BPD?
- b. What are the sources of referrals?
- c. Are the selected assessment measures helpful in facilitating a clearer understanding of the neurodevelopmental and clinical profile of young people with BPD with regards to NDDs, emotion regulation, attachment, and ACEs?
- 2. How many young people that meet criteria for BPD screen positive for ADHD and/or ASD?

## Method

# i. Participants

#### Inclusion Criteria

- Aged between 15-35 years old;
- Must meet a minimum of 2 out of 9 criteria for a BPD diagnosis or already have a diagnosis of BPD;
- Written informed consent
  - For participants under the age of 16, a parent or legal guardian must consent on their behalf.

## Exclusion Criteria

Non-English speaker

## ii. Recruitment

**a.** The study was presented to numerous mental health teams and services across NHS Greater Glasgow & Clyde. Participants were then referred by a mental health professional to the study from a range of those services: Community Mental Health Teams (CMHTs), Primary Care Mental Health Teams (PCMHTs), Clinical Psychology Services, Community Adolescent Mental Health Services (CAMHS), Personality Disorder Teams (AMHS).

# iii. Design of study

**a.** This was a feasibility study; descriptive statistics were completed and exploratory analysis conducted.

## iv. Data Collection

**a.** Data were collected over 2 meetings with the researcher, where participants were asked to answer a number of questionnaires.

# **Main Findings and Conclusions**

Twenty-nine young people with BPD, aged between 15 and 33, were recruited. The study found that it is feasible to recruit this population, the greatest source of referrals was from CAMHS, and the assessment measures selected were appropriate to use. The study also found that 58% (n = 17) of participants screened positive for ASD and almost 80% (n = 23) for ADHD. Twenty-two (76%) of the participants had experienced at least 1 ACE. The high proportion of participants screening positive for NDDs warrants further research.

## **Practical Applications and Dissemination**

By investigating the feasibility of conducting a study exploring NDDs in young people with BPD we have increased our understanding of the possible prevalence of NDDs in BPD. This provides an important basis to pursue further research in this area. This study was submitted as part of a research portfolio for the Doctorate in Clinical Psychology and it is hoped the results of the study will be published in an appropriate academic journal.

#### **Abstract**

**Background:** Borderline personality disorder (BPD) is the most common of personality disorders presenting in clinical practice. Limited research has been conducted on the potential overlap of neurodevelopmental disorders (NDDs) and personality disorder. However, increasing evidence demonstrates clinical symptom overlap and/or comorbidity between BPD and Attention Deficit Hyperactivity Disorder (ADHD) and Autism Spectrum Disorder (ASD). Aims: The primary aim was to pilot the feasibility of recruitment of young people with BPD to investigate the prevalence of NDDs. The secondary aim was to investigate profiles of young people with BPD with regards to NDDs, emotion regulation, attachment, and adverse childhood experiences (ACEs). Methods: Participants were recruited from a number of mental health teams and services. Data from psychometric assessment measures were collected over two meetings. Descriptive statistics were completed and exploratory analysis conducted. Results: Twenty-nine young people with BPD, aged between 15 and 33, were recruited. Of this group 58% (n = 17) screened positive for ASD and 80% (n = 23) for ADHD. Twenty-two (76%) of the participants had experienced at least 1 ACE. This pilot study evidenced feasibility of recruitment of young people with BPD, indicating it could be conducted on a larger-scale. The selected psychometric assessment measures were helpful in facilitating a clearer understanding of the neurodevelopmental profile of young people with BPD. Conclusion: Given the importance of early intervention for young people with BPD, understanding the neurodevelopmental profile of these individuals presenting to mental health services may lead to improved long-term outcomes. The high proportion of participants screening positive for NDDs warrants further research.

**Key words**: Borderline Personality Disorder; Neurodevelopmental Disorder; Feasibility; Autism Spectrum Disorder; Attention Deficit Hyperactivity Disorder

Borderline personality disorder (BPD) is a complex mental health problem characterised by a pervasive pattern of instability in affect regulation, impulse control, interpersonal relationships, and self-image (Lieb et al., 2004). It affects about 1.4% of the general population, but it is the most common of personality disorders in clinical practice (The British Psychological Society, 2009). It is crucial to understand the association between risk factors such as adverse childhood experiences (ACEs) and the development of BPD due to its association with significant psychosocial impairment and morbidity, greater usage of mental health resources, and high mortality rate (Fonagy & Bateman, 2006).

BPD typically emerges during adolescence however the condition often goes unrecognised because diagnosis of personality disorder in this age group is difficult and controversial (Chanen, McCutcheon, Jovev, Jackson, & McGorry, 2007b). In fact, mean levels of BPD traits are highest in early adolescence and evidence indicates that the diagnostic criteria for BPD are as reliable, valid and stable before age 18 years as they are in adulthood (Crawford, Cohen, & Johnson, 2005). Importantly, BPD traits in young people also show considerable flexibility and malleability (Lenzenweger & Castro, 2005). Subsyndromal BPD refers to those individuals who do not meet full criteria for BPD (Chanen et al, 2007a); these findings indicate that prevention and early intervention for both BPD and subsyndromal BPD is plausible. Despite increased understanding of neurobiological and psychosocial risk factors for BPD, prospective developmental data on adolescents and young adults are rare (Kaess, Brunner, & Chanen, 2014). To date, there does not appear to be any epidemiological data reporting childhood rates of psychopathology in adults with BPD.

There has been less research on the potential overlap of neurodevelopmental disorders (NDD) and personality disorder, but there is increasing evidence demonstrating clinical symptom overlap and/or comorbidity between Attention Deficit Hyperactivity Disorder

(ADHD) and BPD (Xenaki & Pehlivanidis, 2015). ADHD in BPD is characterized by increased symptoms of impulsivity, additional psychopathology, and increased psychosocial difficulties (O'Malley, 2016). Data from adults with severe borderline personality disorder frequently indicate a history of childhood ADHD symptomology (Philipsen et al., 2008). In clinical practice, inattention and hyperactivity lead to difficulties in the acquisition of knowledge and skills necessary to deal with the consequences of both disorders (Ebert, 2003). Therefore, treatment of comorbid ADHD in BPD patients may enhance psychotherapeutic outcomes, particularly within early interventions. There is significantly less evidence regarding the potential overlap or comorbidity of Autism Spectrum Disorder (ASD) and BPD, which may be in part due to the gender bias of under-reporting ASD diagnoses in females (Loomes, Hull, & Mandy, 2017), and the higher ratio of females diagnosed with BPD versus males (Banzhaf et al., 2012). Available evidence indicated a small proportion of women (15%) with BPD also met criteria for ASD (Ryden, Ryden, & Hetta, 2008) and Dudas et al., (2017) found some evidence of elevated autistic traits in individuals with BPD. At the time of writing, there appears to be no research investigating rates of NDD in either young people with BPD or subsyndromal BPD, highlighting a need for further research to investigate possible comorbid presentations.

Affective dysregulation is a core feature in ASD and ADHD (Hill, Berthoz & Frith, 2004), and is also a central feature of BPD, therefore it is an important focus for investigation because of its links with suicidality (Bowen et al., 2015). The benefits of effective emotion regulation are not only linked to a decreased vulnerability in the development and maintenance of psychopathology, but there are data that suggest that effective emotion regulation promotes mental stability (Putnam & Silk, 2005). Given its feature in both NDD and BPD, exploration into the rate of affective dysregulation in young people with BPD with or without NDD requires further research.

With research increasingly demonstrating the importance of early interventions for improved longer-term psychosocial and physical health outcomes (Chanen, 2015), having a clearer understanding of the neurodevelopmental and clinical profiles of young people with BPD may provide an opportunity for support to be offered in a more tailored, profile-specific way.

#### Aims

The primary aim of this research was to pilot the feasibility of recruitment of young people with BPD and subsyndromal BPD to investigate the prevalence of NDDs. This study further aimed to investigate the profiles of young people with BPD or subsyndromal BPD with regards to NDDs, emotion regulation, attachment, and ACEs.

## 1. Feasibility

- a. Is it feasible to recruit young people meeting criteria for BPD and subsyndromal BPD?
- b. What are the sources of referrals?
- c. Are the selected psychometric assessment measures helpful in facilitating a clearer understanding of the neurodevelopmental profile of young people with BPD with regards to NDDs, emotion regulation, attachment, and ACEs?
- 2. What is the prevalence of positive screens for ADHD and ASD in young people meeting criteria for either BPD or subsyndromal BPD?

#### Method

The research project was embedded within a larger feasibility study, The Pathways Project. The primary objective of the larger feasibility study was to understand the symptomatic overlap between two groups of young people 'at-risk' of developing severe and enduring mental health difficulties, namely young people at risk of, or experiencing firstepisode psychosis and young people with either BPD or subsyndromal BPD. The secondary objective was to establish the prevalence of affective dysregulation, NDDs, and early risk factors (attachment difficulties and childhood adversity), in these two groups. For the purpose of the author's research, it was agreed their focus would be on the secondary objective with the BPD group, but all data collected would be shared with the Pathways project. In addition, any BPD data acquired prior to the author's commencement on the project would be made available to the author to be included in the final data analysis. It was hoped that the feasibility study would assist in developing collaborations with clinical academics across the United Kingdom for a grant proposal to the NIHR for piloting an intervention programme for multi-morbidity amongst adolescents at-risk of severe and enduring mental health difficulties; with a specific treatment focus on affective dysregulation and relational difficulties emerging from attachment difficulties and ACEs.

#### **Participants**

#### Inclusion Criteria

- Any young person aged 15 to 35 years old who meets between 2 and 4 of 9 criteria for the BPD section of the Structured Clinical Interview for DSM-IV II: Personality Disorders (SCID-II) (Chanen et al, 2007a), or already has a diagnosis of BPD.
- Written informed consent

 For participants under the age of 16, a parent or legal guardian must consent on their behalf.

Exclusion Criteria

• Non-English speaker

## **Materials**

Assessment Measures & Diagnostic Interviews

Below is a brief outline of the assessment measures and diagnostic interviews used; detailed descriptions of each can be found in Appendix 2.2. The measures were used to investigate ACEs, attachment, emotion regulation, NDDs, and BPD symptoms, in addition to a diagnostic interview to confirm either subsyndromal or syndromal BPD criteria were met.

Adverse Childhood Experience (ACE) Questionnaire (Felitti et al., 1998).

Psychosis Attachment Measure (PAM) (Berry, Wearden, Barrowclough, & Liversidge, 2006)

Borderline Personality Questionnaire (BPQ) (Poreh et al., 2006)

The Structured Clinical Interview for DSM-IV-II (SCID-II BPD Section) (First, Spitzer, Gibbon, & Williams, 2002)

Difficulties in Emotion Regulation Scale (DERS) (Kaufman et al., 2015)

Adult ADHD Self-Report Scale (ASRS-v.1.1) (Kessler, R. WHO Composite International Diagnostic Interview, 2003)

Autism Symptom SElf-Report for Adolescents and Adults (ASSERT) (Posserud, Breivik, Gillberg, & Lundervold, 2013)

#### **Procedure**

The larger feasibility study (Pathways) was supported by a research assistant who recruited to both arms of the study between December 2016 and July 2018, with the author joining the team to support recruitment between December 2017 to May 2018. Participants were recruited across a number of services within NHS Greater Glasgow and Clyde.

Members of the Pathways research team visited services to introduce the study and eligibility referral criteria to the teams. Psychiatrists, Clinical Psychologists, mental health nurses, and other clinicians were contacted directly via e-mail with information about the study included. Clinicians were asked to identify potentially eligible participants from their caseload.

Any contact details provided by the clinicians and patients were kept securely in a password-protected file that could only be accessed by the author and other members of the Pathways research team. Potential participants were given a minimum of 24 hours before the author contacted them to arrange an appointment to seek informed consent. At the first visit, participants providing informed consent were given the opportunity to ask any further questions about the study and begin the assessments. At the second visit, all remaining measures were completed.

## Settings and Equipment

Interviews were conducted in a number of settings, including the clinic of the referring CAMHS team or CMHT. If required, participants were interviewed at their home but only if the patient's clinician concluded it was safe to do. In those instances, the research staff followed both University of Glasgow and NHS lone worker policies.

## Data Analyses

Analyses for this study were performed using IBM SPSS Statistics v. 25 (SPSS Inc., Chicago, IL, USA). Descriptive and exploratory post hoc analysis were completed. Missing data analysis (MDA) was conducted to determine whether any missing data were completely at random (MCAR) and single imputation (SI) (van der Heijden, Donders, Stijnen, & Moons, 2006) was used by adding their subscale mean scores to generate a new mean score for the missing values.

## Sample Size

Given this research is embedded within a pilot feasibility study, there were few studies available to use as reference in order to generate an estimate of sample size. However, based on methodology used successfully in previous studies of this group (Bechdolf et al., 2010), the study aimed to recruit 30 young people (age 15-35 years), 15 with subsyndromal BPD and 15 with BPD.

## Ethical Conduct of the Study

Managerial approval for the Pathways study was granted on 03 August 2016 (R&D Reference: GN15AM216) (Appendix 2.3) and favourable ethical opinion received from the West of Scotland Research Ethics Committee (REC) (Reference: 16/WS/0133) on 23 August 2017 (Appendix 2.4)

## Disclosure of maltreatment, abuse or neglect

If participants (aged 15) had disclosed any information that indicated maltreatment, abuse or neglect towards them, then the author would have made an enquiry with the local social services team for advice in the initial instance. Following this, a child protection referral would have been made to the appropriate team for investigation, and the participants'

care team informed of disclosure. Any disclosure made by a young person or adult (aged 16 – 35) during the assessment would have been kept strictly confidential within the research team. However, if a disclosure of maltreatment, abuse or neglect was made that could have potentially caused present risk to the child, a child protection referral would have been made to social work services.

## **Results**

## **Feasibility**

Sixty-eight participants were referred to the study, 42 to the subsyndromal BPD arm and 26 to the BPD arm (Figure 1). Participants were referred from primary and secondary care services within NHS GG&C, including Community Mental Health Teams (CMHTs), Child and Adolescent Mental Health Services (CAMHS), and Personality Disorder and Homelessness Services (AMHs).

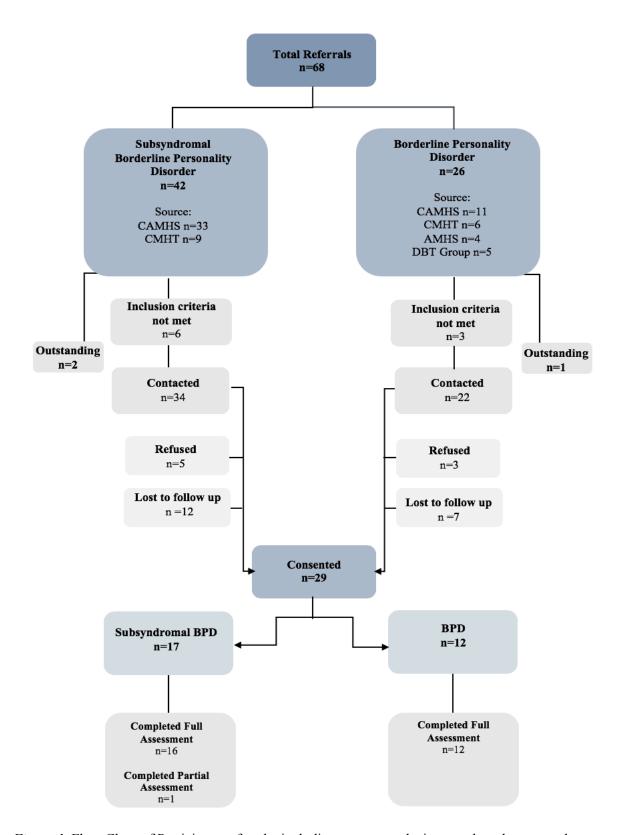


Figure 1. Flow Chart of Participant referrals, including source, exclusions, and total consented

Nine participants did not meet inclusion criteria, as such they were excluded, after which 56 participants were contacted regarding participation, with 3 participants outstanding

at the time of analysis. Eight participants refused participation and 19 were lost to follow-up, with a final 29 participants consenting. Of the 29 consenting participants, the author recruited 15 participants, and the research assistant on the Pathways project recruited 14. The subsyndromal BPD sample comprised 12 females and 5 males (n = 17), with a mean age of 18 (SD = 4.82, minimum = 15, maximum = 33), and the BPD sample comprised 11 females and 1 male (n = 12), with a mean age of 23 (SD = 43.96, minimum = 17, maximum = 30) (Table 2). The total sample comprised 23 females and 6 males, with a mean age of 20 (SD = 5.23, minimum = 15, maximum = 33). Of the participants that were consented, CAMHS provided the highest proportion of referrals (n = 19), followed by CMHTs (n = 6), and a DBT pilot group (n = 4). Twenty-eight participants completed the full assessment (i.e. Visit 1 and Visit 2), and 1 completed half.

Table 2. Descriptive statistics of BPD and Subsyndromal BPD and referral arms

	Referral Arm: Subsyndromal Borderline Personality Disorder	Referral Arm: Borderline Personality Disorder	Total			
<b>Variable</b> N	17	12				
Age	M         SD         Min, Max           18.12         4.82         15, 33	M         SD         Min, Max           23.75         3.96         17, 30	M         SD         Min, Max           20.45         5.23         15, 33			
Gender Female (n, %) Male (n,%)	12 (41.37%) 5 (17.24%)	11 <i>(37.93%)</i> 1 <i>(3.45%)</i>	23 (79.31%) 6 (20.69%)			
Referral Source CAMHS (n, %) CMHT (n, %) AMHs (n, %)	12 (70.56%) 5 (29.42%)	7 (58.33%) 1 (8.33%)	19 (65.52%) 6 (20.70%)			
DBT Group (n, %)	-	4 (33.33%)	4 (13.80%)			

#### **Missing Data Analysis**

A visual inspection of the data indicated the presence of missing data across different scales. As such, missing data analysis (MDA) was conducted to determine whether the data

was missing completely at random (MCAR). Table 3 display's Little's test for each scaled variable, its significance level, and which imputation method was selected. Little's test was found to be non-significant across both scales, indicating the data were MCAR. For both measures, single imputation (SI), shown to produce unbiased estimates and perform well against multiple imputation with small quantities of missing data (van der Heijden et al., 2006), was used by adding their subscale mean scores to generate a new mean score for the missing values.

Table 3. Missing Data Analysis and Imputation Method for BPQ and DERS Psychometric Measures

Scale Variables	Valid Data	N items of the Scale	N items with some missing data	N items completed in full	Participants who missed values N	Missing Values (%)	MCAR (Little's test p > 0.05)	Imputation Method
BPQ	29	80	7	73	3	0.30%	1.00	SI
DERS	29	36	1	35	1	0.09%	1.00	SI

The SCID-II requires a minimum of 5 scores of '3' (threshold) out of 9 items to meet BPD criteria. Twenty-three of the 29 participants met SCID criteria for BPD, as shown in Table 4; of those that did not, 4 met subsyndromal criteria (Chanen et al., 2007), defined as having a minimum of between 2 and 4 scores of '3'. As 27 out of 29 participants met either full or sub-threshold criteria for BPD rather than treating these as two separate groups it was agreed that the participants would be treated as one group, which will henceforth be referred to as BPD. Two participants had missing SCID data, but were retained in the sample.

Fifteen participants met BPQ cut off ( $\geq$ 56) and 14 participants did not (M = 52.28 Mdn = 56.00 SD = 2.20 IQR = 16.00). We further explored the referral pathways to the BPD and Subsyndromal BPD groups by exploring cut off scores on the BPQ. According to this scale a score of  $\geq$  56 is indicative of BPD. Of those referred via the BPD pathway 7 (58.30%) met cut off criteria for BPD. Of those who were referred to the subsyndromal BPD pathway 8

(47.10%) met cut off criteria for BPD. There was no difference in the proportion meeting criteria between the two pathways ( $\chi^2(1) = 0.36$ , p = 0.55).

NDDs, ACEs, Attachment, and Emotion Regulation

Of the 29 participants, 17 screened positive for ASD, as measured by the ASSERT, with total score  $M = 7.66 \, Mdn = 8.00 \, SD = 3.60$  and IQR = 6.00. Twenty-three participants screened positive for ADHD, as measured by the ASRS, with total score  $M = 4.10 \, Mdn = 4.00 \, SD = 0.86$  and IQR = 1.00 (see Table 4). Nine participants had already received an NDD diagnosis of Autism, Asperger's Syndrome, or ADHD prior to taking part in the study; of the 7 in the ASD category, all screened positive on ASSERT and the 2 in the ADHD category screened positive on ASRS, indicating no false negatives. Thirteen participants screened positive on both ASSERT and ADHD measures.

Twenty-two participants (75.86%) had experienced at least one adverse childhood experience (ACE), with emotional abuse occurring most frequently (n = 21), followed by family mental illness or suicide (attempted or completed) (n = 20). Physical abuse (n = 14), parental separation or divorce (n = 13), sexual abuse (n = 12), and familial substance misuse (n = 12) were the next most commonly occurring; see Table 3 for additional ACEs identified. Attachment was measured using the PAM, which assessed two dimensions of attachment, anxiety and avoidance, with higher scores reflecting higher levels of anxiety and avoidance. Results generated  $M = 1.95 \, Mdn = 2.13 \, SD = 0.48$  and IQR = 0.56 for anxious attachment and  $M = 1.75 \, Mdn = 1.75 \, SD = 0.36$  and IQR = 0.44 for avoidant attachment. Emotion regulation was measured using the DERS which yielded a total score of  $M = 130.34 \, Mdn = 135.00 \, SD = 25.16$ . The DERS sub-scale yielded scores as follows: *Non-acceptance of emotional responses* ( $M = 19.66 \, Mdn = 22.00 \, SD = 6.70$ ); *Difficulties engaging in goal directed behaviour* ( $M = 21.31 \, Mdn = 23.00 \, SD = 4.42$ ); *Impulse control difficulties* ( $M = 1.20 \, Mdn =$ 

 $20.45 \ Mdn = 19.00 \ SD = 5.80$ ); Lack of emotional awareness ( $M = 20.93 \ Mdn = 22.00 \ SD = 6.26$ ); Limited access to emotion regulation strategies ( $M = 30.93 \ Mdn = 32.00 \ SD = 6.00$ ); Lack of emotional clarity ( $M = 17.07 \ Mdn = 18.00 \ SD = 4.55$ ).

Table 4. Descriptive statistics of participants with BPD, including SCID, BPQ, NDD, ACE, PAM and DERS measures

	Subsyndromal Borderline	Borderline Personality	Subsyndromal BPD & BPD									
	Personality Disorder	Disorder										
<b>Variables</b> N	17	12	29									
Borderline Personality	1 /	12	29									
Measures												
SCID-II												
BPD Criteria met (%)*	13 (76.47%)	10 (83.33%)	23 (79.31%)									
Subthreshold Criteria	2 (11.76%)	2 (16.67%)	4 (13.79%)									
met (%)**												
4 criteria 3 criteria	1	1 1										
2 criteria	1 1	1										
Missing SCID Data (%)	2 (11.76%)	0 (0.00%)	2 (6.90%)									
	Total Score											
BPQ	M Mdn SD IQR	M Mdn SD IQR	M Mdn SD IQR									
	49.94 49.00 14.57 25.00	55.58 57.00 7.04 12.00	52.28 56.00 2.20 16.00									
Cut-off met (≥56)	8 (47.10%)	7 (58.3%)	15 (51.70%)									
Cut off not met (≤55)	9 (52.90%)	5 (41.70%)	14 (48.30%)									
	F	Borderline Personality Disorde	r***									
	N=29											
Neurodevelopmental	<u>Total Score</u>											
(NDD) Measures	N (%)	M Mdn SD IQR										
ASSERT (ASD)		_										
(% positive screens)	17 (58.60%)	7.66 8.00 3.60 6.00										
ASRS (ADHD)	23 (79.30%)	4.10 4.00 0.86 1.00										
(% positive screens)	23 (77.3070)	4.10 4.00 0.00 1.00										
ASSERT & ASRS (% positive screens)	13 (44.80%)											
(70 postive screens)												
NDD Diagnosis	N (%)											
(Prior to study)												
Autism	1 (3.45%)	1/1 met ASSERT criteria	No false negatives									
Asperger's Syndrome	6 (20.69%)	6/6 met ASSERT criteria	No false negatives									
ADHD	2 (6.90%)	2/2 met ASRS criteria	No false negatives									
Comorbid (2 or more)	0 (0.00%)	-										
	9 (31.04%)											
Adverse Childhood	NT (0/)											
Experiences (ACEs)	N (%)											
Any ACE	22 (75.86%)											
Emotional Abuse	21 (72.41%)											
Physical Abuse	14 (48.27%)											
Sexual Abuse	12 (41.38%)											
Family Substance Misuse	12 (41.38%)											
Domestic Violence	8 (27.59%)											

Family Mental Illness/	20 (68.95%)
Suicide	
Family in Prison	5 (17.24%)
Parental Separation/	13 (44.83%)
Divorce	
Neglect	9 (31.03%)
Not feeling	4 (13.79%)
loved/supported	

Borderline Personality Disorder\*\*\* N = 29

A., 1		Total S	core	
Attachment	M	Mdn	SD	IOR
PAM	171	Muli	SD	IQK
Anxiety	1.94	2.13	0.48	0.56
Avoidance	1.75	1.75	0.36	0.44
	3.5	3.7.1	CIP.	IOD
Emotion Regulation	M	Mdn	SD	IQR
DERS Overall	120.2	4 125 0	0 25 1	6 22 00
Non-Acceptance	19.66	4 135.00 22.00		
Goals	21.31		4.42	
Impulse Control	20.45		5.80	
Emotional Awareness	20.93	22.00	6.26	12.00
Strategies	30.93	32.00	6.00	9.00
Emotional Clarity	17.07	18.00	4.55	6.00

Note \*SCID-II criteria for BPD requires 5 out of 9 criteria to have a response of '3-threshold/true.'

Table 5 shows descriptive data of attachment, emotion regulation, and frequencies of ACEs across the 4 NDD groups: those without any NDD (n = 2); those with ASD only (n = 4); those with ADHD only (n = 10), and those with both ASD and ADHD (n = 13).

Table 5. Descriptive data of BPD & NDD diagnosis and PAM, DERS, and ACEs scores

	BPD & Neurodevelopmental Diagnosis (NDD)															
Variables	No NDD* (n = 2)				<b>ASD only</b> (n = 4)			<b>ADHD only</b> ( n = 10)				ASD & ADHD (n = 13)				
	M	Mdn	SD	IQR	M	Mdn	SD	IQR	M	Mdn	SD	IQR	M	Mdn	SD	IQR
DERS	106.0	0 106.0	00 22.63	3 -	123.25	123.50	13.94	26.25	128.00	128.00	28.28	38.00	136.92	136.00	15.50	21.00
PAM																
Anxiety	1.69	1.68	0.44	-	1.60	1.75	0.31	0.47	1.76	1.75	0.69	1.00	2.20	2.25	0.24	0.25
Avoidance	1.94	1.93	0.08	-	1.66	1.69	0.21	0.41	1.72	1.63	0.35	0.63	1.78	1.75	0.44	0.56
ACE	5.50	5.50	2.12	-	2.50	2.00	3.00	6.00	2.67	2.00	3.00	5.00	5.46	5.00	2.73	5.00

<sup>\*</sup>Note. due to a small sample size, IQR could not be calculated.

<sup>\*\*</sup>Subthreshold (i.e. subsyndromal) criteria is defined as 2 out of 9 SCID criteria met (Chanen et al., 2007)

<sup>\*\*\*23</sup> out of 29 participants met SCID criteria & 4 met subsyndromal SCID criteria so the two groups were combined to form one BPD group.

Sensitivity analyses conducted on the data did not alter the findings in a significant way. As two of the four subgroups had a sample size less than 5, it was decided not to test for differences to avoid potentially erroneous inferences. The No NDD group had the lowest DERS score (Mdn = 106.00), with ASD only Mdn = 123.50, and ADHD only Mdn = 128.00; participants with both ASD and ADHD had the highest score (Mdn = 136.00). PAM Anxiety scores were Mdn = 1.68 for No NDD, Mdn = 1.75 for ASD only, and Mdn = 1.75 for ADHD only. It was found that participants with both ASD and ADHD had the highest score on PAM anxiety, Mdn = 2.25. This was also case for avoidance (Mdn = 1.75) when compared to either ADHD or ASD only (Mdn = 1.63, Mdn = 1.69 respectively). Participants with both ASD and ADHD also had the highest number of ACEs (Mdn = 5.00) as compared to participants with either ADHD (Mdn = 2.00) or ASD alone (Mdn = 2.00).

#### Discussion

The primary aim of this research was to pilot the feasibility of recruitment of young people with BPD and subsyndromal BPD to investigate the prevalence of NDDs. This study further aimed to investigate the profiles of young people with BPD or subsyndromal BPD with regards to NDDs, emotion regulation, and early risk factors such as attachment, and ACEs.

The highest proportion of referrals to the study came from CAMHS which draws attention to the fact that there a number of young people presenting in CAMHS that meet criteria for BPD. This in turn aligns with the evidence base that indicates BPD symptoms often first present in adolescence (Miller, Muehlenkamp, & Jacobson, 2008) and may affirm an on-going need to consider the implications of this for clinical services, where many remain resistant to diagnosing personality disorders with adolescents and young people (Kaess et al., 2014). If early interventions are to be effective in improving long-term prognosis, then there

may be a good rationale for introducing diagnosis of BPD (where appropriate) at an earlier stage.

Feasibility data from this study demonstrated that recruitment of this population is difficult, with a consent rate of 52% for participants approached after referral. Future research may consider increased engagement with CAMHS services to highlight the proportion of individuals screening positive for NDD when presenting with (sub)syndromal BPD. This could involve putting forward the importance of understanding overlapping mental health presentations and the likely impact on the individual, their family and services. This may in turn result in an increased number of referrals. Once consented, completion rates for the full assessment were high, with all participants but 1 completing both visits. This suggests a larger-scale study with this population would be possible, and that the measures selected were appropriate to use with this group.

This study attempted to ascertain the prevalence of emotion regulation, in addition to early risk factors such as ACEs and attachment styles in young people with BPD. Although not all individuals with BPD have a history of ACEs (Fossati, Madeddu, & Maffei, 1999) this study found that a large proportion of young people with BPD did. This finding is more in line with current evidence that indicates many individuals with BPD have in fact experienced ACEs (Ibrahim, Cosgrave, & Woolgar, 2017), with the majority of participants in this study experiencing at least one. With regards to emotion dysregulation, participants in this study reported elevated levels of emotional dysregulation across six subscales; Becerra et al., 2013 found healthy controls had a mean DERS score of 63.68 and participants with comorbid positive NDD screens in this study had a mean score of 136.92 demonstrating much higher levels of emotion regulation difficulties. Overlapping symptoms of emotion regulation difficulties across both ADHD and ASD diagnoses and BPD may have implications for

longer-term psychosocial outcomes, such as increased levels of impulsivity or interpersonal difficulties. Lastly, participants with both ASD and ADHD reported elevated levels of anxious attachment styles compared to those without NDD or with one only. Further research is needed regarding their attachment styles as it may be worth considering how attachment could impact on this participant group's ability to approach their therapeutic intervention, such as how they attach to their therapist. When considering those individuals who may present to CAMHS who are in adolescence, this is a time when identity formation is very salient and will be influenced by their ability to form attachments with others (Steele, Bate, Nikitiades, & Buhl-Nielsen, 2015), which may be negatively impacted upon by comorbid diagnoses of NDD and BPD.

The secondary aim of this study was to investigate the prevalence of NDD in young people with BPD. Almost 60% of young people referred to the study screened positive for ASD and 80% for ADHD. There is sufficient evidence in the literature to indicate that comorbid diagnoses and symptomology overlap of *adult* ADHD and BPD are not uncommon (O'Malley et al., 2016; Davids & Gastpar, 2005). Xenaki and Pehlivanidis (2015) reflect on whether ADHD should be viewed as a potential risk factor for the development of BPD which may warrant further consideration given the findings of this study. Most of the literature to date has focused on adult ADHD, but Fischer, Barkley, Smallfish, and Fletcher (2002) found that children with ADHD had a greater than chance risk for developing BPD in later life.

Presently, there is limited literature investigating symptomatic overlap between BPD and ASD. This lack of literature may be due in part to the gender bias in the diagnosis of ASD in females; research indicates that ASD may be under-diagnosed in females due to potential gender differences in symptom manifestation (Kreiser & White, 2013), leading to a disproportionate risk of females not receiving a diagnosis (Loomes et al., 2017). Dudas et al.,

(2017) compared a sample of participants with ASD to individuals with BPD and found that almost 50% of females with BPD met cut off criteria for ASD as measured by the Autism Spectrum Quotient (AQ). The current study found that 58% of BPD participants screened positive for ASD, in a proportion of participants that were also predominately female. Further research is required to explore specific symptom overlap between these two groups, and potential contributions that may indicate a shared pathway to its development. For example, mentalization, the ability to make sense of others and ourselves in terms of subjective states and mental processes, has been shown to be reduced in patients with BPD, resulting in problems with emotion regulation and difficulties with impulsivity (Bateman & Fonagy, 2010). Reduced capacity to mentalize has also been noted in ASD (White, Hill, Happe, & Frith, 2009) and in adults with ADHD (Chung, Barch, & Strube, 2014). One hypothesis might be that the process of mentalization could reflect a shared pathway between these groups resulting in symptom overlap, which would warrant further research.

Mentalisation in adults with comorbid ADHD and BPD has been found to correlate with high impulsivity, with severity of ADHD symptoms positively related to impairments in mentalising (Perroud et al., 2017); in the case of overlap between ADHD and BPD, impulsivity is prominent across both diagnoses, which could increase self-harming or injurious behaviours (Speranza et al., 2011). When considering young people, their inclination towards more impulsive behaviours puts them at greater risk for engaging in self-harm or suicidality, and more specifically, among adolescents with BPD (Kaess et al., 2014). A recent systematic review concluded that there is a positive association between ADHD and suicidality (Balazs & Kereszteny, 2017). Ryden, Ryden and Hetta (2006) investigated symptomatic overlap between ASD and BPD and found that females with comorbid ASD and BPD were at greater risk of suicidality. Additionally, they found an absence of pronounced self-image disturbances (often considered a common symptom of BPD), which raises the

question of whether NDDs may be misdiagnosed as BPD or whether comorbid diagnoses are going unrecognised, leading to more complicated or treatment-resistant presentations of BPD in clinical practice? If we consider the high proportion of young people with BPD referred into this study that met criteria for ADHD and/or ASD, this provides evidence that further research is required to investigate the impact of NDDs on long-term outcomes, and to explore potential underlying shared pathways, such as mentalization, for example.

#### Limitations

A small sample size makes it harder to generalise across a wider population.

Nonetheless, this study formed part of a large feasibility and pilot study, and lessons can be learned from the recruitment process in order to improve recruitment in the future. A further limitation of the study relates to the positive screens for NDD in those individuals who did not already have a diagnosis; it was not feasible to follow up those individuals with a formal standardised assessment, such as the Autism Diagnostic Observation Schedule (ADOS) for ASD for example, in order to confirm diagnosis. This would be a recommendation to include in any future studies. Screens cannot be read as confirmation and thus, although there were no false negatives, we do not know the false positive rate for the tools used to identify NDDs in this study.

As previously mentioned, subsyndromal BPD criteria refers to individuals who meet between 2 and 4 threshold scores out of any 9 SCID criteria. This study recruited young people aged between 15 and 33, so it is important to consider for future research whether the concept of subsyndromal BPD is appropriate to use with this research group, given their potentially different stages of neurodevelopmental maturity. For example, evidence has demonstrated that an individual's frontal lobes, an area involved in inhibition, impulsivity, decision making, and emotion regulation (Steinberg, 2005), are still developing until their

early twenties (Johnson, Blum, & Giedd, 2009). As such, those individuals who present to CAMHS services meeting subsyndromal BPD criteria may in fact be exhibiting behaviour that could be better accounted for by a 'developing' brain, as opposed to emerging personality disorder symptoms. Additionally, they may score differently on psychometric or self-report measures of emotion regulation or NDD as compared to those individuals who are neurodevelopmentally mature by late twenties or early thirties. Therefore, future research of this type may consider investigating adolescents separately to young adults (i.e. over 25s) in order to try account for these neurodevelopmental maturational differences.

It is also important to consider the representativeness of the recruited sample from the clinical populations within services from which they derived. As it was not feasible to ascertain this demographic information regarding the wider clinical population, it may be that the sample obtained represents a biased sub-group of the population. Therefore, it would be the author's recommendation that should this study be replicated or conducted on a larger scale, it should aim to collect demographic information from the selected services so as to provide a more accurate representativeness estimation.

#### **Clinical Implications**

This study highlights the need to investigate the comorbidity of NDDs in BPD further and to consider reflecting on current service pathways. If increasing evidence indicates frequent co-morbid presentations of undiagnosed NDD in young people with BPD, then services may need to consider how best to meet their needs. For example, young people with ADHD and BPD may respond differently to specific therapeutic interventions as compared to those with ASD. If young people presenting to services with (sub)syndromal BPD were automatically assessed for any underlying NDD, this could improve early interventions which in turn might improve long-term outcomes and reduce the risk for developing acute

psychopathology. If services begin to introduce NDD screening as standard practice for individuals presenting with (sub)syndromal BPD, formal diagnosis will be required for those who screen positive. This has clinical implications given the demands formal assessment places on a service, as for example, gold standard diagnosis for ASD requires completion of a comprehensive neurodevelopmental history taking, behavioural observations, parent-report information, and completion of a diagnostic tool such as the ADOS (Falkmer, Anderson, Falkmer, & Horlin, 2013). Although this may present a challenge to services, they are arguably reasonable ones that could be justified based on preliminary data. Clinicians approaching the assessment of young people presenting to their services with (sub)syndromal BPD may need to consider screening for difficulties in their neurodevelopment, as well as asking about the young person's early developmental environment.

#### **Future Research**

Future research could look at the number of referrals that CAMHS receives for query diagnosis of NDD that would meet either subsyndromal or syndromal criteria for BPD. Given the higher proportion of participants with BPD screening positive for NDDs, it would be useful to further investigate any potential mediation between BPD symptom severity and NDDs, ACEs, and emotion regulation. It may also be that the validity of current BPD diagnostic criteria may need to be reconsidered to include an NDD component.

#### Conclusion

This pilot study evidenced the feasibility of recruitment of young people with BPD, indicating it could be conducted on a larger-scale. The selected psychometric assessment measures were helpful in facilitating a clearer understanding of the neurodevelopmental and clinical profile of young people with BPD with regards to NDDs, emotion regulation, attachment, and ACEs. The study also found that the majority of young people with BPD

screened positive for ASD and/or ADHD. Research has shown that individuals with BPD experience high levels of psychosocial impairment and morbidity, greater usage of mental health resources, and high mortality rates (Fonagy et al., 2006). Given the importance of early intervention for young people with BPD (Chanen et al., 2007b), having a clearer understanding of the neurodevelopmental profile of these individuals presenting to mental health services may lead to improved long-term outcomes.

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#### **Appendices**

## Appendix 1.1: Author Submission Requirements for Journal of Mental Health

#### **Instructions for authors**

Thank you for choosing to submit your paper to us. These instructions will ensure we have everything required so your paper can move through peer review, production and publication smoothly. Please take the time to read and follow them as closely as possible, as doing so will ensure your paper matches the journal's requirements. For general guidance on the publication process at Taylor & Francis please visit our Author Services website. This journal uses ScholarOne Manuscripts (previously Manuscript Central) to peer review manuscript submissions. Please read the guide for ScholarOne authors before making a submission. Complete guidelines for preparing and submitting your manuscript to this journal are provided below.

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*Journal of Mental Health* is an international, peer-reviewed journal publishing high-quality, original research. Please see the journal's Aims & Scope for information about its focus and peer-review policy. Please note that this journal only publishes manuscripts in English.

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#### Structure

Your paper should be compiled in the following order: title page; abstract; keywords; main text introduction, materials and methods, results, discussion; acknowledgments; declaration of interest statement; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figures; figure captions (as a list).

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Please include a word count for your paper.

The total word count for Review Articles should be no more than 6000 words. All other articles should be no more than a total of 4000 words. We do not include the abstract, tables and references in this word count. Manuscripts are limited to a maximum of 4 tables and 2 figures.

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Please refer to these quick style guidelines when preparing your paper, rather than any published articles or a sample copy.

Any spelling style is acceptable so long as it is consistent within the manuscript. Please use double quotation marks, except where "a quotation is 'within' a quotation". Please note that long quotations should be indented without quotation marks.

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Papers may be submitted in Word format. Figures should be saved separately from the text. To assist you in preparing your paper, we provide formatting template(s). Word templates are available for this journal. Please save the template to your hard drive, ready for use.

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- 1. **Author details.** All authors of a manuscript should include their full name and affiliation on the cover page of the manuscript. Where available, please also include ORCiDs and social media handles (Facebook, Twitter or LinkedIn). One author will need to be identified as the corresponding author, with their email address normally displayed in the article PDF (depending on the journal) and the online article. Authors' affiliations are the affiliations where the research was conducted. If any of the named co-authors moves affiliation during the peer-review process, the new affiliation can be given as a footnote. Please note that no changes to affiliation can be made after your paper is accepted. Read more on authorship.
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- 9. **Supplemental online material.** Supplemental material can be a video, dataset, fileset, sound file or anything which supports (and is pertinent to) your paper. We publish supplemental material online via Figshare. Find out more about supplemental material and how to submit it with your article.

- 10. **Figures.** Figures should be high quality (1200 dpi for line art, 600 dpi for grayscale and 300 dpi for colour, at the correct size). Figures should be supplied in one of our preferred file formats: EPS, PS, JPEG, GIF, or Microsoft Word (DOC or DOCX). For information relating to other file types, please consult our Submission of electronic artworkdocument.
- 11. **Tables.** Tables should present new information rather than duplicating what is in the text. Readers should be able to interpret the table without reference to the text. Please supply editable files.
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- 13. Units. Please use SI units (non-italicized).

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When submitting an Original Article or Research and Evaluation, please include a sentence to confirm that ethical approval has been granted (with the name of the committee and the reference number) and that participants have given consent for their data to be used in the research.

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## Appendix 1.2: Quality Assessment Checklist for Qualitative Research Studies – Patients' and Clients' Perspectives (SBU, 2016)

Author:Year:	Id	ciitii	icatio	n no:	
Overall assessment of study quality:					
High ☐ Modera	ate 🗆	Low [			
Instructions:					
<ul> <li>"Unclear" is used when the information is not re</li> <li>N/A (not applicable) is used when the question</li> <li>There are comments of clarification to some of these are found at the back of this document.</li> </ul>	is not relevant.	oaper.			
		Yes	No	Unclear	N/A
1. Aim					
a) Is the study based on a well-defined statement problem or a well-formulated research question					
Comments on aims, discussion of problem, resear	ch questions, etc				
		Yes	No	Unclear	N/A
2. Sample selection					
a) Is the sample selection relevant?					
b) Is the method of selection clearly described?					
c) Is the context clearly described?					
d) Is a relevant ethical discussion included?					
e) Is the relationship between the researcher and the selected sample clearly described?					
Comments on sample selection, patient characteri	stics, context, etc				
3. Data collection					
a) Is the data collection procedure clearly describe	ed?				
b) Is the data collection relevant?					
c) Has data saturation been achieved?					
d) Has the researcher managed his own pre- understanding in relation to the data collection	?				
Comments on data collection, data saturation etc					
4. Analysis					
a) Is the analysis clearly described?					
b) Is the method of analysis relevant in relation to the data collection procedure?				_	
c) Has saturation in terms of analysis been achieve	ed?				
d) Has the researcher managed his own pre- understanding in relation to the analysis?					
Comments on method of analysis, saturation etc					
5. Results					
a) Are the results logical?					
b) Are the results comprehensible?					
c) Are the results clearly described?					
d) Are the results presented in relation to a theoretical framework?					
e) Is a hypothesis, theory or model generated?					
f) Are the results transferable to a similar setting (	context)?				
g) Are the results transferable to a different setting	g (context)?				
Comments on the clarity, adequacy etc of the resu	lts				

## Comments of clarification to the Quality assessment check-list for qualitative research studies – patients' and clients' perspectives:

#### 1. Aim

The following aspects should be considered:

- the aim of the study
- why it is important
- its relevance
- whether qualitative research methods are appropriate for investigating the field/answering the research question.

#### 2. Sample selection

The following aspects should be considered:

- whether the researcher has presented the background to the chosen method of sample selection
- whether the researcher has presented the procedure for selecting the participants
- whether the researcher has presented the reasons for selecting the participants
- whether the researcher has stated the number of participants selected
- whether the researcher has described whether anyone declined to participate and if so, why
- whether the researcher emphasises ethical aspects in more detail than merely "informed consent" and "ethical approval"
- whether the researcher has described the relationship between the researcher and the informant and how this might have influenced data collection, e.g. a debt of gratitude, dependent relationship etc.

#### 3. Data collection

The following aspects should be considered:

- if the setting for data collection was justified
- if the method used to collect the data is described (e.g. in-depth interview, semi-structured interview, focus group, observations, etc)
- if the researcher has motivated the choice of data collection method
- if it is explicitly disclosed how the selected method of data collection was undertaken (e.g. who conducted the interview, how long the interview took, whether an interview guide was used, where the interview was conducted, how many observations were made, etc)
- if the method was modified during the study (if so, is it described how and why this was done)
- if the collected data are clear (e.g. video or audio recording, notes, etc)
- if the researcher has discussed whether saturation has been reached, i.e. when further data collection does not yield any new data (not always applicable)
- if an argument on saturation is applicable, consider whether it is reasonable, i.e. actually validated on good grounds.

#### 4. Analysis

The following aspects should be considered:

- if the analytical process is described in detail
- if the analytical process is in accordance with any theoretical explanation or proposal on which the data collection was founded
- if the analysis is based on a theme, is it described how this theme was arrived at?
- if tables have been used to clarify the analytical process
- if the researcher has critically reviewed his own role, potential bias or influence on the analytical process
- if there is saturation of analysis (is it possible to find more themes based on the citations presented?).

#### 5. Results

The following aspects should be considered:

- if the results/findings been discussed in relation to the aims of the study or the research question
- if adequate reasoning about the results is presented or if the results comprise merely citations/presentation of data
- if the results are presented clearly (e.g. is it easy to distinguish between citation/data and the researcher's own input)
- if the results are presented with reference to the theoretical explanation or proposal on which the data collection and analysis were based
- if adequate data have been presented to support the results to what extent contradictory data have been highlighted and presented
- if the researcher has critically reviewed his own role, potential bias or influence with respect to the analytical process
- if the researcher has discussed the transferability of the results or other areas of application for the results.

Appendix 1.3: Criteria for assessment of scientific quality of a study conducted with qualitative research methods (SBU, 2016).

High quality	Moderate quality	Low quality
Clearly described setting (context)	Setting (context) is ambiguous	Setting (context) not clearly described
Well-defined question to be addressed	Research question is ambiguous	Question to be addressed vaguely defined
Well-described sampling process, data collection method, transcribing process and method of analysis	Some ambiguities in sampling process, data collection method, transcribing process and method of analysis	Sampling process, data collection method, transcribing process and method of analysis not clearly described
Well-documented awareness of methodology	Some ambiguities regarding the awareness of methodology	Poorly documented awareness of methodology
Systematic, stringent presentation of data	Ambiguous presentation of data	Presentation of data is not systematic
Clearly demonstrates that interpretation is based on the data	Some ambiguity as to whether interpretation is based on the data	Unclear that interpretation is based on the data
Includes a discussion of the trustworthiness and dependability of the interpretations	Some ambiguity as to the trustworthiness and dependability of the interpretations	Discussion whether the trustworthiness of the interpretation is poor or missing
The results are presented in the context of previous research on the topic	Some ambiguity in presentation of the results in the context of previous research on the topic	Contextualising of the results in relation to previous research omitted or poorly developed
Implications for clinical practice are well-formulated	Proposed implications for clinical practice are ambiguous	The implications for relevant clinical practice routines are not presented or unclear

#### Appendix 1.4: Noblit & Hare (1988) Seven-step process of Meta-Ethnography

- Getting started deciding on a research question that is worth answering and one that could be informed by qualitative research
- 2. Deciding what is relevant to the initial interest deciding what would be of interest to your audience, including defining the focus of the synthesis, finding relevant studies, and making decisions about what should be included
- Reading the studies becoming familiar with the content and detail of the included studies and noting emerging themes or metaphors
- 4. Determining how the studies are related creating a list of themes or metaphors, juxtaposing them, and determining how they are related
- 5. Translating the studies into one another comparing metaphors and concepts from each study with other included studies
- 6. Synthesising translations higher order interpretation of comparisons from step five leading to a line of argument synthesis
- 7. Expressing the synthesis presenting the results which is usually done through writing a paper for publication

# Appendix 1.5: Two additional synthesised themes not included in main body of review \*Control\*\*

The idea that individuals with BPD could control their behaviours, such as engagement in self-harm, and their emotional responses, was a theme that arose across three of the seven studies. Individuals with a diagnosis of BPD appeared to feel as if others felt they chose to engage in self-harm or destructive behaviours; "they're thinking... that you can choose not to overdose or you can choose not to feel suicidal. I don't think one chooses to wake up one morning and say "Gee, I think I'll be suicidal today" (Nehls, 1999, p. 289). Participants felt that self-destructive behaviour was often considered manipulative by others, with one individual explaining: "You walk into the emergency room, and they don't want to treat you because you did this to yourself...they think it's just attention seeking" (p. 287). Others described experiencing a lack of control when discussing self-harm, despite feeling as though others perceived them as having full control of their actions: "you don't know you're going to do it, you don't think to yourself I might go home in a minute and cut my arms" (Fallon, 2003, p. 396). Bonnington and Rose (2014) acknowledged that a number of the negative generalisations surrounding individuals with BPD were focused on the idea of control, with individuals often being labelled as attention-seeking, manipulative, and troublemaking.

## Diagnosis

Some participants felt diagnosis had the potential to be helpful, but labelling did not; participants "were being labelled and judged versus diagnosed and treated" (Nehls, 1999, p. 288). Nehls argues that though diagnosis could be used to help develop care plans, the participants she spoke with led the author to conclude that the label of BPD perpetuated a sense of being marginalised and mistreated: "It was the ramification of a negative label, not

the diagnosis itself, that was problematic" (p. 288). Some viewed diagnosis as a means of reinforcing a sense of hopelessness, "...to have the diagnosis means you are just screwed. Once you have that on a piece of paper in a medical file, it's over..." (p. 287); This sentiment was echoed by another, stating that "[diagnosis] was the killing of hope" (Horn et al. 2007, p. 262). Others reflected on the paradox of receiving a diagnosis, in that they believed the criteria for BPD diagnosis fit, however the diagnosis itself did not provide any meaningful or purposeful change, particularly with regards to directing treatment. Horn et al. (2007) identified diagnosis as both rejecting and about not fitting for individuals they interviewed, with one individual stating that the diagnosis "...was just like a name, it didn't really mean much" (p. 261), with others believing the diagnosis was not useful or helpful (Bonnington & Rose, 2014).

Some individuals found having a diagnosis was helpful, as it provided them an opportunity to better understand and conceptualise their difficulties (Fallon, 2003). They viewed diagnosis as a source of information, facilitating their understanding of BPD, and for some they felt it instilled a sense of hope. For others, the diagnosis provided containment and a sense of control: "I had something I could firmly grasp...I've been diagnosed and I feel safe" (Horn et al. 2007, p. 260). As in both Fallon (2003) and Horn et al. (2007) papers, four out of five individuals interviewed by Fromene and Guerin (2014) found their diagnosis to be useful as it provided a better understanding of their difficulties, "I like to know what's wrong with me...so that I can at least know why I feel the way I feel and go through the different emotions" (p. 575).

#### Appendix 2.1: Author Submission Requirements for Journal of Personality Disorders

#### **Instructions to Authors**

Regular Articles: Reports of original work should not normally exceed 30 pages (typed, double-lined spaces, and with standard margins, including tables, figures, and references). Occasionally, an author may feel that he or she needs to exceed this length (e.g., a report of a series of studies, or a report that would benefit from more extensive technical detail). In these circumstances, an author may submit a lengthier manuscript, but the author should describe the rationale for a submission exceeding 30 pages in the cover letter accompanying the submission. This rationale will be taken into account by the Editors, as part of the review process, in determining if the increased length is justified.

Invited Essays and Special Articles: These articles provide an overview of broad-ranging areas of research and conceptual formulations dealing with substantive theoretical issues. Reports of large-scale definitive empirical studies may also be submitted. Articles should not exceed 40 pages including tables, figures, and references. Authors contemplating such an article are advised to contact the editor in advance to see whether the topic is appropriate and whether other articles in this topic are planned.

*Brief Reports:* Short descriptions of empirical studies not exceeding 20 pages in length including tables, figures, and references.

**Web-Based Submissions**: Manuscripts must be produced electronically using word processing software, double spaced, and submitted along with a cover letter to http://jpd.msubmit.net. Authors may choose blind or non-blind review. Please specify which option you are choosing in your cover letter. If you choose blind review, please prepare the manuscript accordingly (e.g., remove identifying information from the first page of the manuscript, etc.). All articles should be prepared in accordance with the *Publication Manual of the American Psychological Association*. They must be preceded by a brief abstract and adhere to APA referencing format.

**Tables** should be submitted in Excel. Tables formatted in Microsoft Word's Table function are also acceptable. (Tables should not be submitted using tabs, returns, or spaces as formatting tools.)

**Figures** must be submitted separately as graphic files (in order of preference: tif, eps, jpg, bmp, gif; note that PowerPoint is not acceptable) in the highest possible resolution. Figure caption text should be included in the article's Microsoft Word file. All figures must be readable in black and white.

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**References**: Authors should consult the publication manual of the American Psychological Association for rules on format and style. All research papers submitted to the *Journal of Personality Disorders* must conform to the ethical standards of the American Psychological Association. Articles should be written in nonsexist language. **Any manuscripts with references that are incorrectly formatted will be returned by the publisher for revision**.

#### **Appendix 2.2 Description of Assessment Measures & Diagnostic Interviews**

Adverse Childhood Experiences. The Adverse Childhood Experience (ACE) Questionnaire (Felitti et al., 1998) is a 10-item self-report measure developed to identify childhood experiences of abuse or neglect, and family dysfunction such as domestic abuse, and substance misuse. Higher scores predict greater incidences of mental and physical ill-health in later life, with a maximum score of 10.

Attachment. The Psychosis Attachment Measure (PAM) (Berry, Wearden, Barrowclough, & Liversidge, 2006) is a 16-item self-report measure that explores associations between anxious and avoidant attachment styles and psychotic symptoms in clinical samples. Participants are asked to rate the extent to which each statement describes how they relate to others on a four-point Likert scale, from "not at all" to "very much." Total scores are calculated by adding each item then dividing by 8 to calculate individual anxiety and avoidant scores; higher scores indicate greater levels of anxiety or avoidance.

*Borderline Personality Disorder*. The Borderline Personality Questionnaire (BPQ) (Poreh et al., 2006) is a scale for the assessment of Borderline Personality symptoms based on DSM-IV criteria. The BPQ consists of 80 items that categorise into 9 sub-scales: Impulsivity; affective instability; abandonment; relationships; self-image; suicide/self-mutilation; emptiness; intense anger; and quasi-psychotic states. A total sum score of  $\geq$  56 indicates the participant likely meets DSM-IV criteria for BPD ( $\geq$  3 on 5 or more items of SCID-II BPD).

The Structured Clinical Interview for DSM-IV-II (SCID-II BPD Section) (First, Spitzer, Gibbon, & Williams, 2002) is a semi-structured interview guide for making major DSM-IV-TR diagnoses, with this section of the measure used specifically to assess for BPD. Rating guidelines of the SCID-II suggest that BPD is present when at least 5 items are coded as '3 – threshold/true.'

*Emotion Regulation.* Difficulties in Emotion Regulation Scale (DERS) (Kaufman et al., 2015) is a validated self-report measure designed to assess for emotion regulation difficulties in adolescents and adults. It consists of 36 items that fall into 6 sub-scales: non-acceptance of emotional response; difficulties engaging in goal-directed behaviour; impulse control difficulties; lack of emotional awareness; limited access to emotion regulation strategies; and lack of emotional clarity. Participants were asked to indicate on a 5-point Likert-type scale how often the items apply to themselves, with 1 = almost never (0-10%), 2 = sometimes (11%-35%), 3 = about half the time (36%-65%), 4 = most of the time (66%-90%), and 5 = almost always (91%-100%). The DERS total score ranges from 36 - 180 but there are no official clinical cut off scores, with higher scores indicate greater difficulties in emotion regulation.

Neurodevelopmental Disorder Screens. The Adult ADHD Self-Report Scale (ASRS-v.1.1) (Kessler, R. WHO Composite International Diagnostic Interview, 2003) is a symptom checklist consistent with the eighteen DSM-IV TR criteria for ADHD. Six of the eighteen questions are found to be the most predictive of symptoms consistent with ADHD, which make up Part A of the ASRS. Scores are ranked on a scale of 0 to 4, (Never; Rarely; Sometimes; Often; Very Often) with those falling under the predictive category being marked in dark shaded boxes in Part A. Four or more marks falling in the darkly shaded boxes indicates symptoms that are highly consistent with ADHD in adults.

Autism Symptom SElf-Report for Adolescents and Adults (ASSERT) (Posserud, Breivik, Gillberg, & Lundervold, 2013) is a brief self-report screen for autism symptoms in adolescents and adults. Response options are "not true" (score 0) – "somewhat true" (score 1) – "certainly true" (score 2), leading to a score range of 0–16 points. The suggested cut off score for ASD is greater or equal to 8, but it should be highlighted that this is a screening tool, rather than a diagnostic tool.

#### Appendix 2.3: Managerial Board Approval



Administrator: Ms Kirsty Therson Telephone Number: 0141 232 1814 E-Mail: <u>Kirsty.theron2@ggc.scot.nhs.uk</u> Website: www.nhsggc.org.uk/r&d R&D Management Office West Glasgow ACH Dalnair Street Glasgow G3 8SW

3 August 2016

Dr Ruchika Gajwani University of Glasgow Caledonia House West Glasgow ACH Dalnair Street Glasgow G3 8SJ

#### NHS GG&C Board Approval

Dear Dr R Gajwani,

Study Title: From attachment to psychopathology: affective dysregulation and

neurodevelopmental disorder in young people at-risk of severe and enduring

mental illness

Principal Investigator: Dr Ruchika Gajwani
GG&C HB site Community Mental Health
Sponsor NHS Greater Glasgow and Clyde

R&D reference: GN15AM216
REC reference: 16/WS/0133
Protocol no: V2.0; 24/06/16

I am pleased to confirm that Greater Glasgow & Clyde Health Board is now able to grant **Approval** for the above study.

#### **Conditions of Approval**

- 1. For Clinical Trials as defined by the Medicines for Human Use Clinical Trial Regulations, 2004
  - a. During the life span of the study GGHB requires the following information relating to this site
    - i. Notification of any potential serious breaches.
    - ii. Notification of any regulatory inspections.

It is your responsibility to ensure that all staff involved in the study at this site have the appropriate GCP training according to the GGHB GCP policy (<a href="www.nhsggc.org.uk/content/default.asp?page=s1411">www.nhsggc.org.uk/content/default.asp?page=s1411</a>), evidence of such training to be filed in the site file.

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Board Approval\_GN15AM216

- 2. For all studies the following information is required during their lifespan.
  - a. Recruitment Numbers on a monthly basis
  - b. Any change of staff named on the original SSI form
  - c. Any amendments Substantial or Non Substantial
  - d. Notification of Trial/study end including final recruitment figures
  - e. Final Report & Copies of Publications/Abstracts

#### Please add this approval to your study file as this letter may be subject to audit and monitoring.

Your personal information will be held on a secure national web-based NHS database.

I wish you every success with this research study

Yours sincerely,

Ms Joanne McGarry Research Co-ordinator

Cc: Rebecca Nelson (Research Asst)

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Board Approval\_GN15AM216

#### **Appendix 2.4: Research Ethics Committee Approval**

## **WoSRES**

#### West of Scotland Research Ethics Service



Dr Ruchika Gajwani Clinical Psychology Research Fellow/Honorary Clinical Psychologist University of Glasgow Academic Unit of Mental Health and Wellbeing Caledonia House Child and Adolescent Psychiatry Yorkhill Hospital Glasgow G3 8SJ West of Scotland REC 3
West of Scotland Research Ethics Service
West Glasgow Ambulatory Care Hospital
(former Royal Hospital for Sick Children Yorkhill)
Dalnair Street
Glasgow G3 8SJ

www.nhsggc.org.uk

Date 23<sup>rd</sup> August 2017

Your Ref Our Ref

Direct line 0141 232 1805

E-mail WOSREC3@ggc.scot.nhs.uk

#### Dear Dr Gajwani

Study title:	From attachment to psychopathology: Affective dysregulation and neurodevelopmental disorder in young people at-risk of severe and enduring mental illness
REC reference:	16/WS/0133
Amendment number:	AM03-1
Amendment date:	18 August 2017
IRAS project ID:	207465

Thank you for submitting the above amendment, which was received on 18 August 2017. It is noted that this is a modification of an amendment previously rejected by the Committee (our letter of 21st July 2017 refers).

The modified amendment has been considered on behalf of the Committee by the Vice Chair.

#### **Summary of Amendment**

Amendment to the protocol and information sheets to include information on the clinical psychology trainee major research project.

#### Ethical opinion

I am pleased to confirm that the Committee has given a favourable ethical opinion of the modified amendment on the basis described in the notice of amendment form and supporting documentation.

#### Approved documents

The documents reviewed and approved are:

Document	Version	Date
Notice of Modified Amendment	AM03-1	18 August 2017
Participant information sheet (PIS) [Child]	3	25 July 2017
Participant information sheet (PIS) [Participant]	4	25 July 2017
Participant information sheet (PIS) [Informant]	4	25 July 2017
Participant information sheet (PIS) [Parent/Guardian]	4	25 July 2017

F	Research protocol or project proposal [Clean]	5	08 August 2017
F	Research protocol or project proposal [Tracked]	5	08 August 2017

#### R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

#### 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.

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <a href="http://www.hra.nhs.uk/hra-training/">http://www.hra.nhs.uk/hra-training/</a>

16/WS/0133:

Please quote this number on all correspondence

Yours sincerely

Lin Jamen

Liz Jamieson REC Manager

On behalf of Mrs Rosie Rutherford, Vice Chair

Copy to: Mr Paul Dearie, NHS Greater Glasgow and Clyde

## **Appendix 2.5: Research Proposal**



#### **DOCTORATE IN CLINICAL PSYCHOLOGY**

SUBMISSION COVER PAGE

Name of Assessment: MRP Proposal

Title of Project: ASD and ADHD: Understanding Neurodevelopmental pathways to

Borderline Personality Disorder

**Matriculation Number: 2051582** 

Date of Submission: May 29<sup>th</sup>, 2017

Version Number: 8.0

Actual Word Count: 3,518 (including references)

**Maximum Word Count: 3,000** (excluding appendices)

#### Abstract

Background: Borderline personality disorder (BPD) is the most common of personality disorders in clinical practice. Limited research has been conducted on the role of neurodevelopmental disorders (NDD) in the development of personality disorder. However, increasing evidence demonstrates clinical symptom overlap and/or comorbidity between Attention Deficit Hyperactivity Disorder (ADHD) and BPD. Affective dysregulation is a core feature in disorders such as Autism Spectrum Disorder (ASD) and ADHD, and is also a core feature of BPD. Given its feature in both NDD and BPD, exploration into the rate of affective dysregulation in young people with BPD requires further research, as do contributing mechanisms, such as adverse childhood experiences (ACEs). Aims: To assess the prevalence of ASD and ADHD in young people meeting criteria for early BPD (emerging and established); and to establish the level and rate of affective dysregulation in young adults with BPD with and without NDD. Hypothesis: Higher rates of ACEs and the presence of NDD predict worse symptom severity in young adults with emerging or established BPD. Methods: This study is part of a larger feasibility study (PATHWAYS) that will recruit 30 NHS patients across NHS Greater Glasgow and Clyde with early BPD. I aim to recruit an additional 20 for a total of n=50. Data will be analysed using a linear regression model. Applications: By developing a greater understanding of the neurodevelopmental comorbidity profile of patients with BPD, and investigating the mechanisms contributing to affective dysregulation, we may be able to develop more targeted interventions of BPD for adolescents and young adults to improve long-term outcomes.

**Key words**: Borderline Personality Disorder, Neurodevelopment, Affective Dysregulation, Young adults

#### Introduction

Embedded in attachment theory is its association with affect (mood) regulation, which provides a framework for understanding developmental pathways to affective dysregulation in young people at-high-risk of severe and enduring mental health problems (Gajwani, Patterson & Birchwood, 2013). Early risk markers such as childhood trauma, neglect and attachment dysfunction are found to have long lasting consequences on sensitivity towards stress and a significantly higher risk for developing psychopathology later on in life (Kendler, Kuhn & Prescott, 2004).

Increasing numbers of longitudinal studies have shown that childhood adversity, specifically maltreatment, increases the risk for personality disorders (Johnson et al., 1999) during early adulthood, and is related to poor affective regulation and increased risk of suicidality. Whilst the link between child maltreatment and personality disorder is not exclusive, it is crucial to understand the association between risk factors such as maltreatment to the development of BPD due to the psychosocial impairment and morbidity, greater usage of mental health resources, and high mortality rate associated with BPD (Fonagy & Bateman, 2006).

Borderline personality disorder (BPD) is a severe mental disorder, characterised by a pervasive pattern of instability in affect regulation, impulse control, interpersonal relationships, and self-image (Lieb et al., 2004). It affects about 1.4% of the general population, but it is the most common of personality disorders in clinical practice (The British Psychological Society, 2009), affecting up to 10% of psychiatric outpatients and 20% of inpatients (Lieb et al., 2004). BPD usually emerges during adolescence however the condition often goes unrecognised because diagnosis of PD in this age group is controversial (Chanen, McCutcheon, Jovev, Jackson, & McGorry, 2007b). In fact, mean levels of BPD traits are highest in early adolescence and evidence indicates that the diagnostic criteria for BPD are as reliable, valid and stable before age 18 years as they are in adulthood (Crawford, Cohen, & Johnson, 2005). Importantly, BPD traits in young people also show considerable flexibility and malleability (Lenzenweger & Castro, 2005). These findings indicate that early intervention for early BPD is crucial.

Despite increased understanding of neurobiological and psychosocial risk factors for BPD, prospective developmental data on adolescents and young adults are rare (Kaess, Brunner, & Chanen, 2014). There is a small amount of data to indicate that families of children and adolescents with BPD have significantly greater rates of psychopathology, including depression and anti-social disorders (Goldman, D'Angelo, & DeMaso, 1993) though further

research is needed. To date, there does not appear to be any epidemiological data reporting childhood rates of psychopathology in adults with BPD.

Glasgow-based research on maltreated children has shown that, in middle childhood, psychiatric disorder in the context of maltreatment tends to manifest as complex, overlapping neurodevelopmental difficulties (Minnis, 2013). There is recent evidence from the Sweden Twin study (Dinkler et al., in press JCPP) to show that maltreatment increases the neurodevelopmental disorders (NDD) load but does not cause neurodevelopmental disorders. It is however unknown whether these neurodevelopmental disorders (e.g. Attention Hyperactivity Disorder (ADHD), Autism Spectrum Disorder (ASD)) and any associations with maltreatment are linked to the development of severe and enduring mental health problems in adolescence/early adulthood.

There has been less research on the role of neurodevelopmental disorders in the development of personality disorder. There is increasing evidence demonstrating clinical symptom overlap and/or comorbidity between ADHD and BPD (van Dijk et al., 2012; Xenaki, 2015). ADHD is a frequent comorbidity in BPD (Matthies & Philipsen, 2014) and is characterized by increased symptoms of impulsivity, additional psychopathology, comparatively lower intellectual and attentional functioning and increased psychosocial difficulties (O'Malley, 2016). Data from adults with severe borderline personality frequently indicate a history of childhood ADHD symptomology (Philipsen et al., 2008). In clinical practice, inattention and hyperactivity lead to difficulties in the acquisition of knowledge and skills necessary to deal with the impairing consequences of both disorders (Ebert, 2003). Therefore, treatment of comorbid ADHD in BPD patients may enhance psychotherapeutic outcomes, particularly within early interventions.

Affective dysregulation is a core feature in disorders such as ASD and ADHD (Hill, Berthoz & Frith, 2004; Brotman et al., 2010), therefore this could be considered a viable area for further research. Affective dysregulation is also a core feature of BPD and is a particularly important focus for investigation because of its links with suicidality (Bowen, Balbuena, Peters, Leuchen-Mewis, & Baetz, 2015). Given its feature in both neurodevelopmental disorders and BPD, exploration into the rate of affective dysregulation in young people with BPD with or without a NDD requires further research. Of particular interest is exploration of the mechanisms that contribute to affect dysregulation in young adults with early BPD, namely Adverse Childhood Experiences (ACEs) and NDD.

Early intervention in BPD is considered important for long-term outcomes (Chanen et al., 2007b). By developing a greater understanding of the neurodevelopmental comorbidity profile of BPD patients, and exploring the pathways from NDD and ACEs to BPD, we may be able to develop more targeted interventions of BPD for adolescents and young adults to improve long-term outcomes. The benefits of effective emotion regulation are not only linked to a decreased vulnerability to the development and maintenance of psychopathology, but there are data that suggest that effective emotion regulation promotes both mental and physical stability as well as improvement in overall functioning (Putnam & Silk, 2005).

#### Aims & Hypotheses

#### **Aims**

- 1. To assess the prevalence of ASD and ADHD in young people meeting criteria for early Borderline Personality Disorder (both emerging and established BPD).
- 2. To establish the level and rate of affective dysregulation in young adults with BPD, with and without NDD.

#### **Hypothesis**

We hypothesise that higher rates of ACEs and the presence of NDD predict worse symptom severity in young adults with early BPD.

#### Plan of Investigation

#### **Participants**

The PATHWAYS study aims to recruit young people (age 15-35) with early Borderline Personality disorder (EBPD) (n=30), using methodology used successfully in previous studies with this group (Chanen, Jovev, & Jackson, H., 2007a). I aim to recruit an additional 20 young people with EBPD, for a total n=50. For each young person recruited I hope to recruit an informant, who must know the participant well enough to answer questions about their everyday behaviours and their mental health (as detailed below). When the participant is sixteen or older, we will ask them to suggest an informant for us to contact for further information. If the participant is under the age of sixteen and unable to consent, the consenting parent or legal guardian will be asked to participate as the informant. The recruitment of EBPD groups will involve NHS services (child and adolescent mental health services and adult mental health services within Greater Glasgow and Clyde NHS), student

counselling services, the general population and non-statutory (third sector) mental health services.

#### **Inclusion and Exclusion Criteria**

#### Inclusion criteria

#### For BPD

- Written informed consent
- · Aged between 15 and 35 years' old
- Any young person who meets 2 out of the 9 criteria for the Borderline Personality
   Disorder section of the SCID-II

#### For Informants

- Written informed consent
- Age 16+
- The informant must know the participant well enough to answer questions about their everyday behaviours and their mental health, in addition to their developmental and NDD history.
  - o This may include a guardian, partner, parent, sibling, or key worker.
- For participants under the age of sixteen, the informant must be their parents or legal guardian

#### **Exclusion criteria**

#### For BPD

- Non-English speaker
- No informed consent

#### For Informants

- Under the age of sixteen
- Any person unable to answer questions about the participant's everyday behaviours and mental health, in addition to their developmental and NDD history.
- No informed consent

#### **Recruitment Procedures**

#### Identification of participants and consent

This study is part of a larger feasibility study (PATHWAYS) with NHS patients within NHS Greater Glasgow and Clyde. The PATHWAYS study will develop close relationships with psychiatrists, primary care and secondary mental health services including Community Mental Health Teams (CMHTs), Primary Care Mental Health Teams (PCMHTs), Clinical Psychology Services, Community Adolescent Mental Health Services (CAMHS), Personality Disorder Teams (AMHS) and non-statutory (third sector) mental health services. It would be my intention to use these same resources. As the primary focus of my research is with young people with EBPD, I hope to recruit the majority of participants from the Personality Disorder and Homelessness Service (AMHS) in Glasgow.

The larger study is supported by one research assistant who will be recruiting for both EBPD and Psychosis arms of the study. The target sample size for EBPD in PATHWAYS is 30 and I endeavour to recruit an additional 20 for my own study, alongside 20 informants. As my study is part of PATHWAYS, my data will be shared with and included in PATHWAYS data. I will have access to the EBPD data collected by the research assistant. PATHWAYS will recruit from January 2017 to January 2018. As of 13.04.2017, 15 individuals with EBPD or BPD have been recruited to PATHWAYS, a rate of 5 individuals per month. To reach their target of 30 individuals, they would need to recruit 2.5 individuals per month until January 2018. As this study is part of PATHWAYS, prior ethical approval has been obtained, however I will be submitting a separate protocol as a substantial amendment to the PATHWAYS study. This will include my intention to recruit an additional 20 individuals with EBPD and their informants.

#### **Measures**

#### **Primary Outcome Measures**

Mini-SCID (First, Splitzer, Gibbon, & Williams, 1995)

Adverse Childhood Experiences Questionnaire (ACE) (Felitti et al., 1998)

Psychosis Attachment Measure (PAM) (Bechdolf et al., 2010)

Borderline Personality Questionnaire (BPQ) (Poreh et al., 2006)

Difficulties in Emotion Regulation Scale Short Form (DERS-SF)(Kaufman et al., 2015)

The Autism Symptom Self-ReporT for adolescents and adults (ASSERT) (Posserud, Breivik, Gillberg, & Lundervold, 2013)

Adult ADHD Self-report scale (ASRS-v 1.1)

Early Symptomatic Syndromes Eliciting Neurodevelopmental Clinical Examinations (ESSENCE, V 1.0) (Minnis, 2013).

Relationship Problems Questionnaire (RPQ) (Yung et al., 2006)

Autism Spectrum Screening Questionnaire (ASSQ) (First et al., 1995)

### Secondary outcome measures

Comprehensive Assessment of At-Risk Mental State (CAARMS) (Yung et al., 2006)

Structured Clinical Interview for DSM-IV II: Personality Disorders (BPD section) (SCID II) (First et al., 1995)

#### **Research Procedures**

\\(\text{i}=\text{i}\)	Matter (Darthelm)	Malt There / Particles :	\(\frac{1}{2} \cdot \cdo
Visit One	Visit Two (Participant)	Visit Three (Participant)	Visit One (Informant)
Provide and discuss information sheet with potential participant, giving enough time for questions. We expect the referrer to be present at the initial meeting to introduce the participant to the researcher.  Note: If the participant is age 15, we would provide information sheet to the parent/guardian as well as the potential participant	Informed consent will be obtained from participants at the initial visit with the researcher. Questionnaires relating to eligibility (CAARMS and SCID-II) will be performed after consent is obtained.  Note: If the participant is age 15, we would get informed consent from the parent/guardian and the potential participant	The remaining measures will be completed at the second visit.	Informed consent will be obtained from the informant at the initial visit, following consent the informant will be asked to complete the measures listed.
Total time: 15-30 minutes	Total time: 60-120 minutes	Total time: 60-120 minutes	Total time: 60 minutes
Provide information sheet	Measures completed: Demographic questionnaire Comprehensive Assessment of At-Risk Mental State (CAARMS) SCID Interview (BPD section) Mini SCID	Measures completed:  Adverse Childhood Experiences Questionnaire  Psychosis Attachment Measure (PAM)  Borderline Personality Questionnaire (BPQ)  Difficulties in Emotion Regulation Scale Short Form (DERS- SF)  The Autism Symptom Self-Report for adolescents and adults (ASSERT) Adult ADHD Self- Report scale (ASRS- v1.1)  Early Symptomatic Syndromes Eliciting Neurodevelopmental Clinical Examinations (ESSENCE v.1)	Measures completed: Demographic Information Relationship Problems Questionnaire Autism Spectrum Screening Questionnaire (ASSQ) ESSENCE (V.1) ASSERT

#### **Data Analysis**

Descriptive analysis will be used to report on demographic and clinical profiles on the sample (Aims 1 and 2). Research question 3 will be analysed using a linear regression

model to explore the pathway of Adverse Childhood Experiences (ACEs), such as neglect, abuse, and trauma, and Neurodevelopmental Disorders (ESSENCE) on EBPD symptom severity.

#### Justification of sample size

The study aims to recruit young people (age 15-35) with early BPD, using methodology used successfully in previous studies of this group (Morrison et al., 2011; Bechdolf et al., 2010). As PATHWAYS is a feasibility study exact effect sizes are unavailable.

#### **Settings and Equipment**

Interviews will be conducted in a number of settings. In the first instance, this will typically either be the participant's GP clinic or the clinic of the referring PCMT, CMHT, AMHS, CAMHS, or third sector mental health services. As part of the PATHWAYS study, ethical approval has been given to conduct home visits when necessary. Participants may be interviewed in their home if this is preferred. In the first instance, home visits will only be carried out in conjunction with key workers or other health staff who regularly meet with the participant in their home. The researcher will only visit a patient's home if the patient's clinician provides a risk assessment and concludes that it is safe to do. The researcher will follow the University of Glasgow lone working policy

(http://www.gla.ac.uk/media/media\_212144\_en.pdf) and the NHS Lone Working Policy (http://www.nhsbsa.nhs.uk/Documents/Lone\_Working\_Guidance\_final.pdf).

A study mobile phone will be provided to the researcher when conducting home visits and the team member will be required to check in with a colleague prior to and after the appointment to ensure they are safe.

#### **Health and Safety Issues**

#### **Researcher Safety Issues**

Potential participants in the trial will be referred by their primary mental health physician or key worker. At the time of referral, the researchers will determine if the referee has any concerns regarding a risk to self or others for the patient. Any risk will be discussed in detail with the referring clinician and with the chief investigator before contacting the potential participant for informed consent. See Appendix B.

#### Participant Safety Issues

None identified at present. See Appendix B for further information.

**Ethical Issues** 

Case report forms and electronic data

All data and paper questionnaires will be anonymized with a unique identifier and stored

securely in locked filing cabinets and secure, password protected servers. Appropriate

access controls will be in place to ensure that access to confidential research information is

restricted to authorised members of the research team.

Ethical conduct of the study

Favourable ethical opinion will be sought from an appropriate REC before patients are

approached to participate in the study through informed consent. This will be added as a

substantial amendment to the PATHWAYS study.

Informed consent

Written informed consent will be obtained from each participant prior to participation.

Referrers will explain the study to potential participants, and I will re-iterate and explain the

exact nature of the study in writing, provision of patient information sheet, and verbally.

Study participants will be informed that they are free to withdraw their consent from the study

at any time.

Financial Issues

None identified presently. See Appendix C.

<u>Timetable</u>

MRP Proposal Submission: Due January 30<sup>th</sup>, 2017

Final Approved MRP Proposal Submission: Due June 5th, 2017

**Practical Applications** 

By developing a greater understanding of the neurodevelopmental comorbidity profile of

BPD patients, and investigating the mechanisms contributing to affective dysregulation, we

may be able to develop more targeted interventions of BPD for adolescents and young

adults to improve long-term outcomes.

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#### Appendix A

## Plain English Summary

**Title:** ASD and ADHD: Understanding Neurodevelopmental pathways to Borderline Personality Disorder.

Background: Borderline personality disorder (BPD) is a severe mental disorder, leading to difficulties controlling emotions, problems with relationships, and self-image. BPD usually emerges during adolescence. Studies have shown that childhood adversity, specifically maltreatment, increases the risk for personality disorders during early adulthood, and is related to poor emotion regulation. It is crucial to understand more about risk factors such as adverse childhood experiences (ACEs), for example abuse and neglect, and neurodevelopmental disorders (NDD) and their relationship to the development of BPD. This is due to the psychological and social difficulties, greater usage of mental health resources, and high mortality rate associated with BPD. One area that requires further research is the role of NDD, such as Attention Hyperactivity Disorder (ADHD) and Autism Spectrum Disorder (ASD), and ACEs in the development of poor emotion regulation, and how that in turn may impact on the severity of BPD symptoms. There is evidence to indicate that there may be individuals with BPD who also have undiagnosed NDD. This has implications for how young people can engage with psychological interventions aimed at improving their mental health.

#### **Aims**

- 1. To assess how many young adults with early BPD also have ASD and ADHD.
- 2. To establish how many and how much, young adults with early BPD have difficulties regulating emotion.

## **Hypothesis**

Higher rates of ACEs and the presence of NDD predict worse symptom severity in young adults with early BPD.

#### **Methods**

## I. <u>Participants</u>

The study is part of a larger feasibility study (PATHWAYS) that aims to recruit 30 young people (age 15-35) with early Borderline Personality disorder (EBPD). I aim to recruit an additional 20 young people with EBPD. For each person recruited, I hope to recruit an informant to answer questions about the young person's mental health.

#### Inclusion Criteria:

### For BPD

- Written informed consent
- Aged between 15-35 years old, and
- Must meet 2 out of 9 criteria for a BPD diagnosis.

#### For informant

- Written informed consent
- Aged 16 or older

- Must know the participant well enough to answer questions about their everyday behaviours and their mental health in addition to their developmental/NDD history.
  - This may include a guardian, partner, parent, sibling, or key worker.
- For participants under the age of 16, the informant must be their parent or legal guardian.

#### Exclusion Criteria:

#### For BPD

- Non-English speakers
- No informed consent

#### For informant

- Under the age of 16
- Unable to answer questions about the participant's everyday behaviours and mental health and their developmental/NDD history.
- No informed consent

## II. Recruitment

This study is part of a larger study with NHS patients within NHS Greater Glasgow and Clyde. We will develop close relationships with Community Mental Health Teams (CMHTs), Primary Care Mental Health Teams (PCMHTs), Clinical Psychology Services, Community Adolescent Mental Health Services (CAMHS), Personality Disorder Teams (AMHS) and non-statutory (third sector) mental health services.

#### III. Consent

Once referred, an initial meeting with the potential participant will be arranged. They will be given information sheets and an opportunity to

discuss the study and ask questions. Written informed consent will be taken if participant would like to proceed.

## IV. <u>Design of study</u>

This study is an exploratory study and will use descriptive statistics and linear regression to analyse the data.

## V. Data collection

Data will be collected over 2 meetings where participants will be asked to answer a number of questionnaires. A meeting will be arranged with their informant who will also complete questionnaires.

## **Key Ethical Issues**

All data and paper questionnaires will be anonymized and stored securely in locked filing cabinets and secure, password protected servers. Ethical approval will be sought from an appropriate research ethics committee before patients are approached to participate in the study through informed consent.

## **Practical Applications and Dissemination**

By increasing our understanding of patients with BPD and investigating the factors that contribute to difficulties regulating emotion, we may be able to develop more targeted interventions of BPD for adolescents and young adults to improve long-term outcomes. This study will be submitted as part of my research portfolio for the Doctorate in Clinical

Psychology. I hope to publish the results of this study in an appropriate academic journal.

Word Count: 552

## **Appendix B** (anonymised)

## WEST OF SCOTLAND/ UNIVERSITY OF GLASGOW DOCTORATE IN CLINICAL PSYCHOLOGY

## **HEALTH AND SAFETY FOR RESEARCHERS**

1. Title of Project	ASD and ADHD: Understanding Neurodevelopmental pathways to Borderline Personality Disorder
2. Trainee	
3. University Supervisor	
4. Other Supervisor(s)	
5. Local Lead Clinician	
6. Participants: (age, group or subgroup, pre- or post-treatment, etc.)	Young people with Early Borderline Personality Disorder (both emerging and established), age: 15- 35
7. Procedures to be applied (e.g., questionnaire, interview, etc.	Interviews and Questionnaires Questionnaires will be: - Mini-SCID - Adverse Childhood Experiences Questionnaire (ACE)
	<ul> <li>Psychosis Attachment Measure (PAM)</li> <li>Borderline Personality Questionnaire (BPQ)</li> <li>Difficulties in Emotion Regulation Scale Short Form (DERS-SF)</li> <li>The Autism Symptom Self-Report for adolescents and adults (ASSERT)</li> <li>Adult ADHD Self-report scale (ASRS-v 1.1)</li> </ul>

	- Early Symptomatic Syndromes Eliciting Neurodevelopmental Clinical Examinations (ESSENCE, V 1.0) - Relationship Problems Questionnaire (RPQ) -Autism Spectrum Screening Questionnaire (ASSQ) - Comprehensive Assessment of At-Risk Mental State (CAARMS) - Structured Clinical Interview for DSM-IV II: Personality Disorders (BPD section) (SCID II)
8. Setting (where will procedures be carried out?)  i) Details of all settings	GP Clinic (NHS) PCMHT/CMHT Clinic (NHS) Personality Disorder and Homelessness Team (AMHS) (NHS) CAMHS Clinic (NHS) Third Sector Mental Health Organisation Offices Home visit
ii) Are home visits involved	Yes (only when necessary, following NHS risk assessment)

#### Participants:

Young people with early Borderline Personality Disorder, aged 15 – 35. Potential risk could be harm to the researcher or participant if a client becomes distressed or aggressive during the assessments. This population group is associated with difficulties regulating emotions, and may have a higher risk of adverse behaviours as a result.

As some of the client group may be aged <16, they would be considered vulnerable with regards to giving informed consent.

Procedures

#### Procedures:

Settings

Participants will be asked to complete a number of questionnaires (as detailed above). Participant could become distressed / agitated / irritated when answering as some of the measures require the participant to think about adverse childhood experiences for example. The questionnaires may also result in a disclosure of childhood maltreatment, including neglect and abuse. There are also quite a lot of questionnaires so it is possible they may become irritated by the

number of questions.

#### Settings:

GP Clinic (NHS), PCMHT/CMHT Clinic (NHS), Personality Disorder and Homelessness Team (AMHS) (NHS), CAMHS Clinic (NHS), Third Sector Mental Health Organisation Offices, Home visit

## 10. Actions to minimise risk (refer to 9)

#### **Participants**

#### **Client Group:**

As I will be recruiting patients who are already involved with NHS services, it is likely clinicians would know in advance whether there is a strong likelihood of the client becoming distressed or aggressive during assessment, to the point of causing harm to the researcher and/or themselves.

## Participant

Procedure

Settings

#### Consent:

For those clients who are aged >16 parents and/or legal guardians will be approached to offer consent on their behalf. Caution will be needed to make sure parents/guardians consent in agreement with the young person.

As per PATHWAYS protocol, participants will be told in advance that they can withdraw at any point.

Information Sheets will be provided alongside the consent form, to each patient prior to the commencement of the assessment. The information sheet will outline the information above and detailed below. Participants will also be given a copy of their consent form.

#### **Procedures:**

#### Distress:

At the beginning of the assessment, patient's will be told that one of the questionnaires asks about adverse childhood experiences and that this may cause them some distress. Should participants become distressed when answering the questionnaires, the following options will be offered:

- taking a break from the interview, and if necessary, re-scheduling for another day.
- reminder that they can leave and/or withdraw from the study at any time
- With their consent, contact their key worker, referrer, or family/friend to let them know they are feeling distressed.

#### Disclosure of maltreatment, abuse or neglect

#### Disclosure by a minor (participant age 15)

If the participant (age 15) or the informant disclose any information that

indicates maltreatment, abuse or neglect towards the participant, then the research team would make an enquiry with the local social services team for advice in the initial instance. Following this, a child protection referral may have to be made to the appropriate team within social services for investigation, and the participants care team informed of disclosure.

#### Disclosure by a young person/adult (Participants age 16-35)

Any disclosure made by a young person or adult during the assessment will be kept strictly confidential within the research team. However, if a disclosure of maltreatment, abuse or neglect could potentially cause risk to a child a child protection referral will be made to social work services, i.e. if historic abuse is disclosed by the participant, and the perpetrator is still in contact or lives with a child, this would be considered a child protection concern that would be referred.

#### Settings:

They may be interviewed in their home if this is preferred. In the first instance, home visits will only be carried out in conjunction with key workers or other health staff who regularly meet with the participant in their home. For example, a community mental health worker, health visitor or key worker. I will only visit a patient's home if the patient's clinician provides a risk assessment and concludes that it is safe to do. I will follow the University of Glasgow lone working policy (http://www.gla.ac.uk/media/media\_212144\_en.pdf) and the NHS lone working policy

(http://www.nhsbsa.nhs.uk/Documents/Lone\_Working\_Guidance\_final.p df). A study mobile phone will be provided to any member of the research team conducting home visits, the team member will be required to check in with a colleague prior to and after the appointment to ensure they are safe. Visits will be conducted within normal working hours.

Trainee signature:	Date:	12.04.2017
University supervise	or signature:	Date: 12.04.2017

## **Appendix C** (anonymised)

## RESEARCH EQUIPMENT, CONSUMABLES AND EXPENSES

Trainee		
Year of CourseSecond Year	Intake Year2015	

Please refer to latest stationary costs list (available from student support team)

Item	Details and Amount Required	Cost or Specify if to Request to Borrow from Department
Stationary		Subtotal:
Postage		Subtotal:
Photocopying and Laser Printing		Subtotal:
Equipment and Software		Subtotal:
Measures		Subtotal:
Miscellaneous	Payment for taking part in the study.  As my MRP is a branch of the PATHWAYS study, I will need to pay £20 to each participant in line with the project. In	

investigators and the university, on the assumption 20 patients are recruited by the trainee, PATHWAYS will pay £20 x 10 patients, and the university will pay £20 x 10 patients, equalling £400 total, with £200 from trainee budget.	Subtotal: £200
	£200
ir u a a tı p a p e £	iniversity, on the assumption 20 patients are recruited by the rainee, PATHWAYS will may £20 x 10 patients, and the university will may £20 x 10 patients, equalling £400 total, with £200 from trainee

For any request over £200 please provide further justification for all items that contribute to a high total cost estimate. Please also provide justification if costing for an honorarium:

Trainee Signature	Date	.29.05.2017	
Supervisor's Signature	.Date 29.0	05.2017	