

Bangor University

DOCTOR OF PHILOSOPHY

Living with psychiatric labels

Lloyd, Emma

Award date:
2015

Awarding institution:
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Living with Psychiatric Labels

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2015

This thesis is submitted as part fulfilment for the degree of the

Doctorate in Clinical Psychology.

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Living with psychiatric labels

This thesis contains three papers which explore people's experiences of living with psychiatric diagnoses. The first paper is a review of the literature relating to young people's experiences and perceptions of stigma resulting from psychiatric diagnoses. The review identified 16 studies: eight qualitative, six quantitative, and two mixed methods. A range of stigma perceptions and experiences were reported by young people with a variety of psychiatric diagnoses. The majority of young people believed that society perceived those labelled with psychiatric diagnoses as different. Stigma was experienced within families, friendships, peer groups, and in school. Experiences ranged from being devalued to being rejected. Young people internalised stigma, resulting in loss of self-worth, feelings of shame and an altered sense of identity. The second paper is an original piece of qualitative research exploring experiences of living with a Borderline Personality Disorder diagnosis, for people who have had contact with the Criminal Justice System. Semi-structured interviews were used to investigate the lived experience of seven people diagnosed with BPD. Through interpretative phenomenological analysis, six themes emerged: A label without meaning; How others see me; How I see myself; Getting into trouble; Power and Control; and The utility of the diagnosis. Participants experienced the diagnosis in a predominantly negative way; experiencing stigma, an altered sense of self, and difficult experiences within mental health services. For some participants, their offending behaviour was attributed to their diagnosis. All participants described experiences of trauma; which was more helpful in making sense of their difficulties than was the diagnosis. The third paper integrates findings from the literature review and the empirical study, discussing implications for theory, future research and clinical practice. Finally my personal reflections of the research process are shared.

Declarations

This work has not been previously accepted in substance for any degree and is not being concurrently submitted in candidature for any degree.

Signed

Date

Statement 1

This thesis is the result of my own investigations, except where otherwise stated. Other sources are acknowledged by footnotes giving explicit references. A list of references is appended.

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Date

Statement 2

I agree to deposit an electronic copy of my thesis (the Work) in the Bangor University (BU) Institutional Digital Repository, the British Library ETHOS system, and/or in any other repository authorized for use by Bangor University and where necessary have gained the required permission for the use of third party material.

Signed

Date

Acknowledgements

I would like to acknowledge a number of individuals who have made the completion of this thesis possible. Firstly, I would like to thank my supervisors Dr James Lea, Dr Robin Owen and Dr Julia Wane for their guidance and support throughout the research. I would also like to thank Dr Gemma Griffith for reading drafts of my work.

To my research participants who took the time to share their stories with me; without them my research would not have been possible- thank you.

I would especially like to thank my wonderful family- mum, granny, Sarah, and Brad for their endless love, support and encouragement throughout clinical training. Thank you for always being there for me- I could not have survived the last three years without you!

Finally, I would like to dedicate this thesis to my late granddad, Harry Evans. Thank you for always believing in me.

Paper 1: Literature Review

Clinical Psychology Review- Notes for Contributors

Clinical Psychology Review publishes substantive reviews of topics germane to **clinical psychology**. Papers cover diverse issues including: psychopathology, psychotherapy, behaviour therapy, cognition and cognitive therapies, behavioural medicine, community mental health, assessment, and child development. Papers should be cutting edge and advance the science and/or practice of clinical psychology. Reviews on other topics, such as psychophysiology, learning therapy, experimental psychopathology, and social psychology often appear if they have a clear relationship to research or practice in **clinical psychology**. Integrative literature reviews and summary reports of innovative ongoing clinical research programs are also sometimes published. Reports on individual research studies and theoretical treatises or clinical guides without an empirical base are not appropriate.

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Manuscripts should be prepared according to the guidelines set forth in the Publication Manual of the American Psychological Association (6th ed., 2009). Of note, section headings should not be numbered. Manuscripts should ordinarily not exceed 50 pages, *including* references and tabular material. Exceptions may be made with prior approval of the Editor in Chief. Manuscript length can often be managed through the judicious use of appendices. In general the References section should be limited to citations actually discussed in the text. References to articles solely included in meta-analyses should be included in an appendix, which will appear in the on line version of the paper but not in the print copy. Similarly, extensive Tables describing study characteristics, containing material published elsewhere, or presenting formulas and other technical material should also be included in an appendix. Authors can direct readers to the appendices in appropriate places in the text. It is authors' responsibility to ensure their reviews are comprehensive and as up to date as possible (at least through the prior calendar year) so the data are still current at the time of publication. Authors are referred to the PRISMA Guidelines (<http://www.prisma-statement.org/statement.htm>) for guidance in conducting reviews and preparing manuscripts. Adherence to the Guidelines is not

required, but is recommended to enhance quality of submissions and impact of published papers on the field.

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Title. Concise and informative. Titles are often used in information-retrieval systems. Avoid abbreviations and formulae where possible. **Note: The title page should be the first page of the manuscript document indicating the author's names and affiliations and the corresponding author's complete contact information.**

Author names and affiliations. Where the family name may be ambiguous (e.g., a double name), please indicate this clearly. Present the authors' affiliation addresses (where the actual work was done) below the names. Indicate all affiliations with a lower-case superscript letter immediately after the author's name and in front of the appropriate address. Provide the full postal address of each affiliation, including the country name, and, if available, the e-mail address of each author within the cover letter.

Corresponding author: Clearly indicate who is willing to handle correspondence at all stages of refereeing and publication, also post-publication. **Ensure that telephone and fax numbers (with country and area code) are provided in addition to the e-mail address and the complete postal address.**

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Abstract: A concise and factual abstract is required (not exceeding 200 words). This should be typed on a separate page following the title page. The abstract should state briefly the purpose of the research, the principal results and major conclusions. An abstract is often presented separate from the article, so it must be able to stand alone. References should therefore be avoided, but if essential, they must be cited in full, without reference to the reference list.

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Highlights are mandatory for this journal. They consist of a short collection of bullet points that convey the core findings of the article and should be submitted in a separate editable file in the online submission system. Please use 'Highlights' in the file name and include 3 to 5 bullet points (maximum 85 characters, including spaces, per bullet point). See <http://www.elsevier.com/highlights> for examples.

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Abbreviations

Define abbreviations that are not standard in this field in a footnote to be placed on the first page of the article. Such abbreviations that are unavoidable in the abstract must be defined at their first mention there, as well as in the footnote. Ensure consistency of abbreviations throughout the article.

Acknowledgements

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

Footnotes

Footnotes should be used sparingly. Number them consecutively throughout the article. Many word processors can build footnotes into the text, and this feature may be used. Otherwise, please indicate the position of footnotes in the text and list the footnotes themselves separately at the end of the article. Do not include footnotes in the Reference list.

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References: Citations in the text should follow the referencing style used by the American Psychological Association. You are referred to the Publication Manual of the American Psychological Association, Sixth Edition, ISBN 1-4338-0559-6, copies of which may be ordered from <http://books.apa.org/books.cfm?id=4200067> or APA Order Dept., P.O.B. 2710, Hyattsville, MD 20784, USA or APA, 3 Henrietta Street, London, WC3E 8LU, UK. Details concerning this referencing style can also be found at <http://humanities.byu.edu/linguistics/Henrichsen/APA/APA01.html>

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Reference style

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

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

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

Young people's perceptions and experiences of stigma related to psychiatric
diagnoses: A review of the current literature

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This paper reviewed the literature from 2009 until October 2014 to investigate young people's perceptions and experiences of stigma related to psychiatric diagnoses. Sixteen articles were identified- eight qualitative studies, six quantitative studies, and two mixed methods studies- which explored young people's perceptions and experiences of stigma related to a psychiatric diagnosis. The review of the qualitative literature identified six main themes: 'Uncertainty regarding diagnosis'; 'A spoiled identity'; 'To disclose or not disclose?'; 'Internalising stigma and shame'; 'Changes in relationships'; and 'Managing a spoiled identity'. Of note was that those diagnosed with psychotic disorders reported increased stigma experiences. The quantitative literature found that societal stigma was perceived in varying ways by young people; being especially pertinent for those diagnosed with anorexia nervosa. Stigma experiences ranged from being devalued to being rejected by others. Self-stigma often resulted in feelings of shame and embarrassment, leading to greater secrecy and isolation. Clinical implications of the findings are discussed which include a move away from the use of psychiatric diagnosis with young people, anti-stigma initiatives which promote a psychosocial rather than medical view of mental health difficulties, and the greater involvement of families of young people in mental health services.

Keywords: Young people, Stigma , Mental health, Psychiatric Diagnosis, Labels

Highlights

- Young people with a range of psychiatric diagnoses experienced stigma
- Stigma was experienced with families, peers, mental health services and schools
- Perceived societal stigma led to fear of disclosure and delayed treatment for some
- Self-stigma resulted in shame, embarrassment, and an altered sense of identity.
- Ways of coping with stigma, such as withdrawal and secrecy, were described

Introduction

The ‘medical’ or ‘disease’ model of mental health difficulties dominates mental health systems in the Western world, with people frequently receiving psychiatric diagnoses as a way to explain their difficulties. It is widely assumed that being diagnosed and treated for a mental health difficulty can have unintended, harmful effects for individuals (Moses, 2009a). One such effect can be stigma, which has been defined as an attribute that within a given social context is deeply discrediting to the individual, who in turn is perceived as ‘tainted’ or ‘discounted’ (Goffman, 1963). A substantive body of research has documented how adults who live with a mental health diagnosis can be stigmatised by others without such a diagnosis (e.g. Corrigan & Kleinlein, 2005).

Different dimensions of stigma related to mental health diagnoses have been identified. Public stigma pertains to the negative social behaviours, reactions, and beliefs directed toward people with mental health difficulties by others with relatively more power (Link & Phelan, 2001). Public stigma is distinguishable from anticipated or perceived stigma. Perceived stigma refers to the extent to which individuals expect to experience public stigma should their stigmatising trait become known to others. Finally, self-stigma (or ‘internalised stigma’) signifies the self-prejudice, shame and sense of constraint experienced when an individual internalises negative stereotypes about his or her difficulties and perceives himself or herself as personifying these (Corrigan & Watson, 2002).

There is a wealth of research exploring adults’ stigma experiences (e.g. Livingston & Boyd, 2010; Mak et al, 2007). This body of research has identified how stigma can have significant consequences for the self-concept, quality of life, and economic opportunities of adults experiencing mental health difficulties (Corrigan & Lundin, 2001; Link & Phelan, 2001; Rusch et al, 2005; Yanos et al, 2001). However, there is a paucity of research

exploring the experiences of adolescents and young people with mental health difficulties. It has been estimated that over half of all mental health difficulties start before the age of fourteen years, and seventy-five per cent develop by the age of eighteen (Murphy & Fonagy, 2012).

Exploring young people's experiences of stigma relating to mental health difficulties is essential as the developmental processes they are undertaking and social contexts they experience are different to those of adults. A central process during adolescence and emerging adulthood is the development of a cohesive and coherent personal identity (Côté, 2006; Erikson, 1980), therefore the effects of stigma during this formative period may have considerable ramifications for an individual's developing identity and associated wellbeing and adjustment (Rappaport & Chubinsky, 2000). Currently, no review has identified and synthesised the literature which asks young people themselves how they perceive and experience stigma relating to mental health diagnoses. This review seeks to address this gap by reviewing qualitative, quantitative and mixed methods literature on the stigma experiences and perceptions of young people who have been received a psychiatric diagnosis.

Method

Data Sources and Search Strategy

The Web of Science, Medline via Pubmed, and Psychinfo electronic databases were searched in October 2014. The search terms used were “adolescent” OR “young people” AND “psychiatric diagnosis” OR “mental illness diagnosis” AND “stigma” OR “experiences of stigma”. Only journals published in English after 2009 were included to capture the most current published research.

The World Health Organization (1989) defines young people as persons in the 10–24 year age group, combining adolescents- ages 10–19, and youth- ages 15–24. This review will use the terms adolescence, youth, and young people to describe people in the stage of life that marks the transition from childhood to adulthood.

Papers were included if they studied young people with a mean age of 20 years or below; had received a psychiatric diagnosis; and explored stigma experiences or perceptions. Papers were excluded if they were not from the perspectives of young people with mental health diagnoses or studied young people at risk of developing mental health difficulties.

The initial search generated 759 articles. The titles and abstracts were screened and 16 were deemed appropriate for consideration. The reference lists and citation lists of these 16 papers were hand searched which generated a further 27 articles. After reading the abstracts 27 articles were rejected (see Literature Review Appendix: Figure 1 for a graphic representation of the search and refinement process). In total 16 papers were included in this review (those marked with an asterisk in the reference list).

Data Analysis

A data extraction table was developed (see Literature Review Appendix: Table 1). There were eight qualitative studies, six quantitative studies and two mixed methods studies which addressed the question: “How might a young person perceive and experience stigma related to a psychiatric diagnosis?” Since the data were not homogenous in quantitative studies a meta-analysis was inappropriate, instead the findings were collated and summarised. The qualitative and quantitative data within the mixed methods papers were separated and analysed in their respective categories.

The eight qualitative studies and qualitative data from two mixed methods papers were reviewed. Each study was read multiple times and notes made regarding the stigma experiences and perceptions reported in the data, and the themes reported by the authors. Notes and themes from each individual study were then compared to look for similarities and differences. The themes were then grouped to create over-arching themes, using the terminology employed in the reviewed literature.

Results

Qualitative studies

Ten papers were included that used qualitative methods. 266 young people were interviewed and the mean age of participants was 17 years (ranging from 12-29 years). In terms of diagnosis received, one study did not specify (Polvere, 2011); two focussed on depression (McCann, 2012; Issakainen, 2014); and the remaining studies included young people with a range of diagnoses including mood disorders, anxiety disorders, behavioural disorders, and attention deficit hyperactivity disorder (ADHD). Elkington et al (2012) and Elkington et al (2013) were the only studies to include young people diagnosed with psychotic disorders. The same participants were used in Kranke et al (2010) and Kranke and Floersch (2009); in Elkington et al (2012) and Elkington et al (2013); and in Moses (2009a) and Moses (2010a).

The analysis revealed six overarching themes. Each study did not necessarily contribute to each theme. The themes that emerged were: (1) 'Uncertainty regarding diagnosis'; (2) 'A spoiled identity'; (3) 'To disclose or not disclose?'; (4) 'Internalising stigma and shame'; (5) 'Changes in relationships'; and (6) 'Managing a spoiled identity'.

Table 1. The presence of themes in each qualitative study

	Uncertainty regarding diagnosis	A spoiled identity	To disclose or not to disclose?	Internalising stigma and shame	Changes in relationships	Managing a spoiled identity
Polvere (2011)	X	X		X	X	
Kranke et al (2011)	X	X	X	X		X
Kranke et al (2010)	X	X	X	X	X	X
Kranke & Floersch (2009)	X	X		X	X	X
Elkington et al (2012)		X	X	X	X	X
Elkington et al (2013)		X		X	X	
Issakainen (2014)		X	X	X	X	X
McCann et al (2011)			X	X		X
Moses (2010a)		X			X	X
Moses (2009a)	X					

- ***Uncertainty regarding diagnosis***

A theme present in five of the studies was uncertainty regarding the diagnosis received and how this contributed to stigma. Participants in Polvere's (2011) research described receiving multiple, often inconsistent diagnoses and being placed on medication for disorders that they were later told they did not have. This experience caused them to doubt their current diagnosis and question the social construction of mental health disorders more broadly. The majority of participants in Moses's (2009a) study indicated uncertainty and confusion about how to conceptualise their difficulties, and many struggled to articulate their difficulties appearing unaccustomed to reflecting on the nature of their mental health diagnosis.

In an attempt to make sense of diagnoses, young people in Kranke and Floersch (2009) and Kranke et al (2011) linked their personal meanings to culturally mediated stereotypes. The statements they made about people experiencing mental health difficulties

were often similar to ideas that they heard from family, peers or the popular media, using derogatory terms such as “psycho” to describe people who need to take medication (Kranke et al, 2010, p.895). This indicates how limited understanding of mental health diagnoses can result in stigma as young people rely on culturally mediated stereotypes to make sense of their own difficulties and those of others.

- *A ‘spoiled identity’*

In his work on stigma, Goffman (1963) described how stigma can result in a ‘spoiled identity’, meaning the stigma disqualifies the stigmatized individual from full social acceptance by others. The concept of a ‘spoiled identity’ was present in eight of the studies, with many young people articulating a general understanding that the larger society perceived those labelled with ‘mental illness’ as different (Issakainen, 2014; Elkington et al, 2012). Diagnosis was described as impacting on social interactions, with labelled individuals positioned in a manner that “limits their humanity”: “Because when you’re diagnosed with a mental illness you lose all your human rights” (Polvere, 2011, p.332). Young people described how others often now saw them as their diagnosis (Elkington et al, 2012); with emotional responses and reactions now viewed through a lens of psychopathology, as a ‘symptom’ as opposed to being normative human experience (Polvere, 2011).

Elkington et al (2012) was the only qualitative study to compare the narratives of youth diagnosed with psychotic disorders and those diagnosed with non-psychotic disorders. Only youth diagnosed with non-psychotic disorders voiced their belief that not everyone stigmatised against individuals with mental health difficulties. This finding suggests that young people diagnosed with psychotic disorders may experience greater stigma in relation to their diagnosis than those diagnosed with non-psychotic disorders; however other studies did

not make this distinction as young people diagnosed with psychotic disorders were not included in the samples.

- ***To disclose or not to disclose?***

Reluctance to disclose diagnosis to others was discussed by participants in five studies. A number of reasons for not disclosing were cited by young people, such as to protect from ‘differentness’, protect their self-esteem, preserve their reputation and social connection with peers (Kranke et al, 2011). The struggle with disclosing diagnosis is lamented in the words of this young person: “I think the bad things would be the stigma associated with it...because you’d be treated differently” (McCann et al, 2012, p.337). Rejection following disclosure of diagnosis was especially salient for youth diagnosed with psychotic disorder in Elkington et al (2012), who described experiences which were confrontational, severe, and blaming. For young people who are already experiencing significant difficulties, fear of rejection and rejection experiences could have longer term implications for their mental health.

- ***Internalising stigma and shame***

Young people in eight of the studies described internalising experiences of rejection and the stigmatising beliefs of the larger society, resulting in self-stigma and shame. Mental health difficulties were described in a range of ways such as ‘a vulnerability’, ‘a flaw’, being ‘less than’ (Polvere, 2011) and ‘crazy’ or ‘abnormal’ (Kranke et al, 2010). Almost all participants in Elkington et al (2012), diagnosed with both psychotic and non-psychotic disorders, articulated beliefs about themselves as a person with a ‘mental illness’, suggesting that they had engaged with and internalised stigmatising messages. A loss of self-worth following diagnosis was especially prominent in youth diagnosed with psychotic disorders.

Some narratives included references to how diagnosis had impacted on identity, infiltrating and shaping young people's sense of self (Polvere, 2011; Kranke et al, 2011). Acknowledging that young people who are in the process of developing a sense of their identity, in the context of experiencing mental health difficulties, do internalise stigma messages is an important issue for mental health services to consider when diagnosing young people.

- *Changes in relationships*

Young people in seven of the studies described changes in interpersonal relationships following diagnosis. Negative changes in relationships were typically described by youth diagnosed with psychotic disorders in Elkington et al (2013), and only youth with non-psychotic disorders described improvements in their relationships. The difference between these diagnostic groups was not explored in other studies.

A range of responses from parents following diagnosis were described such as minimising difficulties (Issakainen, 2014) or rejecting the diagnosis and dissuading them from seeking treatment (Elkington et al, 2013). Stigmatising messages from within families left young people feeling blamed, devalued, and rejected (Moses, 2010a), with negative familial perceptions being linked to feelings of shame as stereotypes were reinforced (Kranke et al, 2010). The prevalence of stigma reported within families by young people in these studies highlights the role mental health services can play in working with families to reduce stigma. This may be especially pertinent for those diagnosed with psychotic disorders.

Stigma experiences with school staff were described such as unsympathetic teachers (Kranke et al, 2011), behaviours and symptoms being misinterpreted (Kranke & Floersch, 2009), and being underestimated, unfairly blamed, avoided, excluded, disliked or feared (Moses, 2010a). Within these three studies a significant proportion of young people were diagnosed with 'behavioural disorders' such as conduct disorder and ADHD. It is possible

that these young people's difficulties may be more visible in the school environment in comparison to other diagnoses, e.g. depression, and therefore may attract more attention and result in negative interactions. School is a key site where youth developmental tasks are accentuated and enacted, particularly peer relationship and identity formation (Kranke et al, 2010). These findings identify the potentially detrimental effect of stigma experienced in this environment on young people's development.

This theme highlights the significant influence that changes in familial, peer and school relationships can have on young people. This finding is especially pertinent as Kranke et al (2010) found in their research that the negative impact of stigma was reversed by positive familial, peer and school perceptions. Furthermore, these changes in relationships were reported by young people with a range of diagnoses.

- ***Managing a 'spoiled identity'***

In seven of the studies young people described different ways of coping with their stigmatised identity. One such way was withdrawing from social interaction (Kranke & Floersch, 2009; Kranke et al, 2010; McCann et al, 2012; Elkington et al 2012; Issakainen, 2014), which was seen as protecting from stigma by reducing the possibility of differences being detected by others, however often led to increased loneliness and alienation.

Some young people described interacting with others who also experienced mental health difficulties (Kranke et al, 2010). This led to a sense of feeling 'almost normal' (Issakainen, 2014), and a sense belonging and acceptance, which Kranke and Floersch (2009) termed 'positive stigma avoidance'. This suggests that when embedded in a social context with peers who are 'in the same boat' (Moses, 2010a), friends are perceived as not being in a position to stigmatise, thus providing young people with a way of preserving their self-esteem.

Another way of coping with stigma was to create distance between themselves and the labelled group, with young people redefining the stigmatised group so that it did not include them. A subtle hierarchy of stigmatisation was described by some participants in Elkington et al (2012), with those diagnosed with non-psychotic disorders speaking of their difficulties in terms of being normal but needing a bit of help, thus separating themselves from the ‘crazier’ group. This finding is concerning as it indicates that young people diagnosed with psychotic disorders are at risk of further stigmatisation, however the other studies did not explore this.

This theme highlights how young people with a range of different diagnoses make efforts to cope with the stigma associated with their diagnosis. A variation of coping styles is reflected in the young people’s narratives, with some being more adaptive than others.

Quantitative studies

Six quantitative studies and quantitative data from two mixed methods studies were reviewed. The mean age of participants was 15.6 years, and 254 young people were included in the studies. One paper (Maier et al, 2014) focussed on females diagnosed with Anorexia Nervosa (AN), whilst the other studies used samples with varying diagnoses including mood disorders, anxiety disorders, attachment disorders, ADHD, alcohol or drug abuse disorders, and conduct disorders, and also a high rate of diagnostic comorbidity. Five studies were cross sectional designs (Moses 2009b; Moses, 2011; Moses, 2010b; Moses, 2010a; Moses, 2009a); two were longitudinal studies (Moses, 2014; Moses, 2015); and one used retrospective questionnaires (Maier, 2014). It is important to note that within the quantitative research, the measures used assess stigma differed between studies, with some using self-developed questionnaires (Maier, 2014, Moses, 2011), and others adapting adult questionnaires for use with young people (Moses, 2009b, 2010b, 2014, 2015, 2010a, 2009a).

Therefore, the validity and reliability of these measures has not been determined. Furthermore, the participants in the studies all had varying diagnoses, with some samples being too small to draw comparisons between diagnostic groups. It is important to note that seven of the eight studies reviewed were by the same author, and the same sample was used within Moses (2011), Moses (2014) and Moses (2015); within Moses (2009a) and Moses (2010a); and within Moses (2009b) and Moses (2010b).

The studies have focussed on young people's perceptions of stigma, their experiences of stigma, and self-stigma, therefore the results will be discussed in terms of these findings.

Perceived stigma

Three studies explored young people's perceptions of public stigma (Moses, 2009b, Moses, 2011, Maier, 2014). Participants in Maier et al's (2014) research had all received a diagnosis of AN, and at least 50% reported that they felt stigmatised by public opinion. 31% reported that they had delayed treatment due to fear of being criticised or blamed and 34% waited for fear of being excluded or degraded. This suggests that young people diagnosed with AN have to wrestle with both the fear of being stigmatised for their difficulties and seeking help. Delays in seeking help may have important prognostic implications for young people.

Young people in Moses' (2009b) research, where the majority were diagnosed with ADHD (53%) or depression/anxiety (34%), reported a fairly low level of perceived societal devaluation. Diagnoses were not consistently or strongly related to their stigma experiences, however some trends were notable. Participants diagnosed with ADHD perceived less societal devaluation, whereas youth with substance abuse/dependence disorder diagnoses reported higher ratings of societal devaluation. However, the ability to decipher the effects of any single diagnosis on stigma in Moses (2009b) is limited by the use of a sample evidencing

a high rate of diagnostic comorbidity. Furthermore, Moses comments that the sample used was not representative of adolescent mental health clients, and therefore this limits the interpretation of these results.

Participants in Moses' (2011) research were most commonly diagnosed with depression (66.7%), followed by anxiety (32.4%) and on average reported "a little" stigma apprehension upon leaving psychiatric hospitalisation. Those who identified as associating with peers with similar difficulties scored significantly lower on stigma apprehension. No difference in stigma apprehension was found by diagnosis.

The varied perceptions of societal stigma reported in these studies may be attributable to the different types of psychiatric diagnosis received by the young people. Research into AN has found that individuals diagnosed are often perceived as being responsible for the onset of their difficulties and as having a significant amount of control over their 'eating disordered behaviours' (e.g. Holliday et al, 2005; Stewart et al, 2006). The young people in Maier's (2014) research may have developed an awareness of these stigmatising perceptions. In terms of those diagnosed with ADHD, it may be that the increasing acceptance of this diagnosis in society as a fairly common neurological disorder (Moses, 2009b), may serve to normalise the experience of young people and exonerate them from blame; however this was not explored in the study. The increasing awareness of depression and anxiety in society may also explain why young people in Moses (2011) described low levels of stigma apprehension.

Stigma Experiences

Five studies explored young people's experiences of enacted stigma (Moses, 2009a; Moses, 2009b; Moses, 2010a; Moses, 2014; Maier, 2014). Two of the studies (Moses, 2009b; Moses 2014) reported that the most common stigma experiences as being disrespected or devalued by others on account of their diagnosis, rather than rejection. Moses (2009b)

found that those who were younger at first treatment reported more personal rejection. Having lived with their diagnosis for a longer period of time, they will have had more opportunities to experience stigma. Moses' (2014) longitudinal research found that social affiliation and identification with popular peers predicted higher stigma ratings at six month follow up after discharge from psychiatric hospital. Also, more friends known to have similar difficulties at time 1 was related to higher stigma ratings at time 2. This finding is in contrast to Moses (2011) where stigma perceptions were lower for those who identified with youth with similar difficulties. The results of these studies point to the importance of how young people situate themselves in terms of social affiliation and the meaning they ascribe to this. It is possible that whilst young people may feel less stigmatised within a group of people with similar difficulties, their association with a stigmatised group may heighten the visibility of 'differences' to others outside the group, resulting in further stigma experiences.

Moses (2009a) found that the extent to which young people refer to their difficulties in psychiatric terms, termed self-labelling, corresponded with reported exposure to negative messages from others, and more exposure to rejection. This was the only study to explore the impact of self-labelling and highlights an important issue for mental health services to consider when diagnosing young people. The extent to which they identify with their diagnosis may have implications for their experiences of stigma.

Self-Stigma

Four studies explored self-stigma (Moses, 2009b; Moses, 2010b; Moses, 2015; Maier, 2014). Participants diagnosed with AN in Maier et al (2014) had internalised wider stigmatising perceptions of AN, affirming stereotypes such as people with AN are attention seeking (49%) and could pull themselves together if they wished to (30%). The extent to which young people identified with their diagnosis (self-labelled) was associated with several

indicators of psychological wellbeing in Moses (2009a). Those who avoided self-labelling scored lower on measures of self-stigma and depression. This suggests that how young people conceptualise and communicate their mental health difficulties may influence their experience of self-stigma. It is possible that identification with psychiatric diagnosis may lead to young people internalising stigmatising messages they are exposed to in society, whereas those who do not identify with the label may be less likely to do so.

Over a quarter of participants in Moses' (2009b) study who were diagnosed with an average of 2.6 different disorders, most commonly ADHD (53%), depression or anxiety (35%) and conduct disorder (31%), reported 'frequently' or 'very often' feeling a sense of shame or embarrassment. Higher self-stigma was associated with more personal rejection experiences and greater secrecy. Youth diagnosed with conduct disorder demonstrated a statistical trend towards less self-stigma. Research indicates that youth diagnosed with conduct disorder often exhibit a low sense of personal responsibility for their behaviour and also socialise with others who present with similar behaviour (Heinze, Toro & Urberg, 2004), therefore this may protect them from internalising stigma.

Moses (2010b) explored adolescents' self-stigma and illness perceptions, and also the stigma and illness perceptions of their parents. 70% of adolescents were diagnosed with at least one affective disorder and 71% with at least one disruptive behaviour disorder. Parent's inclination to conceal their child's diagnosis was the most prominent parental correlate of adolescent self-stigma. This suggests that young people may internalise stigmatising messages relating to shame from their parents resulting in increased self-stigma. However, this was the only study to explore parent's perceptions.

Moses (2015) longitudinal study explored how adolescents discharged from psychiatric hospitalisation anticipate coping with stigma, and how well anticipated coping

strategies predict self-stigma ratings six months following discharge. Young people were most commonly diagnosed with depression (67%). The use of coping styles where individuals aim to gain mastery over thoughts and feelings by using favourable comparisons and cognitive restructuring in order to adapt the situation, were found to help prevent excessive shame or self-devaluation in the longer term. Exploring young people's strategies for coping with stigma is important as adult research has indicated that coping strategies can determine longer term adjustment (Link & Phelan, 2001).

Comparing the findings from qualitative and quantitative studies

Overall, the qualitative and quantitative data both revealed that young people with a variety of psychiatric diagnoses report a range of stigma perceptions and experiences. One of the most prominent findings present in both data related to young people's awareness of negative societal perceptions of psychiatric diagnoses. Both data also demonstrated the deleterious effect of public stigma on young peoples' perceptions of themselves. Many internalised stigmatising messages, resulting in feelings of shame, embarrassment and a loss of self-worth. Different ways of coping with a stigmatised identity were reported by young people in qualitative and quantitative studies; however this was only explicitly explored in one of the quantitative studies (Moses, 2015).

Discussion

This study has reviewed both qualitative and quantitative research relating to young people's perceptions and experiences of stigma relating to mental health difficulties and diagnosis. Four main findings will be discussed in turn: stigma perceptions; stigma experiences; internalised stigma; and coping with stigma.

The first finding identified was that throughout the qualitative and quantitative literature young people with a variety of diagnoses described perceptions of stigmatising societal attitudes, often resulting in detrimental consequences. Fear of being negatively evaluated led to some participants in Maier et al (2014) to delay treatment. This was not explicitly explored in the other studies, but general fear of disclosure and secrecy was reported throughout the qualitative and quantitative literature. Within qualitative studies young people drew on stigmatising stereotypes they were exposed to within their families, peer groups, the media, and wider society to make sense of their own difficulties. The impact of exposure to stigmatising stereotypes was highlighted in Elkington et al (2012) where young people created a hierarchy of stigma; those diagnosed with non-psychotic disorders stigmatising those diagnosed with psychotic disorders. Furthermore, in the two qualitative studies where youth diagnosed with psychotic disorders were specifically interviewed (Elkington et al, 2012; Elkington et al, 2013), they reported more perceived stigma than those diagnosed with non-psychotic disorders. The potential for young people delaying accessing services due to the fear of stigma has long term implications for their future. It has been found that a longer duration of untreated psychosis correlates with poor outcomes for young people (Pentilla et al, 2014). Therefore, whilst society continues to endorse stereotypes, especially in relation to psychosis, then stigma will continue to present as a problem for young people.

The second finding was that in both qualitative and quantitative research young people with differing diagnoses experienced enacted stigma, ranging from ostracism to devaluation. This occurred in a variety of contexts, such as with friends, peers, family and in schools. More enacted stigma was reported in the qualitative research than quantitative research, which may be due to the more varied samples included in the qualitative research and the use of in depth interviews. An important finding in the qualitative research was that

some young people experience stigma from teachers as well as peers. Young people use the school environment as a site for developing a sense of self-esteem, a sense of self, independence and self-efficacy (Brockman, 2003); therefore stigmatising experiences in school have the potential to be very damaging. During the developmental stages of adolescence and emerging adulthood, young people are consolidating their social and world views while simultaneously seeking acceptance and belonging (Erikson, 1980). Therefore, as indicated in the research reviewed, the potential implications of stigma experiences are profound.

The third finding was that across qualitative and quantitative studies, young people with a range of diagnoses internalised stigmatising messages. Throughout the qualitative literature young people described feelings of shame which altered their sense of self. This led to secrecy due to fear of stigmatisation from others if they disclosed their status. The detrimental impact of stigma within the family was identified within both the qualitative and quantitative research. The importance of parental illness perceptions on young people's self-stigma was highlighted in Moses (2010b) quantitative study; however this was the only study to explore this. This emphasises an important point which has arisen from this review, in that stigmatisation is not limited to concrete experiences, but is also associated with a more general perception of stigma related to mental health difficulties.

The fourth finding was that both qualitative and quantitative research found that young people described a myriad of ways in which they attempt to negotiate their stigmatised identity. Qualitative research identified isolation, creating friendships with others experiencing mental health difficulties, and rejecting their diagnosis. These all aimed at minimising stigmatising experiences, perceptions, and self-stigma. Quantitative research identified how coping styles which were aimed at increasing mastery over thoughts and

cognitive restructuring predicted less self-stigma in young people (Moses, 2015). This highlights an important role for mental health services in helping young people to develop adaptive ways of coping with stigma. Without this guidance there is a risk that they may resort to coping styles which may be self-defeating (e.g. withdrawal, isolation) and have a detrimental impact on their mental health.

Clinical implications

One clinical implication could be a change in the way that mental health difficulties are conceptualised within mental health services, and how this is communicated to young people, their families and society. Diagnostic classification frequently used in mental health services may intensify stigma by enhancing the public's sense of 'differentness' when perceiving young people with mental health difficulties. The homogeneity assumed by stereotypes may lead mental health professionals and the public to view individuals in terms of their diagnostic labels, rather than individuals within their specific context. Furthermore, the stability of stereotypes may exacerbate notions that people diagnosed with 'mental illness' do not recover (Corrigan, 2007). The use of psychiatric diagnosis has been criticised for increasingly medicalising distress and behaviour in both adults and children (Division of Clinical Psychology, 2013; Conrad, 2007). Read and Harré (2001) found that the public prefer psychosocial explanations of mental health difficulties over biological ones, ascribing less stigma to psychosocial explanations. This evidence suggests a role for the promotion of a less medicalised and non-stigmatising view of mental health difficulties. This could be achieved through the use of psychological formulation, which focuses on psycho-social explanations for difficulties, rather than psychiatric diagnosis. This would remove the need for labels and transform the language used in mental health services for young people, as language can be a powerful source and sign of stigmatisation (Rusch et al, 2005). This

review has highlighted how this may be especially prominent for young people diagnosed with a psychotic disorder or AN, as these diagnoses carry with them increased stigma.

A second clinical implication is the need for more targeted anti-stigma interventions and mental health awareness/education in schools for both pupils and staff. This is in line with the Time to Change Children and Young People's Programme (Mind, 2012) which aims to tackle the stigma associated with mental health difficulties. They advocate greater training for professionals working with young people around mental health promotion, the negative effects of stigma and ways of accessing help, as well as embedding teaching about good mental health and emotional resilience into school agendas. This review has indicated that young people diagnosed with psychotic disorders and AN can experience increased stigma, therefore anti-stigma education may benefit from more of a focus on these difficulties. By informing young people about mental health difficulties and dispelling any myths, they may be less likely to stigmatise others and more likely to access support from services for their own difficulties. Training could be facilitated by young people who are mental health service users; to empower these young people and normalise the experience of mental health difficulties in their peer groups. One way of targeting negative stereotypes which has shown promise in reducing stigma in adults (Couture & Penn, 2003) is providing opportunities for volunteering with persons with mental health difficulties.

A third clinical implication could be the greater engagement of families of young people with mental health difficulties to promote better knowledge of mental health and the development of effective coping styles. This review found that stigmatising messages and rejection within families had a significant negative impact on the young people and how they view their difficulties. This highlights the importance of engaging families in anti-stigma initiatives and in the mental health services being accessed by the young people. Families

may benefit from greater involvement with mental health professionals to provide them with information and support with the aim of de-stigmatising mental health difficulties. Family support groups may also be an effective way of diminishing stigma, and encouraging adaptive ways of coping. The review has indicated that young people diagnosed with psychotic disorders, and those diagnosed with AN may experience increased stigma within their family; therefore this highlights the need to further support for young people with these diagnoses and their families.

Future research

Research in this area is evolving, however much more is needed. An important finding in this review has been the differing impact of stigma on young people depending on the diagnosis they received. Of note is the evidence from the qualitative research that young people diagnosed with a psychotic disorder perceived and experienced more stigmatising responses from others; even from those who also have a psychiatric diagnosis. Also, the one quantitative study exploring young people diagnosed with AN reported significant stigma experiences. This emphasises the need for further research with young people with such diagnoses in comparison to other diagnoses. Future research utilising large or diagnostically homogenous samples is important for untangling the effects of diagnosis type on youths' stigma experiences.

Future research should be carried out in different contexts where young people are developing a sense of identity, such as school, and home and with wider society. Further evidence of young people's experiences in these different contexts could inform the development of effective interventions. Also, research could explore the experiences of young people accessing different mental health services e.g. inpatient, outpatient. Research that takes into account diversity, such as including young people of different ethnic

minorities, different sexualities, and different ages; as the contexts young people find themselves in may vary as a result of these factors and thus impact on stigma experiences.

Limitations of current review

This review acknowledges several limitations. A limitation of the quantitative studies was that all studies, apart from one, were by the same author and multiple papers used the same participant group. Qualitative studies also included different papers using the same data set by the same authors. This limits the generalisability of the results as it reflects the views of a small group of participants, with specific difficulties, and in a specific context.

Another limitation is the heterogeneity in terms of diagnosis received, and the differences in how these were explored. In both qualitative and quantitative research the young people had received differing diagnoses; however the difference in stigma experiences between diagnoses was not explored in much of the research. Furthermore, within the qualitative research Polvere (2011) was not explicit about diagnoses received by participants, and Issakainen (2014) comments that many participants had diagnosis of depression but did not specify how many.

Summary

Recognising its limitations, this review modestly suggests that young people perceive and experience significant stigma related to mental health diagnoses, especially those diagnosed with AN or psychotic disorders. Stigma can result in a plethora of difficulties such as changes in relationships; feelings of shame; a negative impact on identity development; and lead young people to find ways to manage their stigmatised identity which are often self-defeating. Suggestions for improving young people's experience include using a psychological formulation approach rather than diagnostic approach for conceptualising

mental health difficulties; increasing engagement of families in mental health services; and anti-stigma education in schools which promote a psycho-social perspective on mental health difficulties. Understanding the stigma of mental health in young people is a worthy endeavour, as there is the potential for longer term psycho-social implications for young people.

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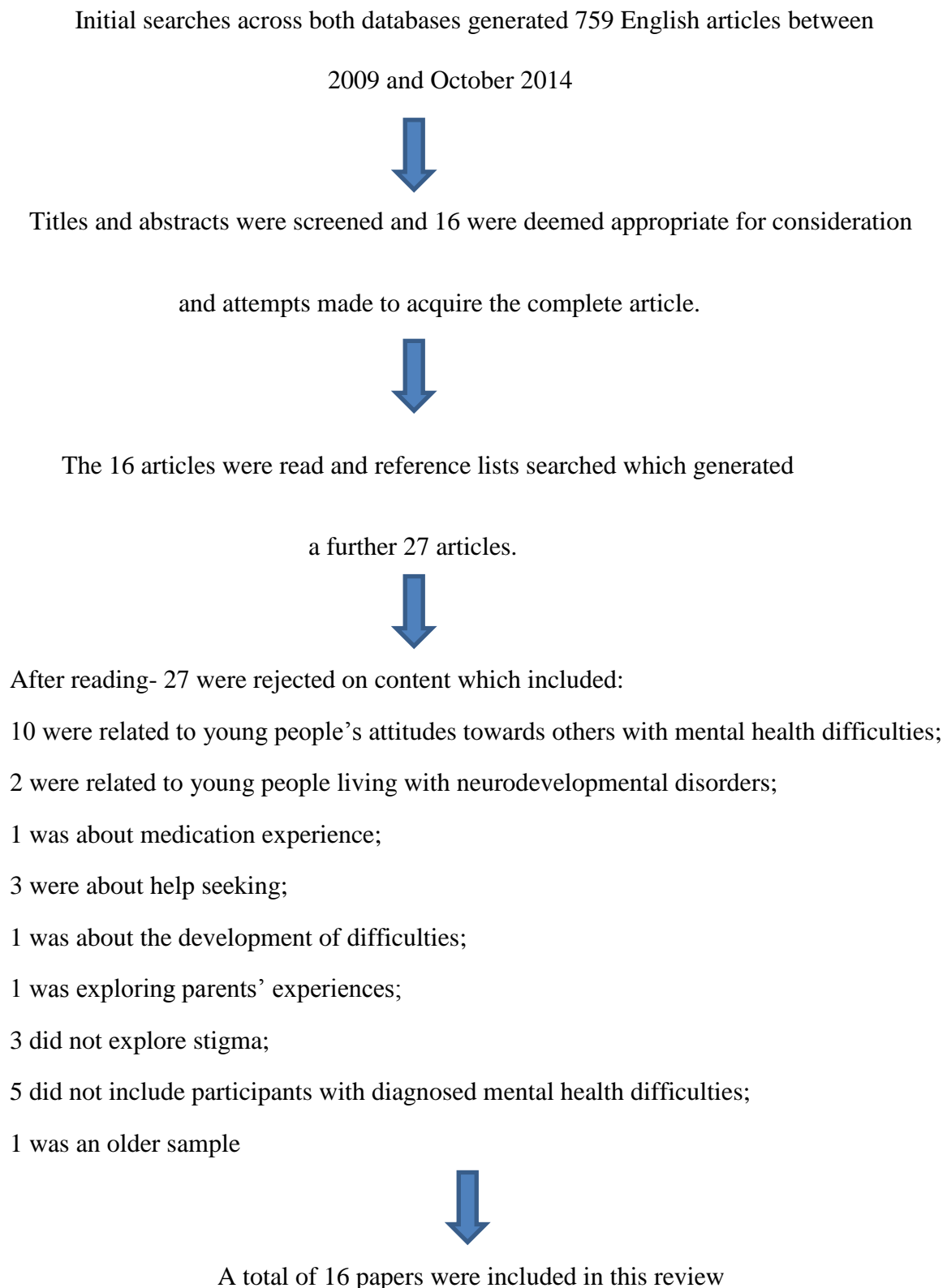
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Literature Review Appendix: Figure 1: Literature search process

Literature Review Appendix: Table 1. Data extraction table of studies for the literature review

Author and year	Participant Demographics	Brief description of Method	Summary of Main findings	Limitations
Polvere 2012	N= 12 Mean age 19.8 years Diagnoses not specified	Semi-structured interviews. Qualitative analysis based on Miles & Huberman, 1994	Negative psychosocial ramifications resulting from having a mental health diagnosis. Negative impact of receiving a mental health diagnosis on peer relationships. Psychosocial ramifications of stigma in the context of a social interaction and the manner in which stigma infiltrates and shapes one's sense of self.	Reflects the perspectives of youth currently involved in 'Youth Movement'- might have a more empowered and agentic stance than other young people.
Kranke Floersch Kranke Munson 2011	N= 27 Mean age 14.4 years Over 74% diagnosed with mood disorder, and 56% ADHD, some had more than 1 diagnosis. All taking psychiatric medication.	Semi structured interview tool- 'TeenSEMI' 150 open ended questions- questions relating to 9 areas.	The findings revealed a self-stigma model comprising three narrative components: stereotype, differentiate and protect.	Excluded youth who had not taken medication in the last 30 days. Sample not representative of all youths with MI or taking medication.

Kranke Floersch Townsend Munson 2010	N= 40 Mean age 14.2 years 77.5% mood disorder 67.5% ADHD 45% ODD/CD 15% Anxiety disorder 20% other	Semi structured interview, thematically analysed using Link et al's (1989) modified labelling theory	90% of the sample endorsed at least 1 of Link et al's (1989) constructs of secrecy, shame, and limiting social interaction. Additional themes emerged indicating that the perceptions of adolescent's family members and school environments can accentuate their experience of stigma or serve as a protective barrier against it.	Possible sources of variance that may have contributed to the differential distribution of stigma themes not examined- uneven developmental trajectories, gender, ethnicity, type of classroom setting.
Kranke Floersch 2009	N=40 Mean age 14.2 years 77.5% mood disorder 65.5% ADHD 45% ODD/CD 15% Anxiety disorder 20% other	Semi structured interview tool- 'Teen SEMI'	Themes include: Ostracism from peers and social exclusion. Lack of awareness about the meaning of MI Positive effects of interactions with others in similar condition Unsympathetic teachers	Small sample Voluntary, self-selected sample
Elkington Hackler Mckinnon Borges Wright 2012	N=24 Mean age 18.1 years 29% diagnosed with a psychotic disorder. 71% diagnosed with non-Psychotic disorders.	Thematic analysis of the interview texts using Link and Phelan's (2001) model of stigmatization.	Participants reported experiences of stigma within their families and social networks. Labelling may influence self-concept and the strategies in which youth engage to manage a stigmatized identity.	Voluntary, self-selected sample Small sample size. Concentrated in one geographical location. Reliance on self-report .

Elkington Hackler Walsh Latack Mckinnon Borges Wright Wainberg 2013	N=20 Mean age 19 years 25% diagnosed with psychotic disorder. 75% diagnosed with non-psychotic disorders.	In depth interviews and use of vignettes. Thematic analysis.	Four main themes: (1) societal perceptions of those with MI as partners (societal stigma); (2) individual experiences of stigma within relationships (individual level); (3) internalised stigma of self as a partner (social-psychological processes) and (4) managing a stigmatised identity by engaging in sexual risk behaviours	Voluntary, self-selected sample Small sample size. Concentrated in one geographical location. Reliance on self-report
Issakainen 2014	N= 81 Mean age 19.5 years Self-identified as having depression and some diagnosed (not specified)	Data collected via the internet- 3 ways: Written narratives Online group discussion Interviews	Reliance on two stigmatizing cultural conceptions—‘depression as a mental illness’ and ‘depression as a matter of pulling oneself together’—to account for why they were perceived as abnormal, and for the absence of empathy for their distress. To cope with these stigmatizing conceptions, they resorted to reframing their experience of ‘depression as a normal but serious affliction’.	Voluntary, self-selected sample
Mccann Lubman Clark 2011	N=26 Mean age 18 years Depression as primary diagnosis	Interpretative Phenomenological Analysis	Four themes were found: (1) struggling to make sense of their situation; (2) spiralling down; (3) withdrawing; (4) contemplating self-harm or suicide.	Voluntary, self-selected sample

Maier et al 2014	<p>N= 36</p> <p>Mean age 19.3 years</p> <p>former clients diagnosed with AN</p> <p>mean time of assessment after discharge was 5.6 ± 1.2 years</p>	<p>Retrospective questionnaire</p> <p>Pilot of the 'Questionnaire on stigmatisation in patients with anorexia nervosa' QSAN</p>	<p>Feelings that society held negative stereotypes of individuals with AN, concrete experiences of stigmatization and discrimination, and rejection by peers were reported.</p> <p>High degree of self-stigmatization.</p>	<p>Possibility of retrospective recall bias- over or underestimation of stigma</p> <p>QSAN not validated</p>
Moses 2009b	<p>N=60</p> <p>Mean age 14.8 years</p> <p>ADHD/ADD 53%</p> <p>Depression or anxiety 34%</p> <p>CD 31%</p> <p>Bipolar disorder NOS 27%</p> <p>PTSD 20% AODA 20%</p> <p>ODD 19%</p> <p>RAD 12%</p> <p>OCD 5%</p>	<p>Cross sectional</p> <p>Measures adapted from existing stigma scales used with adults and from youth stigma scales related to other illnesses.</p>	<p>On average, fairly low levels of perceived societal devaluation.</p> <p>Most commonly endorsed stigma experiences pertaining to personal rejection involved being disrespected by others</p> <p>Between 25% and 32% of participants reported frequently or very often feeling a sense of shame or embarrassment.</p>	<p>Small sample size</p> <p>Voluntary, self-selected sample.</p> <p>Measures used not validated</p>

Moses 2011	<p>N=102</p> <p>Mean age 15.3 years</p> <p>66.7% depression, 32.4% anxiety, mood disorder NOS 18.6%, ADHD 13.7%, PTSD 8.8%, ODD or CD 6.9%, AODA 5.9%, bipolar 5.9%, OCD 5%, other 7.8%</p>	<p>Assessed within 7 days of discharge from their first psychiatric hospitalisation with a range of measures.</p>	<p>On average the participants reported “a little” stigma apprehension. 21% reported substantial stigma apprehension.</p> <p>Highlights the role of social context and external contingencies of self-worth in determining adolescent’s perceptions of stigma related threat.</p>	<p>Time lag in assessing stigma apprehension after hospitalisation by several days (3-7).</p> <p>Small sample.</p> <p>Some measures were new and untested.</p>
Moses 2014	<p>N=80</p> <p>Mean age 15.3 years</p> <p>54.9% had comorbid conditions; depressive disorder 66.7%, Anxiety disorder 32.4%, Mood disorder NOS 18.6%, ADHD 13.7%, PTSD 8.8%, bipolar 5.9%, SU disorder 6.9%, OCD 2.9%, other 7.8%, 6.9% ODD or CD</p>	<p>2 interviews:</p> <p>Time 1= within 7 days of =discharge,</p> <p>Time 2= 6 months later.</p> <p>Retention rate 78.4%</p> <p>A range of measures used.</p>	<p>Six months following discharge from psychiatric hospital 70% reported experiencing one or more aspects of enacted stigma.</p> <p>Most reported was not outright social rejection but rather a general devaluation, disrespect, emotional insult, and being underestimated by others.</p> <p>Data indicates that youths’ social identifications and affiliations may be more relevant for their experiences of MI stigma than other social characteristics.</p>	<p>Short duration of follow up.</p> <p>Small sample size.</p> <p>High representation of mood disorders limits generalisability of results.</p>

Moses 2015	<p>N=102/ 80 (follow up)</p> <p>Mean age 15.3 years</p> <p>Mostly mood and anxiety disorders. 67% depression. ADHD 7%, AODA 8%, ODD or CD 5%.</p>	<p>Two face-to-face interviews that assessed coping and self-stigma.</p> <p>Modified Response to Stress Questionnaire</p>	<p>Youth reporting higher self-stigma ratings at follow-up anticipated using more disengagement and effort to disconfirm stereotypes and less secondary control engagement coping at baseline.</p> <p>Anticipated use of secondary control engagement coping was uniquely significant in predicting participants' self-stigma when controlling for baseline self-stigma. At the same time, higher baseline self-stigma ratings predicted less adaptive coping (disengagement and effort to disconfirm stereotypes) at follow-up.</p>	<p>Self-selected sample.</p> <p>Small sample size –limited statistical power.</p> <p>Measure not validated for use with young people.</p>
Moses 2010b	<p>N=60</p> <p>parent child dyads</p> <p>Mean age of young person 14.8 years</p> <p>70% at least 1 affective disorder.</p>	<p>Adapted questionnaires</p>	<p>20% of adolescents and parents reported significant concerns related to self-stigmatisation.</p> <p>3 most prominent factors associated with adolescent's self-stigma ratings included adolescents' perceptions of social skill deficits and trauma as causal factors pertaining to their mental health challenges as well as parents inclination to conceal their mental health problems.</p>	<p>Sample size limits external validity, power to detect all potential significant relationships.</p> <p>Lack of an adequate measure of illness severity.</p> <p>Measures adapted for purpose of study- psychometric properties largely untested.</p>

Moses 2010a	<p>N=56</p> <p>Mean age 14.9 years</p> <p>71.4% affective disorder 69.9% disruptive behaviour disorder, PTSD 21.4%, AODA 19.6%, RAD 10.7%</p>	<p>Mixed methods design.</p> <p>Semi Structured interviews followed by closed ended questions and rating scales (not specified)</p>	<p>Greatest number of participants experienced stigmatisation in relationships with peers (62%).</p> <p>46% described experiencing stigmatisation by family members.</p> <p>35% reported stigma perpetuated by school staff.</p>	<p>Measurement and sampling.</p> <p>Complexity and variation in problems</p>
Moses 2009a	<p>N=54</p> <p>Mean age 14.9 years</p> <p>83% diagnosed with more than one disorder</p> <p>45.3% diagnosed with an affective and disruptive type disorder</p>	<p>Mixed methods design.</p> <p>Semi structured interviews and adapted measures.</p>	<p>A minority of adolescents self-labelled.</p> <p>Adolescents who self-labelled reported higher ratings on self-stigma and depression.</p>	<p>Small, self-selected sample.</p> <p>Lacked adequate measure for symptom severity.</p> <p>Cross sectional design precludes the identifying directional relationships between self-labelling and psychological wellbeing.</p>

Paper 2: Empirical Study

Social Science & Medicine- Notes for Contributors

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Research highlights are a short collection of 3 to 5 bullet points that convey an article's **unique contribution to knowledge** and are placed online with the final article. We allow 85 characters per bullet point including spaces. They should be supplied as a separate file in the online submission system (further instructions will be provided there). You should pay very close attention to the formulation of the Research Highlights for your article. Make sure that they are **clear, concise and capture the reader's attention**. If your research highlights do not meet these criteria we may need to return your article to you leading to a delay in the review process.

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“People think you’re mad, you’re bad”: An IPA study exploring experiences of living with
a Borderline Personality Disorder Diagnosis

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Borderline Personality Disorder is a controversial diagnosis, provoking debates surrounding its reliability, validity, and utility in clinical practice. It is frequently diagnosed in mental health services, and a significant number of people diagnosed with Borderline Personality Disorder are involved in the Criminal Justice System. The purpose of this study was to explore experiences of living with a Borderline Personality Disorder diagnosis, for individuals who had experienced contact with the Criminal Justice System. Seven people were interviewed between November 2014 and March 2015, in North Wales. Subsequent transcriptions were analysed using Interpretative Phenomenological Analysis. Six main themes emerged from the data: A label without meaning; How others see me; How I see myself; Getting into trouble; Power and control; and The utility of the diagnosis. Overall, the study highlighted the participants' predominantly negative experiences of the diagnosis. Positive experiences were linked to access of services such as psychological therapy. The diagnosis held no meaning for some participants, and interactions with mental health professionals often left them feeling powerless. Traumatic experiences were described by all participants, and for them, this provided a more useful explanation for their difficulties than the diagnosis. Contact with the Criminal Justice System was described by some participants as a consequence of coping with difficult emotions. For others, it was attributed to the diagnosis. A move away from the use of this diagnosis within services is suggested. The benefits of using psychological formulation to make sense of people's experiences, which acknowledges the impact of trauma and abuse on the development of mental health difficulties, is discussed.

Research Highlights

- Experiences of the diagnosis were predominantly negative
- The diagnosis had a negative impact on identity; feeling different and abnormal
- Stigma was experienced in society and in mental health services
- Some participants attributed their offending behaviour to the diagnosis
- All participants reported experiences of trauma and/or abuse

Key words

Borderline Personality Disorder

Criminal Justice System

Stigma

Trauma

Labels

Diagnosis

North Wales

Introduction

Psychiatric discourse, embodied in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5, APA, 2013, p.645) defines personality disorder (PD) as “an enduring pattern of inner experience and behaviour that deviates markedly from the expectations of the individual's culture, is pervasive and inflexible, has an onset in adolescence or early adulthood, is stable over time, and leads to distress or impairment.” Borderline Personality Disorder (BPD) is a specific category of PD, described as “a pervasive pattern of instability of interpersonal relationships, self-image, and affects, and marked impulsivity” (APA, 2013). BPD is a controversial diagnosis, provoking debate among people with personal experience of the diagnosis, mental health staff, criminal justice agencies, and policy makers. These debates surround the reliability and validity of the diagnostic criteria, and the utility of the construct itself (Tyrer, 1999).

BPD in Mental Health Services and the Criminal Justice System

BPD is generally the most prevalent category of personality disorder diagnosed in non-forensic mental healthcare settings (NCCMH, 2009). Within the Criminal Justice System (CJS), it is estimated that 60-80% of male prisoners and 50% of female prisoners meet the criteria for PD compared with 6-15% of the general population (Sainsbury Centre for Mental Health, 2009). The prevalence of BPD diagnosis for women in prison is estimated to be 20% (NOMS, 2011). There has been less research into the prevalence of those diagnosed with PD within the probation service, however a recent study identified that 47.4% of participants were ‘likely cases’ of PD (Brooker et al, 2011). This indicates that many people will experience both a BPD diagnosis and contact with the CJS.

The police are commonly a first point of contact for a person in a mental health crisis. Every year some 11,000 people are taken to a police station as a 'place of safety' under the Mental Health Act. Up to 15% of incidents with which the police deal are thought to have some kind of mental health dimension (Sainsbury Centre for Mental Health, 2011). Many people who have had contact with the CJS will require support from community mental health services. Therefore, there are a number of means by which people can come into contact with both the CJS and mental health services.

Criticisms of Borderline Personality Disorder

Like all psychiatric diagnoses, BPD reflects a particular way of understanding emotional distress and coping strategies as 'symptoms', located within the individual rather than the broader social context. The debate surrounding psychiatric diagnosis has been highlighted in a position statement released by the Division of Clinical Psychology (DCP, 2013). They argue that functional psychiatric diagnoses, including PD, have limited reliability, questionable validity, result in stigma, and medicalise distress.

The diagnosis of BPD is fraught with procedural and classification difficulties (Tyrer, 2001). Outpatient settings most often rely on unstructured interviews to assess for BPD, even though inter-clinician reliability of the BPD diagnosis is poor (NCCMH, 2009). Furthermore, there is evidence of difficulties in differentiating between the various PD diagnoses (Silverstein, 2007).

The lack of reliability and validity have led to many opposing the use of the diagnosis, arguing that it is rendered meaningless, other than as a means to oppress and stigmatise (Johnstone, 2000). The diagnosis has been criticised for frequently being used within the mental health professions as little more than a 'sophisticated insult' (Herman, 1992), and an

invalid ‘catch-all’ label which can further damage women who have suffered abuse (Proctor, 2007). It has been argued that the BPD diagnosis fails to capture the experience of the individual, with many receiving the diagnosis having been victims of abuse (Ramon, Castillo & Morant, 2001). Castillo (2000) describes how the diagnosis can exacerbate the effects of trauma, as it can lead to a negative service response, and also reinforce a damaged sense of self.

Service user experiences of personality disorder diagnosis

Due to the potential negative implications of psychiatric diagnoses for service users, it is important to explore how service users experience living with the diagnostic label of ‘Borderline Personality Disorder’. However, qualitative studies investigating the experiences of individuals living with the BPD label are limited. Previous research has identified the negative impact of the PD label on the attitudes of professionals towards service users (Nehls, 1999; Ramon et al, 2001, Stalker, Ferguson & Barclay, 2005). Service users have also described stigma surrounding the act of diagnosis and the label itself (Nehls, 1999; Ramon et al., 2001; Stalker et al., 2005; Horn, Johnstone & Brooke, 2007).

One study has explored service user’s experiences of the BPD label (Horn et al, 2007). Diagnosis was experienced both positively and negatively by participants. Positive aspects of the diagnosis related to a sense of now knowing what was wrong, and having access to services, support and therapy. Negative aspects concerned experiences of rejection by services, being judged negatively by others, and that the diagnosis was without meaning. Trusting and accepting relationships helped participants to counteract the negative self-image they felt the diagnosis communicated to them; providing hope and optimism. The authors suggest that alternative ways of understanding the self, such as a social constructionist perspective, may be more useful than the BPD diagnosis.

Research has also explored the experience of having a PD diagnosis within the context of medium secure and community forensic services (Black, Thornicroft & Murray, 2012). Participants described two facets of their lived experience (1) the way they see themselves in light of their offending and social background and (2) the pejorative nature of the personality disorder and their need to distance themselves from it.

Aim of present study

This research focuses upon people's experiences of living with a BPD diagnosis, for individuals who have also had contact with the CJS. Contact with the CJS was defined as: prison, forensic mental health services, probation services, or the police. This research is a progressive step to develop further understanding of the complex relationship between BPD diagnosis and human experience; in a population where experiences of the diagnosis may be particularly complex due to involvement with the CJS. There has been no research undertaken with this group of individuals, therefore the present study aims to contribute to the literature by gaining an in-depth account of how a diagnosis of BPD has impacted on the participants' identity, relationships, and behaviour.

Method

Qualitative Methodology

An Interpretative Phenomenological Analysis (IPA; Smith, Flowers & Larkin, 2009) approach was used to explore and understand participants' experiences of living with a BPD diagnosis. IPA is phenomenological in its approach as it aims to understand the personal meaning attached to an individual's experience; it is the subjective rather than 'objective' elements of experience that are prioritised. The interpretative component refers to the researcher's own dynamic contribution to this process. It is recognised that a researcher's

interpretations are influenced by their own preconceptions, in that the personal world of the participants is interpreted through the personal world of the researcher. This relationship encompasses a double hermeneutic in which “the researcher is trying to make sense of the participants trying to make sense of what is happening to them” (Smith et al, 2009, p.3).

Recruitment

Participants were recruited from Community Mental Health Teams, Forensic Psychiatric Outpatient Service, and the Probation Service in North Wales. Access to participants was arranged by contacting services and presenting the research to professionals at team meetings. In accordance with the principles of IPA, recruitment was constrained by explicit inclusion/exclusion criteria to obtain homogeneity within the sample:

Inclusion:

- Aged between 20-65 years of age.
- Formally diagnosed with Borderline Personality Disorder by a psychiatrist, or forensic/clinical psychologist.
- Lived with the diagnosis for a minimum of 2 years.
- A history of involvement with the CJS, including: prison, probation, forensic mental health services or the police.

Exclusion

- Significant mental health difficulties which could be exacerbated by the research procedure, identified by the professional involved in their care.
- English not spoken to a standard sufficient to participate in interviews.
- Significant communication or intellectual disability restricting ability to give informed consent and/or participate in interviews.

Participants

Seven participants took part in the study; four females and three males, aged between 28 and 60, who lived in the same local health authority. All participants had been diagnosed with BPD by a Psychiatrist; and had lived with the diagnosis for over two years (see research appendix: Table 1 for participant demographic information). All participants had previous involvement with the CJS, as identified by professionals involved in their care. Participants' offences were only known if disclosed during the interviews. Individuals were identified by professionals, provided with written information about the research and invited to participate.

Data Collection

An interview schedule was developed to provide guiding questions for the interviews, through discussion with the research supervisors and broad reading of research in the area. This was designed to be open and expansive, allowing the participants to reflect on four areas of their experience: receiving a BPD diagnosis; the meaning and importance of the diagnosis; whether the diagnosis had influenced how others relate to them; and whether the diagnosis has altered their perceptions of themselves (see General Appendix 1). Participants' offence histories were not the focus of the research, rather their experience of the BPD diagnosis; therefore the research team decided that participants would not be explicitly asked about this. Interviews took place between November 2014 and March 2015 in North Wales. Prior to each interview, time was set aside for the researcher to describe the research and for the participant to ask any questions. Written consent was obtained before each interview. All participants consented to anonymised quotes being used. Interviews lasted between 40 and 60 minutes and were audio recorded. Participants were given a £10 voucher at the beginning of the interview, so it did not interfere with their decision to leave.

Data analysis

Following the guidelines provided by Smith et al (2009) each interview was transcribed then read several times to familiarise the researcher with the data. Each transcribed interview was analysed, looking for preliminary comments and interpretations of the text, such as similarities and differences, echoes, amplification and contradictions in what was being said. Transcripts and notes were reviewed to identify interconnected themes, with observations grouped according to the context and meaning being conveyed. This was achieved through 'abstraction' where similar/related themes were housed within superordinate categories, and assigned conceptually defined titles that summarised how each cluster of themes was interlinked. The same process was repeated for each transcript, with care taken, as far as possible to 'bracket' the ideas and themes from previous cases whilst the next case was being analysed. Superordinate themes from each analysed case were identified and reviewed for connections and relationships between them. From this process superordinate themes for the group were identified.

The credibility of the researcher's analysis was assessed through independent audit of the interview transcripts. Two of the research supervisors (JL & JW) read through the analysed interviews and checked that the themes were situated within the data and credible. The researcher and research supervisors then discussed themes and interpretation for all interviews.

Ethical considerations

Ethical approval was granted by the North Wales NHS Research Ethics Committee; NHS R&D; Bangor University Ethics Committee; and the National Offender Management Service (NOMS).

Reflexivity

The first author (EL) was in her final year of clinical psychology training whilst undertaking this research. A critical stance on the use of diagnostic categories was held, with strong doubts regarding the usefulness of psychiatric diagnoses to understand a person's distress. During the research, this stance was not revealed to the participants, so as not to influence their responses.

Results

Six super-ordinate themes were drawn from the analysis: A label without meaning; How others see me; How I see myself; Getting into trouble; Power and control; and The utility of the diagnosis. These themes are described and illustrated with quotes from interviews to demonstrate each theme and component sub-theme. Table 2 displays which participants identified with which themes (Research appendix: Table 2).

A label without meaning

What does it mean?

Participants struggled to understand the meaning of the BPD diagnosis. Both Elen and Jen questioned the diagnosis asking "What does it mean?" For four participants, the difficulty in understanding the meaning was attributed to a lack of explanation from their Psychiatrist. Kate described how: "They never went into any depth about my diagnosis. Never explained a thing to me." Jen stated: "I've never really been explained what this borderline thing is, this borderline personality disorder, I've never been explained it." Kate's use of the word "depth" suggests that the diagnosis held a shallow, superficial meaning to her. Jen's description of a "borderline thing" reflects how she perceives the diagnosis as an

object which cannot be precisely defined. Living with this superficial, imprecise diagnostic label was experienced as frustrating and perplexing, and appeared to render the diagnosis as meaningless.

In addition to the lack of explanation given, the clinical language used to convey the diagnosis was described as unclear and confusing. Alex spoke of his experience of receiving a diagnosis: “I didn’t understand...just big words...just confusing...I don’t understand it.” George commented: “I didn’t like the title because I didn’t understand what it meant, Borderline Personality Disorder...what does borderline mean and why is it a personality disorder?” These quotations suggest that the diagnosis and diagnostic language had meaning for the diagnostician; however this meaning was not shared with the participants. There was a sense that participants felt lost in the clinical language of services, without any guidance to assist them in finding meaning.

The search for meaning

The frustration and uncertainty led to a search for meaning for some participants. Alex suggested a way that would help him understand: “If they had a big booklet telling you exactly or instructions on what to do...if they made an instruction manual.” Alex’s request for “an instruction manual” suggests that the meaning of this diagnosis was something he was required to construct himself. Alex had asked his psychiatrist for more information; however he described how this was not provided: “every time I ask the psychiatrist they can’t tell me nothing... so it’s just living on a guess of what it means.” Other participants did not consider asking for further explanation. This infers that they felt that they were not privy to the information; they were alone with the diagnosis, “living on a guess” and endeavouring to attribute their own meaning. However, this could also indicate that for some, the diagnosis

was perceived as a meaningless label, not entering into their awareness in their day to day lives, and therefore did not warrant further exploration.

How others see me

Societal perceptions of BPD

For six of the participants there was an awareness of how society judged those diagnosed with BPD negatively. Elen described how: “People are scared of other people who have got this personality disorder because they think that they are...Jekyll and Hyde or...a monster.” This description evokes a powerful image of danger and unpredictability. It also infers that those diagnosed have dual personalities, alternating between ‘good’ and ‘bad’. These public perceptions were especially damaging for Elen and Jen, as they did not know the meaning of the diagnosis, and were therefore left with only the awareness of the stigma. Elen later described herself as “Jekyll and Hyde”, suggesting that she had internalised some of the stigmatising perceptions she had encountered, believing herself to embody this dual identity. This resulted in feelings of anger and shame, as she struggled with this stigmatised, feared identity which had been imposed on her through this diagnosis.

Tom attributed negative public perceptions to media portrayals: “people think...you’re mad, you’re bad...people believe what they see on TV, even if it’s a film. Someone with a personality disorder is always the one that’s the mad axe man or the murderer.” Tom’s description of the dual perception of those diagnosed as being “mad” and “bad”, reflects how a BPD diagnosis can be associated with criminality. Participants’ histories of involvement with the CJS may have increased the salience of this association, and the possibility of experiencing ‘double stigma’- for both the BPD diagnosis and involvement with the CJS.

Being treated differently

Three participants felt the diagnosis held specific meanings in mental health services. Tom stated: “You do feel like you’re wasting their time, they make you feel like that...they’re very abrupt...because you’ve not got schizophrenia...” Sally commented: “(the) nurse expects you to swear, to threaten, to lash out, to abuse.” These quotations reflect some of the negative perceptions held by mental health professionals in regards to the BPD diagnosis. For Tom, he was made to feel like he was “wasting their time”, as if the BPD diagnosis was not perceived as a diagnosis worthy of support. Sally’s description reflects the expectations that those diagnosed with BPD are dangerous and will act violently. The use of the word “abuse” is interesting as she discussed the impact of her own experiences of abuse on her life, and this diagnosis appeared to transform her from the abused to the abuser.

Some participants described how they were perceived as the diagnosis. Sally stated: “They generalise everyone and no-one is an individual.” She gave an example of an experience: “I’m in my room and I can’t do something and on hearing swearing and shouting...(a) nurse, mental health trained (thinks) attention seeking behaviour. Me, I’m getting frustrated because I can’t do something.” This suggested that participants felt they were no longer considered by others as an individual, now being seen as a diagnosis and corresponding symptoms. Their emotional responses and behaviours were now viewed through a diagnostic lens, with the BPD label replacing their individuality and personal expression.

What if others find out?

Participants described apprehension about disclosing their diagnosis to others. Tom explained how:

“I’m still a bit...choosy who I tell. I mean people that I’ve been around for a long time...as far as they’re concerned I’ve still got depression, and that’s as far as it goes. It’s only people that I really trust that I tell.”

When talking about her family’s awareness of the diagnosis, Kate stated that “they just put it under one big label of depression” and when explaining her difficulties to others “I just said depression.” These comments can be interpreted as a way of protecting themselves from the stigma associated with the BPD diagnosis by using a less stigmatised diagnosis to explain their difficulties. Depression is often perceived as a common affliction that is not permanent and can improve with treatment. However, the BPD diagnosis places the problem within the individual’s personality, implying permanence.

For two participants, disclosure was not an option. Elen stated: “I don’t talk to my family about it” explicitly stating that this was because “People are scared of this personality disorder...that’s why I don’t say nothing.” Elen was clear that she felt her family would reject her if she did disclose, thus confining her to secrecy and isolation. For George, who did disclose his diagnosis, his experiences were those of rejection: “I’ve lost all my friends, they’ve all gone.” He also went on describe how: “nobody wants to know you because they think ‘ugh, he is mental’.” These comments inferred that the diagnosis had marked him as different in the eyes of others, as “mental”, someone to be feared and rejected.

How I see myself

Loss of normality

For many of the participants the diagnosis impacted on their sense of self. For Alex the diagnosis meant he was now disabled: “It’s basically a disability; I can’t get rid of it. It’s just going to be stuck there for the rest of my life.” Whereas Kate’s understanding of her diagnosis was “it’s a lifetime illness.” This use of language indicates that participants had engaged with, and internalised, medical understandings of their difficulties. There was a consensus between some of the participants that they were destined to a lifetime of struggling to cope. The diagnosis conveyed a sense of being permanently ‘disabled’, being stuck with their difficulties; as the diagnosis places difficulties within the context of their personalities. This engendered a sense of hopelessness regarding their futures; feeling stuck, not knowing how to move forward.

For some of the participants, the diagnosis indicated that they were now different to others. Elen described how since diagnosis: “I don’t class myself as normal or like anybody else, I just class myself as being non-normal”. Jen echoed Elen’s feelings of abnormality and difference imparted by the diagnosis. This suggests that the diagnosis signified the loss of ‘normality’; changing their perception of themselves, and impacting negatively on their sense of self.

I’m just me...

In contrast, participants also voiced the wish to not be perceived as different to others due to their diagnosis. Sally stated: “I just see me as me, I’m not different to anyone else, I just have difficulties.” Elen was angry at others perceptions of her based on her diagnosis: “Take me for who I am, not what I am. I’m just as good as them.” Tom said: “We’re just the

same as anybody else. I have borderline personality disorder; I am not borderline personality disorder.” These quotations reflect a refusal to be defined by the diagnosis, as it was perceived as an ‘attack’ on their identity, attempting to usurp their individuality and sense of self. Both Elen and Tom make a distinction between themselves- who I am- and how others have categorised them- what I am. This reflects a clear sense that they feel the diagnosis does not define them as people.

Getting into trouble

This theme described the different ways participants spoke of their previous involvement with the CJS.

Coping

For five of the participants, previous contact with the CJS was discussed as the consequence of trying to cope with difficult memories and ensuing emotions. Jen described how she used alcohol as a way to block out painful memories; however this often led to loss of control:

“I get alcoholic blackouts... I don’t remember. I say some terrible things, I do some terrible things and I don’t remember I’ve done it. One day I could end up in prison for the rest of me life for doing something I won’t remember. I’ve been to prison six times in the past, through alcohol abuse, through police assault. I’ve never thieved or anything like that.”

Jen’s assertion that she has “never thieved” suggests a desire to distance herself from those who engage in intentional criminal behaviour. This inferred that offending was seen as a consequence of an endeavour to cope with difficulties; that their ways of coping brought

them into contact with the CJS. However, it is also possible that this was a way to manage some of the shame associated with past experiences within the CJS.

The shield of diagnosis

For two participants, their offending was discussed in relation to their diagnosis. Following a period of being “in and out of prison”, Elen described being diagnosed stating: “they (psychiatrist) put it down to personality disorder.” This suggested that others felt that her offending behaviour warranted a diagnosis of BPD; however this may also be a way to distance herself from the process. Alex described how: “It (BPD) makes me get into trouble all the time with the police.” He also reflected on the people he met in prison: “They’re just the same as me. They’ve either been...they’ve blatantly got something wrong with them otherwise...why would they do the things they do?” This indicated that Alex was questioning the role of his diagnosis in his offending behaviour. His use of the pronoun “It” places the responsibility for the “trouble” he has encountered with the diagnosis and not with himself. This evoked the idea that the diagnosis can serve to act as a shield; as if shielding from the responsibility for actions.

Power and Control

Participants described the complex relationship they experienced with mental health professionals.

A label given to you

The majority of the participants described the diagnosis as something decided by and given by others. Kate explained how “They seemed to put it together in one way or another.” Jen spoke of her diagnosis in terms of being labelled by another: “He’s labelled me with it, Dr (name).” When describing his experience of being diagnosed, George stated “If that’s the

general consensus or opinion of mental health and that's what they're matching me up against, then...yeah." These recollections of receiving a diagnosis included a clear distinction between the professionals who made the diagnosis, and the person who received the diagnosis. These depictions of being "matched up", "put together" and "labelled" by another -"they"- suggested that this experience was not collaborative; diagnosis was something that was done to them rather than shared with them.

Feeling powerless

For five participants, their interactions with mental health professionals left them feeling without choice. Jen described how: "I think they (psychiatrists) just label people with these things just to shut them up." George reported how "I've got to the stage now where if someone says 'you've got this, you've got that'... (sighs) just put it in the pot." These comments suggest that the diagnosis was experienced as something that was out of their control, and they felt powerless to change it. The diagnostic process placed the mental health professional as the 'expert' in the position of power, leaving the participants without a voice; as if silenced by the diagnosis. George's sigh when discussing the diagnosis suggests that he feels exhausted by the process; it was futile to disagree, his only option was to accept the diagnosis.

Regaining control

The feeling of powerlessness led some participants to take action. Sally explained "I've had battles with different people" having researched the diagnosis "to challenge a psychiatrist...whether or not this diagnosis was still valid." This description evokes an image of going to war with professionals, fighting to regain some of the power that has been lost. Jen sought the opinions of her friends and family: "I've asked people 'do you think I've got a personality problem?'...people I've known for years (have said) 'no I don't' think you've got

a personality problem'. Many a person has said that to me." This re-affirmed for Jen how she felt about the diagnosis; allowing her to feel more in control.

Participants suggested ways in which to improve service user experiences. Sally emphasised how: "They (mental health professionals) need to look at things from a patient's perspective, not from the textbook perspective, to be able to have insight into what is happening." Elen, Alex and Tom discussed the importance of service user led groups. Elen stated: "What people should do is have a club or some form of premises where people who've got this disorder can meet other people who've got the same disorder or disease. They can talk it through." This suggests that connecting with others who have had similar experiences would facilitate understanding and acceptance; something many participants felt they were not receiving from services.

These quotations illustrate how participants were uncomfortable with the powerless feelings that diagnosis and interactions with mental health professionals engendered. The focus on the "textbook perspective" removed their voice, rendering them powerless. Regaining control meant making their voice heard, through challenging or changing the system and connecting with others.

The utility of the diagnosis

Is this the answer?

For three of the participants, the diagnosis provided them with an answer that they had been searching for over many years of involvement with mental health services. Tom described relief following diagnosis stating "I know there's something wrong with me now and I know what it is." His diagnosis meant he could engage in Dialectical Behaviour Therapy (DBT) which he felt had changed his life considerably: "I am not the same person

that I was when I came into therapy.” This reflects the transformative nature of effective therapeutic intervention. Throughout Tom’s narrative, his experience of diagnosis was enmeshed with his experience of therapeutic intervention; one could not be separated from the other.

Conversely, other participants did not perceive the diagnosis as useful. Jen was angry and frustrated with the diagnosis: “I haven’t got a personality problem, I get on with everybody (...) they’ve misdiagnosed me.” When asked to reflect on her diagnosis Sally vented her frustration: “Mdiagnosis! (laughs) You’ll have to excuse me, to me that’s just laughable.” Sally’s reaction suggests that to her the diagnosis is so ludicrous as to be amusing. However, there was poignancy in her humour, as it masked the seriousness of her reality; she was stuck with a diagnosis that she rejected.

For those participants who did accept the diagnosis, there was often a dialectic in their narratives; sometimes accepting the diagnosis and at other times rejecting it. It appeared that both positions could be true for them at different times. This dialectic stance infers a sense of uncertainty regarding the utility of the diagnosis.

Who is this diagnosis useful for?

There was a general consensus between participants that the diagnosis was most useful for mental health professionals. Tom described how: “You might find it easier to label, this is my BPD group, this is my depression group...in everyday life I don’t think it’s helpful, I don’t think It’s helpful at all.” Tom accepted the diagnosis as being useful for him in the context of receiving access to services; however outside of this, the diagnosis was not seen as useful. This suggests that the diagnosis does not place the interests of the service user as paramount; rather, participants felt it made the lives of professionals easier.

Making sense of difficulties- experiences of trauma and abuse

All participants made reference to histories of trauma and abuse, with six people making reference to their experience of abuse in childhood. Sally explained how her difficulties stem from her early traumatic experiences: “I believe it is because of my past history...which was a traumatic childhood with abuse”. She also experienced the diagnosis as blaming her for her experiences: “it holds the adult responsible for everything that wasn’t her fault”. George described how: “Some of my childhood was marred with things that happened with my parents and school, when I was a young kid and teenager (...) that scarred me for life”. Jen and Tom both described how they had previously been diagnosed with Post Traumatic Stress Disorder (PTSD); a diagnosis they could both identify with as it explicitly acknowledges the psychological sequelae of traumatic experiences.

These quotes clearly demonstrate how the participants make sense of their difficulties in the context of their early traumatic experiences. George’s powerful description of being “scarred for life” reflects how many participants felt regarding the lasting impact of their traumatic experiences. There was a disconnect between their trauma experiences and the BPD diagnosis, in that they spoke of trauma but not in relation to their diagnosis. This disconnect was interpreted as the BPD diagnosis not being a useful way to conceptualise their difficulties, as it did not acknowledge their experiences. The abuse they had experienced was their reality, and was useful in explaining their difficulties, whereas the diagnosis was not.

Discussion

This study has revealed many of the complexities of the lived experience of people diagnosed with BPD. Some findings were consistent with the current literature and some

novel themes emerged. The impact of the BPD diagnosis was multi-faceted; however the diagnosis was predominantly experienced in a negative way.

Positive aspects of diagnosis centred on diagnosis providing an answer and some understanding of their difficulties. It was clear that the most positive experiences of diagnosis were those which had led to access to services, therapy and support. This echoes the earlier findings of Horn et al (2007). Of concern was that only three out of the seven participants had received an intervention other than medication.

Previous research has indicated that people diagnosed with BPD experience stigma and isolation (Stalker et al, 2005; Ramon et al, 2001). Participants in this research had encountered stigmatising messages relating to dangerousness and violence. It appeared that some participants had internalised these stigmatising perceptions, which impacted on their sense of self. A vast body of research has demonstrated the negative impact of internalised stigma on a range of psychosocial variables such as hope, self-esteem, and empowerment (Livingston & Boyd, 2010). Limited understanding of the diagnosis meant that the only information about BPD available to some participants was stigmatising beliefs held by others. This fear of stigma led to concern about disclosing the diagnosis to others, resulting in secrecy and isolation. Furthermore, experiences within the CJS appeared to lead to concerns about experiencing 'double stigma'- being perceived as both 'mad' and bad'.

Stigma was also experienced within mental health services. Corrigan (2007) has commented that the homogeneity assumed by stereotypes may lead mental health professionals to view individuals in terms of their diagnostic labels. This was reflected in some participants' experiences of being viewed through a 'diagnostic lens' by mental health professionals. Research has also found that BPD diagnosis attracts more negative responses from mental health staff (Markham & Trower, 2003; Deans & Meocevic, 2006). Participants

in this study described being perceived as ‘time wasters’ or ‘attention seekers’ by professionals.

The diagnosis influenced participants’ perception of themselves. Their difficulties were framed within a medical understanding, which engendered a sense of permanence. For some, the diagnosis signified they were different and no longer “normal”. These findings reflect the argument put forward by the DCP (2013) who state that the language of disorder and deficit can negatively shape a person’s outlook on life, their self-esteem and sense of self. People sought help and support from mental health services, however were often left feeling stigmatised and different following diagnosis. Even those who accepted the diagnosis as being helpful did not want to be defined by it.

Contact with the CJS was largely discussed by participants as a consequence of coping with difficult emotions. However, for two participants it was described as a consequence of their diagnosis. Black et al (2013) identified how some people within forensic mental health services developed a ‘forensic identity’; identifying themselves as ‘bad’, which was reinforced by the additional indicator from the PD diagnosis. PD can be interpreted negatively from its wording alone; implying that there is fundamentally something wrong with one’s personality (Stalker et al, 2005). This indicates that having this diagnosis in the context of also being labelled an offender may have detrimental effects in terms of how people perceive themselves. There is a risk of individuals attributing their offending behaviour to their diagnosis, as it indicates that there is something ‘wrong’ with them. This may remove their sense of personal agency and hope for change. It has been argued that personality disorders may be described as judgements of social deviance (Rose, 2006). Some participants had been diagnosed following contact with the CJS, which raises questions regarding the pathologisation of criminal behaviour.

Throughout the participants' narratives, complex and frequently difficult experiences with mental health services were described. An unequal balance of power between 'expert' and 'patient' was experienced by many, leaving participants feeling powerless. The lack of collaboration and understanding in these relationships resulted in frustration, with some participants feeling that it was easier to accept diagnosis than to disagree. There was a general consensus that the diagnosis was most useful for professionals, and of no use outside of services. Participants wanted to feel understood and accepted and felt that this would be best achieved through connections with other service users.

In this study, all of the participants made reference to traumatic experiences, with the majority of the participants reporting abuse in childhood. They placed their difficulties in the context of their abuse histories; the legacy of their experiences. Traumatic experiences were not spoken about in terms of the diagnosis, suggesting the BPD diagnosis did not help to make sense of their experiences. This is in agreement with research by Ramon et al (2001) who stated the use of PD diagnosis fails to capture the experience of the individual, with many receiving the diagnosis having been victims of abuse. Further evidence for this came from two participants who had received diagnoses of PTSD, which they could relate to as it acknowledges that difficulties result from traumatic experiences.

Implications for clinical practice

The overtly negative experiences of the BPD diagnosis reported by participants in this study indicate that, as suggested by the DCP (2013), a paradigm shift is needed within mental health services- moving away from the use of disease models and diagnosis. Dillon and May (2002) state that clinical language has risked colonising people's experiences and beliefs, and can also risk compounding anxiety and powerlessness experiences. The stigma attached to

the diagnosis both within society and within mental health services continues to be detrimental to those diagnosed with BPD.

Rather than viewing people's difficulties as 'symptoms', there needs to be an understanding of people as actively making sense of the events and circumstances of their lives. Evidence is growing that many extreme experiences can be understood as normal, even adaptive, responses to social and relational adversities of various types (Boyle & Johnstone, 2014). For many participants who had experienced abuse in childhood, their experience was lost in the diagnosis. Read, Dillon and Lampshire (2014) emphasise the importance of asking people not just what 'symptoms' they have but what happened to them in childhood and since. The development of mental health services centred on concepts of trauma rather than illness could lead to better outcomes for individuals (Holmes, 2012).

One way of promoting a psychosocial understanding of mental health difficulties in clinical practice is through the use of formulation. Formulation can be described as a summary of a client's difficulties which is based on psychological theory, and informs intervention (Johnstone & Dallos, 2006). This approach allows for the more constructive and rewarding role of collaborating with service users to create meaningful narratives about their distress and predicaments. This focus on individual experiences provides a better framework for understanding difficulties, and the acknowledgement of the role of trauma in the development of difficulties. This is also a pertinent issue for the CJS. Adopting a psychological perspective would allow for consideration of experiences which may have led people to come into contact with the CJS, such as early trauma and social deprivation. Thus, helping people to make sense of their experiences, access appropriate support, and promote recovery.

There was a consensus between the participants that service users should be given a voice. This suggests that services should empower service users to develop support networks, groups, and training for professionals. The aim should be to promote hope, recovery, decrease stigma, and improve people's lives. This is especially pertinent for those who struggle with the stigma of being labelled as 'personality disordered' and an 'offender'.

Limitations and Further Research

The participants in this research were all currently involved with services, and were willing and able to participate. Furthermore, the participants were all of the same ethnicity (white) and nationality (Welsh). The aim of IPA is not to produce generalizable findings, as the views expressed speak to, and for the people who participated. The themes developed may be applicable to similar populations, however may not be representative of all people diagnosed with BPD. Future research could consider the experience of the diagnostic label with people of different ethnicities and in different contexts. This research was cross-sectional in design and so could not discern whether participant experiences changed over time; such as with more engagement with services through therapeutic intervention and/or service user support. Longitudinal research could be undertaken to explore these possibilities. Quantitative research could also be undertaken to explore the issues arising from this research, to gain the perspectives of larger numbers of participants.

Conclusion

The findings of this study add to the growing evidence base regarding people's experiences of living with a BPD diagnosis. Experiences of the diagnosis were predominantly negative for participants. The diagnosis largely failed to capture the experiences of individuals, minimising the impact of trauma and abuse on the development of difficulties.

For those involved with the CJS, the diagnosis can risk pathologising criminal behaviour, and lead to people attributing their behaviour to BPD. A paradigm shift is needed in the way services conceptualise people's experiences; acknowledging trauma, promoting recovery and hope and diminishing stigma.

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Research Paper Appendix:

Table 1: Demographic information of the participants.

'Name'	Age	Services currently accessing	Diagnosis	Time since diagnosis
Kate	50	Forensic Psychiatric Outpatient	BPD	10 years
Sally	50	Probation and Community Mental Health	BPD	20 years
Elen	50	Probation	BPD	15 years
Jen	60	Community Mental Health	BPD	30 years
Alex	28	Community Mental Health	BPD	2 ½ years
Tom	48	Community Mental Health	BPD	5 years
George	46	Community Mental Health	BPD	8 years

Paper 3: Contributions to Theory and Clinical Practice

Contributions to Theory and Clinical Practice

This final paper integrates findings from the literature review and empirical study to consider their combined impact. It is presented in three sections: 1) contributions to theory and recommendations for future research; 2) clinical implications; and 3) personal reflections on the research process and outcomes.

1) Contributions to Theory and Recommendations for Future Research

Three pertinent issues arising from the research will be discussed in terms of contributions to theory and future research: stigma; the use of Borderline Personality Disorder (BPD) in the Criminal Justice System (CJS); and experiences of trauma.

Stigma

The findings of both the empirical study and the literature review highlight the potentially damaging impact of stigma related to psychiatric diagnosis for young people and adults. Whilst stigma was the focus of the literature review, it was not explicitly explored in the empirical study. However, the issue of stigma was discussed by every participant. This indicates that stigma continues to be a significant issue for those living with psychiatric diagnoses.

Exploration of the literature revealed two prominent conceptualisations of stigma related to mental health difficulties: Corrigan's (2000) Social Cognitive Model; and Link and colleagues' (Link, Cullen & Struening, 1989; Link, Miotznik & Cullen, 1991) Modified Labelling Theory (MLT). These will be briefly outlined in turn.

Corrigan's (2000) social cognitive theory of stigma focusses on public stigma- the reaction of the public to people with mental health difficulties. The theory identifies different

cognitive, emotional and behavioural aspects of public stigma: Stereotypes (cognitive knowledge structures), prejudice (cognitive and emotional consequences of stereotypes) and discrimination (behavioural consequences of prejudice). A signal, such as a psychiatric label, can yield stereotypes about people with mental health difficulties e.g. dangerousness. Endorsement of such stereotypes can result in an emotional reaction e.g. fear. This can lead to discrimination against the labelled person e.g. rejection.

Modified Labelling Theory (Link et al, 1989; Link et al, 1991) focusses on the experience of people with mental health difficulties and the process of self-stigma. The theory posits that individuals with mental health difficulties are stereotyped in society. Those labelled are viewed as inferior and discriminated against. For those who are labelled, the societal devaluation of mental health difficulties becomes personally relevant. This internalisation process can result in reduced self-regard and the use of defensive coping strategies, such as secrecy and withdrawal from others. Writing from a sociological perspective, Link et al (1989) emphasise two societal aspects of stigma. Firstly, as a precondition of stigma, differences between persons have to be noticed, to be regarded as relevant and labelled accordingly; this labelling process is at the core of MLT. Secondly, for stigma to unfold, the stigmatising group has to be in a more powerful position than the stigmatised group.

The two theoretical models are compatible, with MLT connecting social cognitive theory with the more societal aspects of stigma. Both the literature review and the empirical study highlighted the deleterious effects of public stigma e.g. devaluation, rejection, and of self-stigma e.g. shame, isolation, on the lives of those living with psychiatric diagnoses. The findings of both the literature review and the empirical study highlight how these processes of public stigma and self-stigma correspond with the processes outlined within these theoretical models. The diagnostic labels applied to individuals led to stereotypical perceptions by others

and experiences of being treated differently. Of concern were people's experiences of stigma within mental health services. Participants in the empirical study reported being perceived as their diagnosis by mental health professionals. This is consistent with the findings of the literature review. Diagnostic labels create categories which communicate difference from the majority; resulting in a separation of 'us' from 'them' (Link & Phelan, 2001). Recent research by Corrigan et al (2015) found that participants (members of the general public) who viewed people with mental health difficulties as different were likely to endorse prejudice and discrimination towards that group. In addition, perceived difference undermined beliefs that people with mental health difficulties can recover or should have personal power over their lives. Therefore, the use of psychiatric diagnoses by mental health professionals promotes the perception of those with mental health difficulties as different. This serves to perpetuate stigma both in society and within mental health services.

Participants in the empirical study were also exposed to an additional layer of stigma, resulting from their contact with the CJS. Research has identified how those labelled as both 'mentally ill' and as 'offenders' suffer from the double stigma of being perceived as both 'mad' and 'bad' (Thornberry & Jacoby, 1979; Roskes et al, 1999). This was discussed by participants in regards to the BPD diagnosis and Personality Disorder (PD) in general. For example, Tom's description of being perceived as "mad and bad" and Elen's description of "Jekyll and Hyde" suggest that the BPD diagnosis carries with it stigma related to dangerousness, unpredictability, and an association with criminal behaviour. Furthermore, these public perceptions of dangerousness and violence were seen to be perpetuated by media portrayals of "mad axe men" with personality disorders. This stigma was internalised by some, such as Elen, who also described herself as "Jekyll and Hyde", resulting in feelings of shame, and leading to isolation.

Diagnosing young people with Borderline Personality Disorder

The stigma experienced by both the young people diagnosed with psychiatric disorders in the literature review, and the adults diagnosed with BPD in the empirical study raise an issue worthy of discussion: the application of the BPD diagnosis to an adolescent population. The literature review studies did not include young people with this diagnosis. Diagnosing BPD in young people raises controversy, as there are questions regarding the appropriateness of applying adult criteria during the fluid developmental period of adolescence (Bleiberg, 1994). Some of the ‘symptoms’ of BPD may in fact fall within a range of normative developmental behaviours for adolescents. The transition into adulthood can be difficult for many young people and as such they may engage in risky behaviours such as alcohol/substance abuse, and violence (Gilbert, et al, 2012). These behaviours can increase the likelihood of contact with agencies such as health, social services, and criminal justice (Haldenby et al, 2007; Waston et al, 2009). Anxieties over troubled and ‘risky’ youth can lead to the desire to label behaviour that is not socially acceptable (Gilbert et al, 2012). This risks pathologising socially unacceptable behaviour; an issue which arose in the empirical study.

A central process during adolescence and emerging adulthood is the development of a cohesive and coherent personal identity (Côté, 2006). The participants in the empirical study described how the BPD diagnosis and associated stigma impacted on their sense of self. Young people in the literature review also described how their diagnosis had impacted on their sense of self. This suggests that for those who are in the process of developing their identity and sense of self, there may be considerable ramifications when receiving a BPD diagnosis.

Future research

The experience of double stigma – for both the BPD diagnosis and offending- is an area that would benefit from further research. Quantitative research could explore the prevalence of double stigma both within the CJS and within mental health services. The use of questionnaires would enable a larger number of people to participate. Qualitative research could explore individual experiences of double stigma in more depth. Potential research questions could address the impact of double stigma on people's relationships with others, their sense of self, and whether they experience self-stigma.

There is a paucity of research regarding the use of the BPD diagnosis with young people. Future research could explore how many young people are receiving this diagnosis, at what age, and in what setting e.g. community mental health settings, inpatient settings. It would be interesting to explore how many young people involved with the CJS receive the diagnosis. Qualitative research could explore how young people experience this diagnosis. Research questions could include: Do they experience stigma related to this diagnosis? What is the impact of the diagnosis on their developing sense of self? Follow up studies could assess the longer term impact of the diagnosis.

Borderline Personality Disorder and the Criminal Justice System

All participants in the empirical paper had experienced some form of contact with the CJS. The original aim was to recruit participants diagnosed with BPD solely from within the Probation Service, as it was communicated that there were a large number (80+) of people who met this criteria in North Wales. However, it was later discovered that the majority of people who were identified as having BPD were not formally diagnosed. There is very little research relating to the health of offenders in the community, even though the National

Probation Service manages over 175,000 offenders in the community (Brooker et al, 2008). The literature available does not explain why so many people are perceived to have BPD but have not been diagnosed. It may be related to the limited availability of clinicians to facilitate the diagnostic process. However, it may also be an issue related to stigma, whereby people who are perceived as difficult to manage may be ascribed this label. It also raises questions regarding the consequences for those being informally labelled with BPD in this way. The benefit of receiving the diagnosis identified by participants in the empirical paper was access to services, therapy and support. It is unclear how this diagnosis would be of benefit to those within the CJS.

A further issue arising from the empirical paper was the impact of diagnosing BPD on people's perceptions of their offending behaviour. For some, the BPD diagnosis made them question their offending behaviour and attribute it to their diagnosis e.g. Alex described how "it (BPD) gets me into trouble with the police." One focus of forensic research with offender populations has been to explore locus of control (e.g. Fisher et al. 1998). The locus of control theory (Rotter, 1966) posits that people who perceive causes of events as being a result of factors within themselves, such as effort or ability, are described as having an 'internal' locus of control. Those who believe such outcomes to be generally dependent on outside factors that they are unable to influence are described as having an 'external' locus of control. It appeared that being given a BPD diagnosis in the context of offending behaviour led to some participants developing an 'external locus of control.' The diagnosis indicated that there was something 'wrong' with them and that this was permanent. This led some to view their offending behaviour a product of their diagnosis, having little control over their actions, thus removing their personal agency for the decisions they have made.

How others perceived offending behaviour was also an issue raised within the empirical paper, with some participants describing how they were diagnosed following contact with the CJS. The criteria defined in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5, APA, 2013) require the clinician to make judgements about people's behaviour against expectations, and ascribe deviations to individuals. Therefore, it is arguable that people can be given this label based primarily on the fact that they do not express themselves, interact with others, or conduct their daily lives in ways that are considered socially acceptable or desirable. In this sense, personality disorders can be described as judgements of social deviance. Rose (2006, p.481) argues that this risks pathologising criminal behaviour through the "psychiatrization of the human condition". Draine et al (2002) have argued that too often social problems become mistakenly simplified as psychiatric problems, therefore it becomes inferred that mental health difficulties themselves are a prime explanatory factor for social problems such as crime. Individuals with mental health difficulties are disproportionately involved in the CJS because they are also members of other groups at high risk of being arrested, i.e. substance users, are unemployed, have fewer years of formal education, have lower incomes and are at higher risk of incarceration. There is a greater risk of being arrested as a result of these other factors, independent of mental health difficulties (Draine et al, 2002).

Future research

The paucity of high quality research into the prevalence of mental health difficulties amongst people under probation supervision indicates that this is an area which requires further research. Research could explore the number of people experiencing mental health difficulties, and also demographic factors e.g. age, ethnicity. There is also a need to explore how the probation service identifies people as having a BPD. If these factors are considered,

services will be better placed to develop to meet the needs of individuals with mental health difficulties within the probation service.

There is a need for further research exploring how individuals diagnosed with BPD within the CJS make sense of their behaviour. Research could explore if being diagnosed alters individuals' perceptions of offending behaviour, exploring factors such as locus of control. Research could also explore how these perceptions impact on engagement in therapeutic interventions, and longer term outcomes such as re-offending and recovery.

Experiences of Trauma

A pertinent issue arising from the empirical paper was participants' experiences of trauma and abuse. Dillon et al (2012, p.146) argue that "a rapidly expanding literature confirms an extremely high prevalence of trauma and abuse in all psychiatric presentations." Bandelow et al. (2005) conducted a study comparing the prevalence of traumatic childhood life events for people diagnosed with BPD compared to a 'healthy' control group. Almost every person diagnosed with BPD reported that they had experienced traumatic events during childhood (only 6.1% did not), while 61.5% of the control group failed to report any such events. Among the identified influential factors were sexual abuse, poor parental rearing styles, and being separated from parents. This correlation between traumatising early-life events and BPD diagnosis raises the question of whether such individuals are, in fact, experiencing a 'mental illness', or whether their problematic behaviours are the product of coping responses they have developed to deal with an aversive childhood.

Participants in the empirical paper largely described the BPD diagnosis as an unhelpful way to view themselves. The majority made sense of their difficulties as a consequence of experiences of trauma and abuse, and this was seen as unrelated to their

diagnosis. The diagnostic process locates BPD as an internal deficit, thus denying the role of social determinants such as abuse, trauma and oppression in causing psychological distress (Shaw & Proctor, 2005; Wirth-Cauchon, 2001). This suggests that trauma-focussed approach offers greater understanding than the use of a BPD diagnosis which does not acknowledge traumatic experiences.

Dillon, Johnstone and Longden (2012) posit that distress can be understood as meaningful responses to trauma and loss. They describe a new paradigm for understanding emotional distress, which is a strongly evidence based synthesis of findings from trauma studies, attachment theories and neuroscience. The main elements of the paradigm will be briefly outlined.

Attachment theory proposes that infants require a relationship with an emotionally sensitive caregiver who provides consistent, predictable and affectively attuned care throughout their early years (Bowlby, 1969). During these formative experiences with a caregiver, mental representations of the caregiver, the self, and the self in relation to others are developed. These mental representations, termed Internal Working Models (Bowlby, 1969), may be retained across the lifespan. They serve as a 'script' and 'blueprint' which influence interactions in subsequent relationships, providing a framework for interactions and expectations in social situations (Crittenden, 1990). The ideal attachment to a caregiver is secure, which can augment coping ability, buffer stress responses and enhance resilience. However, many individuals experience attachment organisation that is avoidant, ambivalent, or disorganised (Gerhardt, 2004). Disturbance in attachment may increase vulnerability to emotional distress and dysregulation, and autonomic reactivity (Dillon et al, 2012). Research has found secure attachment to be extremely low in people diagnosed with BPD (Levy, 2005).

In addition to the impact of early trauma on attachment, Dillon et al (2012) describe how adversities such as childhood sexual abuse may affect brain development; in terms of the way the brain encodes memory and the impact this has on the autonomic nervous system. They argue that these processes can lead to the presentations seen in those diagnosed with BPD, psychosis, and other psychiatric diagnoses (e.g., voice hearing, self-injury, suspiciousness and lack of trust, anxiety, low mood, and emotional reactivity).

This new paradigm has implications for the use of psychiatric diagnosis, suggesting that “the majority of psychiatric presentations have common origins in some combination of trauma, victimisation or attachment problems” (Dillon et al, 2012, p.151). This provides a meaningful framework for understanding people’s distress, thus removing the need for psychiatric diagnosis.

Future research

The evidence discussed above highlights the value of further research exploring the prevalence of childhood adversity in people receiving psychiatric diagnoses. Learning from people’s insights about their own experiences and how extreme events can induce extreme means of survival is an area worthy of further research. Therefore, qualitative research into people’s experiences, ways of coping with adversity, and stories of recovery would be beneficial.

The paradigm for understanding distress put forward by Dillon et al (2012) highlights areas for further research. Research which focusses on the impact of trauma and abuse on attachment and brain development would add to the expanding evidence base. Further evidence would emphasise the role of trauma in the development of mental health difficulties and allow for the development of effective ways of offering support and interventions.

2) Implications for clinical practice

A number of implications for clinical practice have arisen from this research relating to the provision of services. These will be discussed in turn.

Trauma-informed services

Both the literature review and empirical paper have highlighted a need for the move away from a medical understanding of distress. Timimi (2013) argues that the reliance on diagnostic categories to organise services and treatments does not contribute to improved outcomes for those experiencing mental distress. The use of diagnoses increases stigma and does not adequately explain people's experiences and difficulties. As discussed, the significant incidence of traumatic experiences in those receiving psychiatric diagnoses, infers that a logical step would be for services to employ a trauma model when conceptualising people's difficulties- seeing people as suffering from traumas with psychological consequences, rather than illnesses with biological causes (Johnstone, 2000). If people's behaviours are understood as adverse consequences of trauma - rather than as 'symptoms' of a diagnosis - they can be responded to differently (Holmes, 2012).

Mental health services in Canada and America have developed Trauma Informed Toolkits, which provide advice to organisations on developing trauma informed services (e.g. Guarino et al, 2009; Bolton et al, 2013). Guarino et al (2009, p.17) describe eight foundational principles that represent the core values of trauma informed care, which will be briefly outlined below. The adoption of these trauma informed care principles within mental health services in the UK could lead to improved outcomes for individuals who have experienced trauma.

- *Understanding trauma and its impact:*

Understanding trauma and how it affects people. The recognition that many behaviours and responses that may appear ineffective in the present, represent adaptive responses to past traumatic experiences.

- *Promoting safety:*

Establishing a safe physical and emotional environment where basic needs are met, safety measures are in place, and service provider responses are consistent, predictable, and respectful.

- *Ensuring cultural competence:*

Understanding how cultural context influences perceptions of and responses to traumatic events and the recovery process.

- *Supporting service user control, choice and autonomy:*

Helping service users regain a sense of control over their daily lives and build competencies that will strengthen their sense of autonomy.

- *Sharing power and governance:*

Promoting the equalisation of power differentials across services.

- *Integrating care:*

Maintaining a holistic view of service users and their process of healing. Facilitating communication within and among service providers and systems.

- *Healing happens in relationships:*

The belief that establishing safe, authentic and positive relationships can be corrective and restorative to survivors of trauma.

- *Recovery is possible:*

Understanding that recovery is possible for everyone. Instilling hope by providing opportunities for service user and former service user involvement at all levels of the system.

The use of formulation

An alternative to diagnostic classification, put forward in both the empirical study and the literature review, is a formulation based approach. This approach allows for the understanding of people's difficulties in the contexts of their early experiences. Psychological formulation is described as "a hypothesis about a person's difficulties, which draws from psychological theory" (Johnstone & Dallos, 2006, p.4). This individualised understanding of a presenting problem, in contrast to a more categorical approach of a diagnosis, can lead to a more tailored, individualised approach to intervention. A greater emphasis on psychosocial factors may help to empower the person to recover or find ways to manage their difficulties; rather than relying on medical interventions alone.

In a report by the British Psychological Society on the work of applied psychologists in teams, Onyett (2007) describes how using formulation in teamwork can be an effective way of shifting cultures towards more psychosocial perspectives. He argues that interventions offered by multidisciplinary teams can be guided by psychological formulation. This provides a framework which enables change and therefore supports clients' recovery. The report suggests that the visible presence of psychologists in team decision-making forums, such as during care planning meetings, helps to promote an approach that emphasises the importance of psychological processes in mental health difficulties; therefore, offering an alternative perspective to the medical model.

The Criminal Justice System

These issues are also of importance within the CJS. The Bradley Report (DoH, 2009) recommends the development of psychologically informed pathways within the CJS. The report emphasises that support for offenders 'through the gate' from prison to the community is vital. As discussed, people with mental health difficulties face considerable stigma and

those who are also labelled an offender face a double jeopardy of stigma; including that within the public services that should address their needs.

An issue which was not discussed in the empirical paper, due to it not qualifying for a theme, related to a participant's experiences within the prison service. Alex described very negative experiences in prison where he felt his mental health was dismissed and as such, his psychiatric medication was withheld. He also spoke of his friends who had committed suicide whilst in prison, and the detrimental impact this had on him. This suggests that a change in the way in which the CJS understands and responds to mental health difficulties is required. A report by the Ministry of Justice (2012) described how within prison, 53% of women, and 27% of men reported having experienced emotional, physical or sexual abuse as a child, therefore recognising the impact of trauma on those within the CJS is vital for offering appropriate support. Furthermore, coercive interventions such as seclusion and restraint can cause traumatisation and re-traumatisation in people who have already had traumatic experiences (Fallot & Harris, 2002). A psychologically informed approach which promotes the importance of psychosocial factors in the development of mental health difficulties may result in better outcomes for individuals in the CJS.

Staff training

As discussed, mental health services need to become trauma-informed. The training received by most mental health staff within the NHS prepares them to see a medical problem with a correspondingly medical solution. Specifically, staff training and support mechanisms are required which encourage improved recognition of the effects of trauma (Perrin, 2012). Training should provide an understanding of the profound biological, psychological and social effects of trauma and violence on the individual and an appreciation for the high prevalence of traumatic experiences in people who receive mental health services. Staff

should be trained in approaching people who have experienced trauma by asking ‘what happened to you?’, rather than ‘what is wrong with you?’ (Bolton et al, 2013). Training should be aimed at developing confidence in staff to discuss abuse histories and current experiences of abuse with clients in a sensitive way, and in a safe environment. From this assessment, a plan for intervention can be developed which focusses on the effects of trauma, rather than on a diagnosis with corresponding symptoms.

There is a prominent role for service users in staff training, because of the expertise they bring through their experiences. Many service users who express an interest in becoming involved at service provision level hold a psychosocial perspective on mental health difficulties and therefore can directly aid psychosocial awareness in staff teams (Onyett, 2007).

Finally, integral to trauma-informed services is a robust framework of support for staff working within the service. The provision of regular clinical supervision, reflective practice sessions, and peer support groups- with a focus on self-care- will help to address the personal impact of working with clients who have experienced trauma.

In summary, the issues discussed suggest that services which take a non-medical understanding of emotional distress; that acknowledges the prevalence and impact of trauma, can lead to hope and recovery for survivors of abuse and adversity (Dillon, 2011).

3) Personal reflections on the research process and outcomes.

In terms of my own background, prior to clinical training I spent some time working in low secure mental health services. Whilst working within these services I became acutely aware of the predominance of the medical and diagnostic model of viewing people’s distress. I found these roles challenging, being immersed in these environments where people were

often viewed as diagnostic labels. This was especially pertinent for those diagnosed with personality disorders. The impact of diagnostic labels on individuals has always been an interest of mine, therefore the opportunity to undertake research exploring people's experiences of diagnoses was an exciting prospect.

From the outset, I was very aware of my role as a researcher whilst interviewing participants. This was in contrast to my usual role as a clinician providing therapeutic intervention. Time was spent prior to interviews thinking about ways in which I would manage this different dynamic. During interviews, participants described experiences of abuse, trauma and loss, which were tough to listen to. After each interview I discussed the emotional impact of listening to these experiences with my supervisors. For many participants, the only support they were receiving from services was psychiatric medication. Most spoke of repeated negative experiences within mental health services. This left me with feelings of anger and disappointment for the way they had been treated within services; the services I was working within. One participant told me that she was struggling to cope, and knowing that I was a Trainee Clinical Psychologist, asked me if I would be willing to provide her with psychological intervention. I found this experience difficult as this person had shared their life story with me; however it was not in my remit to provide this kind of support. Whilst designing the research project I spent time discussing with my supervisors how to respond in situations like this; therefore whilst it was a difficult situation, I felt prepared to respond. In discussion with the participant it was agreed that I would notify her care-coordinator that she was experiencing difficulties, and provided her with details of support helplines. This highlighted the importance of designing research which considers different eventualities, and places the welfare of the participants as paramount.

The process of analysing the results and writing up the research presented me with a new challenge; having not previously undertaken qualitative research. I enjoyed immersing

myself in the data; feeling privileged to have met the participants and heard their stories. The analysis of the transcripts, whilst time consuming, was very rewarding. This process emphasised the depth and complexities of people's experiences. However, this process was also difficult at times. I felt a sense of duty to tell the participants stories; to make their voices heard. Therefore, condensing their experiences into a limited number of themes proved a challenge. Time spent discussing themes with supervisors helped with this process.

Listening to participants' stories has led to me think about my future as a Clinical Psychologist within the NHS. This research has equipped me with knowledge that I can apply within services, to promote a move away from the medical and diagnostic view of mental health difficulties. Finally, the process of undertaking research has developed my strength and resilience to deal with intensely stressful periods, and should stand me in good stead for my future career.

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Ethics appendix

Email confirming Bangor University ethics approval

Email received on 13th March 2014.

Dear Emma Laura Catherine,

2013-11884 People's experiences of living with a personality disorder diagnosis in the Probation Service.

Your research proposal number 2013-11884 has been reviewed by the School of Psychology Ethics and Research Committee and the committee are now able to confirm ethical and governance approval for the above research on the basis described in the application form, protocol and supporting documentation. This approval lasts for a maximum of three years from this date.

Ethical approval is granted for the study as it was explicitly described in the application

If you wish to make any non-trivial modifications to the research project, please submit an amendment form to the committee, and copies of any of the original documents reviewed which have been altered as a result of the amendment. Please also inform the committee immediately if participants experience any unanticipated harm as a result of taking part in your research, or if any adverse reactions are reported in subsequent literature using the same technique elsewhere.

Governance approval is granted for the study as it was explicitly described in the application and we are happy to confirm that this study is now covered by the University's indemnity policy.

If any new researchers join the study, or any changes are made to the way the study is funded, or changes that alter the risks associated with the study, then please submit an amendment form to the committee.

Yours sincerely

Everil McQuarrie

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The integrated dataset required for your project will be created from the answers you give to the following questions. The system will generate only those questions and sections which (a) apply to your study type and (b) are required by the bodies reviewing your study. Please ensure you answer all the questions before proceeding with your applications.

Please enter a short title for this project (maximum 70 characters)

People's experiences of living with a personality disorder diagnosis

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2. Select one category from the list below:

- ☐ Clinical trial of an investigational medicinal product
- ☐ Clinical investigation or other study of a medical device
- ☐ Combined trial of an investigational medicinal product and an investigational medical device
- ☐ Other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice
- ☐ Basic science study involving procedures with human participants
- ☐ Study administering questionnaires/interviews for quantitative analysis, or using mixed quantitative/qualitative methodology
- ☒ Study involving qualitative methods only
- ☐ Study limited to working with human tissue samples (or other human biological samples) and data (specific project only)
- ☐ Study limited to working with data (specific project only)
- ☐ Research tissue bank
- ☐ Research database

If your work does not fit any of these categories, select the option below:

☐ Other study

2a. Please answer the following question(s):

- a) Does the study involve the use of any ionising radiation? ☐ Yes ☒ No
- b) Will you be taking new human tissue samples (or other human biological samples)? ☐ Yes ☒ No
- c) Will you be using existing human tissue samples (or other human biological samples)? ☐ Yes ☒ No

3. In which countries of the UK will the research sites be located? *(Tick all that apply)*

- ☐ England
- ☐ Scotland
- ☒ Wales
- ☐ Northern Ireland

3a. In which country of the UK will the lead NHS R&D office be located:

- ☐ England
☐ Scotland
☒ Wales
☐ Northern Ireland
☐ This study does not involve the NHS

4. Which review bodies are you applying to?

- ☒ NHS/HSC Research and Development offices
☐ Social Care Research Ethics Committee
☒ Research Ethics Committee
☐ National Information Governance Board for Health and Social Care (NIGB)
☒ National Offender Management Service (NOMS) (Prisons & Probation)

For NHS/HSC R&D offices, the CI must create Site-Specific Information Forms for each site, in addition to the study-wide forms, and transfer them to the PIs or local collaborators.

5. Will any research sites in this study be NHS organisations?

- ☒ Yes ☐ No

6. Do you plan to include any participants who are children?

- ☐ Yes ☒ No

7. Do you plan at any stage of the project to undertake intrusive research involving adults lacking capacity to consent for themselves?

- ☐ Yes ☒ No

Answer Yes if you plan to recruit living participants aged 16 or over who lack capacity, or to retain them in the study following loss of capacity. Intrusive research means any research with the living requiring consent in law. This includes use of identifiable tissue samples or personal information, except where application is being made to the NIGB Ethics and Confidentiality Committee to set aside the common law duty of confidentiality in England and Wales. Please consult the guidance notes for further information on the legal frameworks for research involving adults lacking capacity in the UK.

8. Do you plan to include any participants who are prisoners or young offenders in the custody of HM Prison Service or who are offenders supervised by the probation service in England or Wales?

- ☒ Yes ☐ No

9. Is the study or any part of it being undertaken as an educational project?

- ☒ Yes ☐ No

Please describe briefly the involvement of the student(s):

This research is being undertaken as part of the researcher's Doctorate in Clinical Psychology at the North Wales Clinical Psychology Programme.

9a. Is the project being undertaken in part fulfilment of a PhD or other doctorate?

- ☒ Yes ☐ No

10. Will this research be financially supported by the United States Department of Health and Human Services or any of

its divisions, agencies or programs?

☐ Yes ☒ No

11. Will identifiable patient data be accessed outside the care team without prior consent at any stage of the project (including identification of potential participants)?

☐ Yes ☒ No

Integrated Research Application System**Application Form for Research involving qualitative methods only****Health Research Authority****Application to NHS/HSC Research Ethics Committee**

The Chief Investigator should complete this form. Guidance on the questions is available wherever you see this symbol displayed. We recommend reading the guidance first. The complete guidance and a glossary are available by selecting [Help](#).

Please define any terms or acronyms that might not be familiar to lay reviewers of the application.

Short title and version number: (maximum 70 characters - this will be inserted as header on all forms)
People's experiences of living with a personality disorder diagnosis

Please complete these details after you have booked the REC application for review.

REC Name:

Wales REC 3

REC Reference Number:

14/WA/0144

Submission date:

11/04/2014

PART A: Core study information**1. ADMINISTRATIVE DETAILS****A1. Full title of the research:**

People's experiences of living with a personality disorder diagnosis: A perspective from individuals within the Probation Service

A2-1. Educational projects

Name and contact details of student(s):

Student 1

	Title	Forename/Initials	Surname
	Miss	Emma	Lloyd
Address	North Wales Clinical Psychology Programme		
	School of Psychology, 43 College Road,		
	Bangor, Gwynedd		
Post Code	LL57 2DG		
E-mail	psp0da@bangor.ac.uk		
Telephone	07792104873		
Fax			

Give details of the educational course or degree for which this research is being undertaken:

Name and level of course/ degree:

This research is being undertaken as part of a Doctorate in Clinical Psychology (D.Clin.Psy).

Name of educational establishment:

North Wales Clinical Psychology Programme.

Name and contact details of academic supervisor(s):

Academic supervisor 1

	Title	Forename/Initials	Surname
	Dr	Robin	Owen
Address	North Wales Forensic Psychiatric Service Ty Llywelyn MSU Bryn y Neuadd Hospital, Llanfairfechan		
Post Code	LL33 0HH		
E-mail	Robin.Owen2@wales.nhs.uk		
Telephone	01248 682 133		
Fax			

Academic supervisor 2

	Title	Forename/Initials	Surname
	Dr	James	Lea
Address	North Wales Clinical Psychology Programme School of Psychology, Bangor University Bangor, Gwynedd		
Post Code	LL57 2DG		
E-mail	j.lea@bangor.ac.uk		
Telephone	01248 383890		
Fax			

Academic supervisor 3

	Title	Forename/Initials	Surname
	Dr	Julia	Wane
Address	North Wales Forensic Psychiatric Service Ty Llywelyn MSU Bryn y Neuadd Hospital, Llanfairfechan		
Post Code	LL33 0HH		
E-mail	Julia.Wane@wales.nhs.uk		
Telephone	01248682133		
Fax			

Please state which academic supervisor(s) has responsibility for which student(s):

Please click "Save now" before completing this table. This will ensure that all of the student and academic supervisor details are shown correctly.

Student(s)

Student 1 Miss Emma Lloyd

Academic supervisor(s)

☒ Dr Robin Owen

☒ Dr James Lea

☒ Dr Julia Wane

A copy of a current CV for the student and the academic supervisor (maximum 2 pages of A4) must be submitted with the application.

A2-2. Who will act as Chief Investigator for this study?

- ☒ Student
☐ Academic supervisor
☐ Other

A3-1. Chief Investigator:

	Title Forename/Initials Surname
	Miss Emma Lloyd
Post	Trainee Clinical Psychologist
Qualifications	BSc (Hons) Psychology and Criminology
Employer	Betsi Cadwaladr University Health Board
Work Address	North Wales Clinical Psychology Programme School of Psychology, 43 College Road, Bangor, Gwynedd
Post Code	LL57 2DG
Work E-mail	psp0da@bangor.ac.uk
* Personal E-mail	
Work Telephone	07792104873
* Personal Telephone/Mobile	
Fax	

* This information is optional. It will not be placed in the public domain or disclosed to any other third party without prior consent.

A copy of a current CV (maximum 2 pages of A4) for the Chief Investigator must be submitted with the application.

A4. Who is the contact on behalf of the sponsor for all correspondence relating to applications for this project?

This contact will receive copies of all correspondence from REC and R&D reviewers that is sent to the CI.

	Title Forename/Initials Surname
	Mr Hefin Francis
Address	School of Psychology Bangor University Bangor, Gwynedd
Post Code	LL7 2AS
E-mail	h.francis@bangor.ac.uk
Telephone	01248388339
Fax	

A5-1. Research reference numbers. Please give any relevant references for your study

Applicant's/organisation's own reference number, e.g. R & D (if available):

Sponsor's/protocol number:

Protocol Version:

1

Protocol Date:

Funder's reference number:

Project website:

Additional reference number(s):

Ref.Number	Description	Reference Number
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Registration of research studies is encouraged wherever possible. You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you have registered your study please give details in the "Additional reference number(s)" section.

A5-2. Is this application linked to a previous study or another current application?

☐ Yes ☒ No

Please give brief details and reference numbers.

2. OVERVIEW OF THE RESEARCH

To provide all the information required by review bodies and research information systems, we ask a number of specific questions. This section invites you to give an overview using language comprehensible to lay reviewers and members of the public. Please read the guidance notes for advice on this section.

A6-1. Summary of the study. *Please provide a brief summary of the research (maximum 300 words) using language easily understood by lay reviewers and members of the public. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, this summary will be published on the website of the National Research Ethics Service following the ethical review.*

Personality disorders are controversial diagnoses, provoking heated debate among people with personal experience of these diagnoses, mental health staff, researchers and policy makers. The debate surrounding psychiatric diagnosis has recently been highlighted in a position statement released by the British Psychological Society, Division of Clinical Psychology (DCP, BPS, 2013). They argue that functional psychiatric diagnoses, including personality disorders, have limited reliability and questionable validity, and serve to medicalise distress. Psychiatric diagnoses can have negative implications for service users, such as stigma, discrimination and low self esteem, therefore it is important to explore how service users experience living with the diagnostic label of 'personality disorder'. However, qualitative studies investigating the experiences of individuals diagnosed with personality disorder are limited, and only one study has explored the experiences of individuals with forensic histories. There has been no such research undertaken with individuals under the management of the probation service, or in rural areas such as North Wales.

The present study aims to contribute to the literature, giving a voice to a group of people who experience particular difficulties and discrimination. It is important to understand how individuals experience these labels, in order to develop ways of offering support. It will hope to gain an in-depth account of how a diagnosis of personality disorder has impacted on the individual's identity, relationships, and behaviour in the context of living in a rural area.

A6-2. Summary of main issues. *Please summarise the main ethical, legal, or management issues arising from your study and say how you have addressed them.*

Not all studies raise significant issues. Some studies may have straightforward ethical or other issues that can be identified and managed routinely. Others may present significant issues requiring further consideration by a REC, R&D office or other review body (as appropriate to the issue). Studies that present a minimal risk to participants may raise complex organisational or legal issues. You should try to consider all the types of issues that the different reviewers may need to consider

During the interview process, participants may describe difficult life experiences. As such there is the potential for the participants to become distressed during interview. The researcher will be sensitive to the emotional state of the participant at all times during the project and be flexible in taking breaks or stopping the interview completely if the participant becomes distressed. The researcher is a trainee clinical psychologist and has the skills necessary to manage high levels of emotion or distress. Participants will be fully debriefed following the interview and encouraged to seek support from their probation officer or care coordinator if they require further support.

To ensure that participants do not have unrealistic expectations of the research, they will be informed that despite the research being undertaken by a trainee clinical psychologist, the aim of the interview is not to provide therapy.

Participants will be under the management of the probation service or forensic service, therefore will have a history of offending behaviours. It is possible that individuals' may disclose criminal behaviour for which they have not been prosecuted. Prior to the interview commencing, the limits of confidentiality will be explained to the participant. They will be informed that if they do disclose such information then the researcher has a duty to pass this on to their probation officer or care coordinator.

A small monetary thank you will be provided to participants to recognise the time given to the research. Grant and Sugarman (2004) suggest that incentives become ethically inappropriate if they unduly influence the decision to participate, act as a coercive inducement, or compromise the dignity of participants. It is also felt that it is ethically questionable not to recognise participation in a time consuming project. A £10 voucher is deemed an appropriate amount as it is small enough to not be coercive, will be explained in the information sheet that it is a thank you for participation to ensure no loss of dignity, and is in line with BCUHB policy.

A6-3. Proportionate review of REC application *The initial project filter has identified that your study may be suitable for proportionate review by a REC sub-committee. Please consult the current guidance notes from NRES and indicate whether you wish to apply through the proportionate review service or, taking into account your answer to A6-2, you consider there are ethical issues that require consideration at a full REC meeting.*

☒ Yes - proportionate review ☐ No - review by full REC meeting

Further comments (optional):

Note: This question only applies to the REC application.

3. PURPOSE AND DESIGN OF THE RESEARCH

A7. Select the appropriate methodology description for this research. Please tick all that apply.

- ☐ Case series/ case note review
- ☐ Case control
- ☐ Cohort observation
- ☐ Controlled trial without randomisation
- ☐ Cross-sectional study
- ☐ Database analysis
- ☐ Epidemiology
- ☐ Feasibility/ pilot study
- ☐ Laboratory study
- ☐ Metanalysis
- ☒ Qualitative research
- ☐ Questionnaire, interview or observation study
- ☐ Randomised controlled trial
- ☐ Other (please specify)

A10. What is the principal research question/objective? *Please put this in language comprehensible to a lay person.*

What are the experiences of people who have been diagnosed with a 'personality disorder'?

A11. What are the secondary research questions/objectives if applicable? *Please put this in language comprehensible to a lay person.*

1. How have people made sense of the diagnosis?
2. How has this diagnosis impacted on their relationships, identity, understanding of their behaviour, and opportunities in life?

A12. What is the scientific justification for the research? *Please put this in language comprehensible to a lay person.*

The debate surrounding psychiatric diagnosis has been highlighted in a recent position statement released by the Division of Clinical Psychology (DCP, BPS, 2013). It is argued that functional psychiatric diagnoses, including personality disorders, have limited reliability and questionable validity, and medicalise distress. Their report highlights the significant impact of psychiatric diagnoses on service users' lives. This can be through discrimination due to negative social attitudes towards those with a psychiatric diagnosis, which can create and compound social exclusion. A further issue is that of stigmatisation and negative impact on identity, in that the language of disorder and deficit can negatively shape a person's outlook on life, and their identity and self-esteem. Due to the negative implications of psychiatric diagnoses for service users, it is important to explore how service users experience living with the diagnostic label of 'personality disorder'.

Previous research:

Qualitative studies investigating the experiences of individuals living with personality disorder are limited, and none has been undertaken in individuals under the management of probation services. Four studies have been identified that have explored people's experiences of living with a personality disorder diagnosis (Nehls, 1999; Ramon, Castillo and Morant, 2001; Stalker, Ferguson and Barclay, 2005; Horn, Johnstone & Brooke, 2007). These studies interviewed individuals without a history of offending behaviours. One recent study has explored experience of having a personality disorder diagnosis within the context of forensic secure and community services (Black, Thornicroft & Murray, 2012).

Proposed research:

The present study aims to contribute to the growing literature, giving a voice to a group of people who experience particular difficulties and discrimination. It is important to understand how individuals experience these labels, in order to develop ways of offering support. This research will focus on the experiences of individuals who have a personality disorder diagnosis living in the community, who are under the management of probation services. Research has not been undertaken in this population previously. This is important to explore as research has indicated that about half of individuals under the management of probation services meet the criteria for a diagnosis of a personality disorder (Brooker et al, 2012). People with personality disorder are discriminated against with access to services often denied, because they are stigmatised and regarded as a more difficult group with whom to work (Newton-Howes, 2008). The failure to focus appropriately on issues relating to personality disorder is a barrier to the NHS and National Offender Management Service meeting its objectives of health improvement and public protection (Department of Health, 2010).

This research will also differ from previous research in that participants will be living in rural Welsh communities. It will hope to gain an in depth account of how a diagnosis of personality disorder has impacted on their identity and relationships, in the context of living in a rural area.

A13. Please summarise your design and methodology. *It should be clear exactly what will happen to the research participant, how many times and in what order. Please complete this section in language comprehensible to the lay person. Do not simply reproduce or refer to the protocol. Further guidance is available in the guidance notes.*

Participant recruitment:

Participants will be people aged between 25 and 50 years who have been formally diagnosed with a personality disorder, and have lived with this diagnosis for at least two years. They will be currently under the management of the probation service in North Wales. If not enough participants can be recruited through the probation service, then participants will be recruited from the forensic outpatient service at Ty Llywelyn Medium Secure Unit.

The individual's probation officer or care coordinator will inform the potential participant about the study. Information sheets will then be sent to people who wish to know more. They will be provided with the opportunity to contact the researcher to discuss the research. The person will be given up to 2 weeks to decide about whether to participate.

Design and procedures:

A qualitative research design has been selected, as it will capture the richness of the lived experience of participants. Qualitative research has been recognised as an important contributor to empirical evidence bases (Dixon Woods & Fitzpatrick, 2001). There are a number of different methods within qualitative designs but interpretive phenomenological analysis (IPA) has been selected as it focuses on the lived experience of individuals and how they make sense of a given phenomenon (Smith, Flowers, & Larkin, 2010) and is therefore the most relevant to answering the research questions.

A semi-structured interview will be conducted with participants, focusing on their experience of living with a diagnosis of personality disorder. It is anticipated these interviews will last up to an hour. Interviews will take place in either the probation services offices or Ty Llywelyn Medium Secure Unit. Interviews will take place with the participant and researcher alone to ensure participants feel safe to discuss their experiences freely. Interviews will be digitally recorded, immediately transferred to a password protected laptop and transcribed by the researcher. Once transcribed the data will be anonymised.

Measures

The semi-structured interview schedule will be drawn up with the research supervisors: Dr Robin Owen, Dr James Lea and Dr Julia Wane. The interview will begin with collecting demographic data including participants' age, gender, ethnicity, diagnosis, and time since diagnosis.

The interview will then cover themes of experience of living with diagnosis, relationships with family and friends, and identity. The interview will be flexible, open, and participant led to facilitate the collection of rich data.

Data management and analysis

Digital recordings will be immediately transferred to a password protected laptop where the anonymised transcriptions will also be stored. Interpretive phenomenological analysis (IPA; Smith, Flowers, and Larkin, 2010) has been selected as the qualitative research method as it captures the lived experience of individuals and how they make sense of particular phenomena, such as a diagnosis of personality disorder. IPA also allows the interview schedule to be used flexibly, which will mean the data collected will capture the richest and most important aspects of the participant's lived experience.

The researcher will transcribe the interviews verbatim to aid the analysis process. Transcripts will be analysed using guidelines by Smith, Flowers, and Larkin, 2010.

A14-1. In which aspects of the research process have you actively involved, or will you involve, patients, service users, and/or their carers, or members of the public?

- ☐ Design of the research
- ☐ Management of the research
- ☐ Undertaking the research
- ☐ Analysis of results
- ☒ Dissemination of findings
- ☐ None of the above

Give details of involvement, or if none please justify the absence of involvement.

Participants will be provided with feedback regarding to outcome of the research.

4. RISKS AND ETHICAL ISSUES

RESEARCH PARTICIPANTS

A17-1. Please list the principal inclusion criteria (list the most important, max 5000 characters).

Participants will be between the ages of 25 and 50.

They must have been formally diagnosed with either Borderline Personality Disorder or Anti-Social Personality Disorder by a psychiatrist, forensic or clinical psychologist.

They must have lived with the PD diagnosis for a minimum of 2 years.

Participants will be under the management of probation services or forensic services.

A17-2. Please list the principal exclusion criteria (list the most important, max 5000 characters).

Significant mental health difficulties which could be exacerbated by the research procedure, identified by the individuals probation officer or care coordinator.

Non-fluent English speaker.

Significant communication or intellectual disability.

RESEARCH PROCEDURES, RISKS AND BENEFITS**A18. Give details of all non-clinical intervention(s) or procedure(s) that will be received by participants as part of the research protocol. *These include seeking consent, interviews, non-clinical observations and use of questionnaires.***

Please complete the columns for each intervention/procedure as follows:

1. Total number of interventions/procedures to be received by each participant as part of the research protocol.
2. If this intervention/procedure would be routinely given to participants as part of their care outside the research, how many of the total would be routine?
3. Average time taken per intervention/procedure (minutes, hours or days)
4. Details of who will conduct the intervention/procedure, and where it will take place.

Intervention or procedure	1	2	3	4
Approached regarding the research	1	0	15 minutes	The individual's probation officer or care co-ordinator will provide the individuals with details about the research.
Read information sheet	1	0	30 minutes	To be sent to potential participants for them to read at home.
Request to participate	1	0	5 minutes	Complete reply slip and return in stamped, addressed envelope to research team.
Give consent	1	0	10 minutes	Researcher to gain written informed consent to participate from all participants.
Demographic information collected	1	0	5 minutes	Researcher to ask participant questions relating to age, gender, ethnicity, current offence, diagnosis, when diagnosis was received, and who gave diagnosis.
Research interview	1	0	up to 1 hour	Participant to give detailed description of their experiences of living with a personality disorder diagnosis
Time for questions and debrief following the interview.	1	0	10-20 minutes	Participant to be debriefed, and provided the opportunity to ask any questions.

A21. How long do you expect each participant to be in the study in total?

From being sent information to being sent a summary page of the findings, participants will be involved in the study on some level for a maximum of 18 months. However, participants will only actually be actively involved in the research process for approximately 2 hours.

A22. What are the potential risks and burdens for research participants and how will you minimise them?

For all studies, describe any potential adverse effects, pain, discomfort, distress, intrusion, inconvenience or changes to lifestyle. Only describe risks or burdens that could occur as a result of participation in the research. Say what steps would be taken to minimise risks and burdens as far as possible.

The interviews have the potential to cause some distress to participants, due to the possible difficulties experienced in their lives that they may wish to discuss. The researcher will be sensitive to the emotional state of the participant at all times during the project and be flexible in taking breaks or stopping the interview completely if the participant becomes distressed. This will be discussed with participants prior to commencing interviews. The researcher is a trainee clinical psychologist and has the skills necessary to manage high levels of emotion or distress. Participants will be fully debriefed following the interview and if any issues have arisen they will be encouraged to approach their probation officer or care coordinator.

Participants may have unrealistic expectations of the research in terms of psychological benefits. They will be informed that despite the research being carried out by a trainee clinical psychologist, the aim of the interview is not to provide therapy. However, talking about their experiences may provide some benefits to the participant.

A small monetary thank you will be provided to participants to recognise the time given to the research, which could be seen as coercive. However, a £10 voucher has been deemed a small enough amount to recognise the time given but not unduly influence the person's decision to participate.

A23. Will interviews/ questionnaires or group discussions include topics that might be sensitive, embarrassing or upsetting, or is it possible that criminal or other disclosures requiring action could occur during the study?

☒ Yes ☐ No

If Yes, please give details of procedures in place to deal with these issues:

Discussing personal experiences of living with a personality disorder diagnosis is a potentially sensitive issue. The researcher will allow participants to take their time and either come back to or leave issues that are causing distress. As the research is completely participant led, the entire interview will follow the topics that the participant wishes to discuss.

The participants will have been prosecuted for a criminal offence and be under the management of the probation service or forensic service. It is possible that individuals may disclose criminal activities for which they have not been prosecuted for. The limits of confidentiality will be detailed on the participant information sheet and explained to the participant prior to the interview. They will be informed that any disclosures of crimes will be passed on to their probation officer or care coordinator.

A24. What is the potential for benefit to research participants?

Although no direct therapeutic input will be given, participants may find it beneficial to share their story and be carefully listened to.

Participants may find the experience of being part of research beneficial as they are contributing to scientific understanding.

Participants may find the summary of findings helpful so they can understand what their story has contributed towards and hear the views of other people living with a personality disorder diagnosis.

A26. What are the potential risks for the researchers themselves? (if any)

Managing the emotional and concentration demands of conducting in depth interviews – awareness of these demands, notifying the participant that breaks are appropriate either for them or the researcher, seeking appropriate supervision.

Bringing up issues that participants were not aware of before the project – support will be provided before, during, and after the interview. Any serious levels of distress will be reported to the supervisory team.

Risk to self or others – this will have been assessed and documented by the probation officer or care coordinator working

with the individual. All risk assessment documents will be read in full before recruitment to the study to ensure participants and researchers are not put at risk

There are no issues relating to lone working, as the interviews will take place at probation offices or at Ty Llywelyn Medium Secure Unit, where there will be people present outside the interview rooms.

RECRUITMENT AND INFORMED CONSENT

In this section we ask you to describe the recruitment procedures for the study. Please give separate details for different study groups where appropriate.

A27-1. How will potential participants, records or samples be identified? Who will carry this out and what resources will be used? *For example, identification may involve a disease register, computerised search of GP records, or review of medical records. Indicate whether this will be done by the direct healthcare team or by researchers acting under arrangements with the responsible care organisation(s).*

The Wales Probation Trust has accepted this research proposal (see attached confirmation of access letter) and has agreed to identify individuals based on the inclusion and exclusion criteria. This includes having received a personality disorder diagnosis at least two years previously. The probation officer working with the individual will confirm that the individual has received a personality disorder diagnosis and that they are fully aware of this, prior to discussing the research with them. If the individual is interested they will be sent information sheets which state that they have been chosen for this research as they have received a personality disorder diagnosis at least two years ago. They will be given two weeks to respond. During this initial contact with the researcher, the researcher will confirm that the individual has knowledge of their personality disorder diagnosis.

If it is not possible to recruit sufficient numbers of participants from the probation service, then participants will be recruited from the North Wales Forensic Psychiatric Service. Potential participants will be identified by their care coordinator based on the inclusion and exclusion criteria, and the same procedure as detailed above will be used.

A27-2. Will the identification of potential participants involve reviewing or screening the identifiable personal information of patients, service users or any other person?

☐ Yes ☒ No

Please give details below:

Potential participants will be screened by individuals involved in their care i.e. their probation officer or their care coordinator.

A28. Will any participants be recruited by publicity through posters, leaflets, adverts or websites?

☐ Yes ☒ No

A29. How and by whom will potential participants first be approached?

Participants will be first approached by the probation officer involved in their management or their care coordinator. Those who express an interest in participating will be sent an information sheet by the researcher.

A30-1. Will you obtain informed consent from or on behalf of research participants?

☒ Yes ☐ No

If you will be obtaining consent from adult participants, please give details of who will take consent and how it will be done, with details of any steps to provide information (a written information sheet, videos, or interactive material). Arrangements for adults unable to consent for themselves should be described separately in Part B Section 6, and for children in Part B Section 7.

If you plan to seek informed consent from vulnerable groups, say how you will ensure that consent is voluntary and fully informed.

Detailed, easy to understand information sheets will be sent to potential participants. Potential participants will then be given 2 weeks to decide whether or not to participate, and an opportunity to speak to members of the research team to ask questions will be provided. This is felt to be an adequate amount of time to discuss the research with

anyone they feel they need to and weigh up the information provided.

The researcher will obtain written consent from the participant, through asking them to sign a consent form. Consent will also be gained verbally prior to the interview commencing.

If you are not obtaining consent, please explain why not.

Please enclose a copy of the information sheet(s) and consent form(s).

A30-2. Will you record informed consent (or advice from consultees) in writing?

☒ Yes ☐ No

A31. How long will you allow potential participants to decide whether or not to take part?

2 weeks.

A33-1. What arrangements have been made for persons who might not adequately understand verbal explanations or written information given in English, or who have special communication needs? (e.g. translation, use of interpreters)

All information sheets, consent forms, and debrief information will be provided in English and in Welsh, however, due to the inability of the researcher to speak Welsh, interviews will have to be conducted in English.

Due to the nature of the research, in that participants are required to give detailed descriptions of their experiences, which is then transcribed and analysed, any people who are felt to have significant communication or learning difficulties will not be able to participate in the study.

A33-2. What arrangements will you make to comply with the principles of the Welsh Language Act in the provision of information to participants in Wales?

All information sheets, consent forms, and debrief information will be provided in English and in Welsh. However, due to the inability of the researcher to speak Welsh, interviews will have to be conducted in English.

A35. What steps would you take if a participant, who has given informed consent, loses capacity to consent during the study? Tick one option only.

- ☐ The participant and all identifiable data or tissue collected would be withdrawn from the study. Data or tissue which is not identifiable to the research team may be retained.
- ☒ The participant would be withdrawn from the study. Identifiable data or tissue already collected with consent would be retained and used in the study. No further data or tissue would be collected or any other research procedures carried out on or in relation to the participant.
- ☐ The participant would continue to be included in the study.
- ☐ Not applicable – informed consent will not be sought from any participants in this research.
- ☐ Not applicable – it is not practicable for the research team to monitor capacity and continued capacity will be assumed.

Further details:

If the data has been collected, as a sign of respect to the time given to participate, it will be used for the purposes of the research. Once the project is complete, a record of the change in informed consent will be kept and the data will no longer be able to be accessed by the research team.

If you plan to retain and make further use of identifiable data/tissue following loss of capacity, you should inform participants about this when seeking their consent initially.

CONFIDENTIALITY

In this section, personal data means any data relating to a participant who could potentially be identified. It includes pseudonymised data capable of being linked to a participant through a unique code number.

Storage and use of personal data during the study

A36. Will you be undertaking any of the following activities at any stage (including in the identification of potential participants)? (Tick as appropriate)

- ☐ Access to medical records by those outside the direct healthcare team
- ☐ Electronic transfer by magnetic or optical media, email or computer networks
- ☐ Sharing of personal data with other organisations
- ☐ Export of personal data outside the EEA
- ☒ Use of personal addresses, postcodes, faxes, emails or telephone numbers
- ☒ Publication of direct quotations from respondents
- ☐ Publication of data that might allow identification of individuals
- ☒ Use of audio/visual recording devices
- ☒ Storage of personal data on any of the following:
 - ☐ Manual files including X-rays
 - ☐ NHS computers
 - ☐ Home or other personal computers
 - ☐ University computers
 - ☐ Private company computers
 - ☒ Laptop computers

Further details:

Personal Addresses: Participants home addresses will be collected over the telephone to send study information, arrange interview, and in order to send participants a summary of the findings upon completion of the investigation. This will be stored on an encrypted laptop. Participants will each be assigned a number, in order to keep their addresses for a time.

Direct Quotes: All interviews will be transcribed and analysed. Direct quotations will be included in the write-up of the study to illustrate themes. This will be clearly explained in the information sheet and there will be a separate tick box on the consent form to indicate whether the participant consents to this. Pseudonyms will be used when reporting the quotes to maintain anonymity.

Audio Devices: All interviews will be recorded on a digital recording device. During transcription, pseudonyms will be used. Once completed, the recording will be destroyed and the anonymised transcription will be stored in password protected files on the researcher's encrypted laptop. The laptop requires a password to access the computer and all files regarding the research will be password protected.

Laptop Computer: A laptop will be used to write up the investigation. All participant data will be pseudonymised.

A38. How will you ensure the confidentiality of personal data? Please provide a general statement of the policy and procedures for ensuring confidentiality, e.g. anonymisation or pseudonymisation of data.

The researcher requires the address of all potential participants in order to send information relating to the study. Only the addresses of individuals who participate in the research will be kept until the research is complete, in order to provide feedback on the results. This information will be kept in a password protected file on a password protected laptop, and destroyed once feedback has been sent.

A40. Who will have access to participants' personal data during the study? Where access is by individuals outside the

direct care team, please justify and say whether consent will be sought.

Only the researcher will have access to participant's personal data during the study.

Storage and use of data after the end of the study

A43. How long will personal data be stored or accessed after the study has ended?

- ☒ Less than 3 months
☐ 3 – 6 months
☐ 6 – 12 months
☐ 12 months – 3 years
☐ Over 3 years

INCENTIVES AND PAYMENTS

A46. Will research participants receive any payments, reimbursement of expenses or any other benefits or incentives for taking part in this research?

- ☒ Yes ☐ No

If Yes, please give details. For monetary payments, indicate how much and on what basis this has been determined.

A £10 voucher to recognise the time given to the research has been deemed appropriate. This is within Betsi Cadwaladr University Health Board NHS Trust policy and is felt to be enough to recognise the time given, but not so much that it jeopardises the dignity of participants. The voucher will be given after informed consent has been gained and before the interview, so participants do not feel additional pressure during the interview.

A47. Will individual researchers receive any personal payment over and above normal salary, or any other benefits or incentives, for taking part in this research?

- ☐ Yes ☒ No

A48. Does the Chief Investigator or any other investigator/collaborator have any direct personal involvement (e.g. financial, share holding, personal relationship etc.) in the organisations sponsoring or funding the research that may give rise to a possible conflict of interest?

- ☐ Yes ☒ No

NOTIFICATION OF OTHER PROFESSIONALS

A49-1. Will you inform the participants' General Practitioners (and/or any other health or care professional responsible for their care) that they are taking part in the study?

- ☐ Yes ☒ No

If Yes, please enclose a copy of the information sheet/letter for the GP/health professional with a version number and date.

PUBLICATION AND DISSEMINATION

A50. Will the research be registered on a public database?

☐ Yes ☒ No

Please give details, or justify if not registering the research.

This research is not publicly funded and therefore will not be registered on a public database. It will be registered on the Betsi Cadwaladr University Health Board database for the duration of the study, and a paper copy of the completed Doctoral Thesis will be stored at the Bangor University library.

Registration of research studies is encouraged wherever possible.

You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you are aware of a suitable register or other method of publication, please give details. If not, you may indicate that no suitable register exists. Please ensure that you have entered registry reference number(s) in question A5-1.

A51. How do you intend to report and disseminate the results of the study? Tick as appropriate:

- ☒ Peer reviewed scientific journals
- ☐ Internal report
- ☒ Conference presentation
- ☐ Publication on website
- ☐ Other publication
- ☐ Submission to regulatory authorities
- ☐ Access to raw data and right to publish freely by all investigators in study or by Independent Steering Committee on behalf of all investigators
- ☐ No plans to report or disseminate the results
- ☐ Other (please specify)

A53. Will you inform participants of the results?

☒ Yes ☐ No

Please give details of how you will inform participants or justify if not doing so.

A one page summary of findings will be sent to all participants.

5. Scientific and Statistical Review

A54. How has the scientific quality of the research been assessed? Tick as appropriate:

- ☐ Independent external review
- ☐ Review within a company
- ☐ Review within a multi-centre research group
- ☒ Review within the Chief Investigator's institution or host organisation
- ☒ Review within the research team
- ☒ Review by educational supervisor
- ☐ Other

Justify and describe the review process and outcome. If the review has been undertaken but not seen by the researcher, give details of the body which has undertaken the review:

A proposal of the research has been submitted and approved by the research department of the North Wales Clinical Psychology Programme at Bangor University. This proposal was checked through by the research team. The project has also been approved by the Bangor University Psychology Ethics.

For all studies except non-doctoral student research, please enclose a copy of any available scientific critique reports, together with any related correspondence.

For non-doctoral student research, please enclose a copy of the assessment from your educational supervisor/ institution.

A59. What is the sample size for the research? *How many participants/samples/data records do you plan to study in total? If there is more than one group, please give further details below.*

Total UK sample size: 8

Total international sample size (including UK): 8

Total in European Economic Area:

Further details:

This is the maximum number of participants that will be recruited.

A60. How was the sample size decided upon? *If a formal sample size calculation was used, indicate how this was done, giving sufficient information to justify and reproduce the calculation.*

It is recommended by Smith, Flowers, and Larkin (2010) that for Doctoral level qualitative studies using interpretive phenomenological analysis, around 6 to 10 participants are required.

A62. Please describe the methods of analysis (statistical or other appropriate methods, e.g. for qualitative research) by which the data will be evaluated to meet the study objectives.

The present study aims to better understand and explore people's experiences of living with a personality disorder diagnosis using Interpretative Phenomenological Analysis (IPA; Smith, Flowers, and Larkin, 2010). IPA is a qualitative methodology which explores in detail 'personal lived experience and how participants make sense of that experience'. Each interview will be audio recorded and then transcribed. IPA allows the interview schedule to be used flexibly, which will mean the data collected will capture the richest and most important aspects of the participant's lived experiences. Analysis will involve careful examination of these transcripts, and themes will be generated from the text. Theme generation will focus on capturing the essence of each individual participant's personal experience, in relation to their personality disorder diagnosis. When each transcript has been considered individually and themes generated, comparisons will be made between the themes of each of the transcripts.

6. MANAGEMENT OF THE RESEARCH

A63. Other key investigators/collaborators. *Please include all grant co-applicants, protocol co-authors and other key members of the Chief Investigator's team, including non-doctoral student researchers.*

	Title	Forename/Initials	Surname
	Dr	Robin	Owen
Post	Clinical Psychologist		
Qualifications	D.Clin.Psy		
Employer	Betsi Cadwaladr University Health Board		
Work Address	North Wales Forensic Psychiatric Service		
	Ty Llywelyn MSU		
	Bryn y Neuadd Hospital, Llanfairfechan		
Post Code	LL33 0HH		
Telephone	01248 682 133		
Fax			
Mobile			
Work Email	Robin.Owen2@wales.nhs.uk		

	Title	Forename/Initials	Surname
	Dr	James	Lea
Post	Clinical Psychologist		

Qualifications D.Clin.Psy
 Employer North Wales Clinical Psychology Programme
 Work Address North Wales Clinical Psychology Programme
 School of Psychology, Bangor University
 Bangor, Gwynedd
 Post Code LL57 2DG
 Telephone 01248383890
 Fax
 Mobile
 Work Email j.lea@bangor.ac.uk

Title Forename/Initials Surname
 Dr Julia Wane
 Post Consultant Clinical Psychologist
 Qualifications D.Clin.Psy
 Employer Betsi Cadwaladr University Health Board
 Work Address North Wales Forensic Psychiatric Service
 Ty Llywelyn MSU
 Bryn y Neuadd Hospital, Llanfairfechan
 Post Code LL33 0HH
 Telephone 01248682133
 Fax
 Mobile
 Work Email Julia.Wane@wales.nhs.uk

A64. Details of research sponsor(s)

A64-1. Sponsor

Lead Sponsor

Status: ☐ NHS or HSC care organisation
☒ Academic
☐ Pharmaceutical industry
☐ Medical device industry
☐ Local Authority
☐ Other social care provider (including voluntary sector or private organisation)
☐ Other

Commercial status:

If Other, please specify:

Contact person

Name of organisation Bangor University School of Psychology
 Given name Hefin
 Family name Francis
 Address School of Psychology, Bangor University
 Town/city Bangor
 Post code LL7 2AS
 Country UNITED KINGDOM

Telephone 01248388339
 Fax
 E-mail h.francis@bangor.ac.uk

Is the sponsor based outside the UK?

☐ Yes ☒ No

Under the Research Governance Framework for Health and Social Care, a sponsor outside the UK must appoint a legal representative established in the UK. Please consult the guidance notes.

A65. Has external funding for the research been secured?

- ☐ Funding secured from one or more funders
☐ External funding application to one or more funders in progress
☒ No application for external funding will be made

What type of research project is this?

- ☒ Standalone project
☐ Project that is part of a programme grant
☐ Project that is part of a Centre grant
☐ Project that is part of a fellowship/ personal award/ research training award
☐ Other

Other – please state:

A67. Has this or a similar application been previously rejected by a Research Ethics Committee in the UK or another country?

☐ Yes ☒ No

Please provide a copy of the unfavourable opinion letter(s). You should explain in your answer to question A6-2 how the reasons for the unfavourable opinion have been addressed in this application.

A68-1. Give details of the lead NHS R&D contact for this research:

	Title Forename/Initials Surname
	Dr Rossela Roberts
Organisation	Betsi Cadwaladr University Health Board
Address	Ysbyty Gwynedd
	Bangor
	Gwynedd
Post Code	LL57 2PW
Work Email	rossela.roberts@wales.nhs.uk
Telephone	01248384877
Fax	
Mobile	

Details can be obtained from the NHS R&D Forum website: <http://www.rdforum.nhs.uk>

A69-1. How long do you expect the study to last in the UK?

Planned start date: 03/03/2014

Planned end date: 30/06/2015

Total duration:

Years: 1 Months: 3 Days: 28

A71-2. Where will the research take place? (Tick as appropriate)

- ☐ England
- ☐ Scotland
- ☒ Wales
- ☐ Northern Ireland
- ☐ Other countries in European Economic Area

Total UK sites in study 1

Does this trial involve countries outside the EU?☐ Yes ☒ No**A72. What host organisations (NHS or other) in the UK will be responsible for the research sites? Please indicate the type of organisation by ticking the box and give approximate numbers of planned research sites:**

- ☐ NHS organisations in England
- ☒ NHS organisations in Wales 1
- ☐ NHS organisations in Scotland
- ☐ HSC organisations in Northern Ireland
- ☐ GP practices in England
- ☐ GP practices in Wales
- ☐ GP practices in Scotland
- ☐ GP practices in Northern Ireland
- ☐ Social care organisations
- ☐ Phase 1 trial units
- ☐ Prison establishments
- ☒ Probation areas 1
- ☐ Independent hospitals
- ☐ Educational establishments
- ☐ Independent research units
- ☐ Other (give details)

Total UK sites in study: 2

A76. Insurance/ indemnity to meet potential legal liabilities

Note: in this question to NHS indemnity schemes include equivalent schemes provided by Health and Social Care (HSC) in Northern Ireland

A76-1. What arrangements will be made for insurance and/or indemnity to meet the potential legal liability of the sponsor(s) for harm to participants arising from the management of the research? Please tick box(es) as applicable.

Note: Where a NHS organisation has agreed to act as sponsor or co-sponsor, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For all other sponsors, please describe the arrangements and provide evidence.

- ☐ NHS indemnity scheme will apply (NHS sponsors only)
- ☒ Other insurance or indemnity arrangements will apply (give details below)

Bangor University will meet the potential legal liability of the sponsor for harm to participants arising from the management of the research. Please see attached insurance certificate.

Please enclose a copy of relevant documents.

A76-2. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of the sponsor(s) or employer(s) for harm to participants arising from the design of the research? Please tick box(es) as applicable.

Note: Where researchers with substantive NHS employment contracts have designed the research, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For other protocol authors (e.g. company employees, university members), please describe the arrangements and provide evidence.

- ☐ NHS indemnity scheme will apply (protocol authors with NHS contracts only)
- ☒ Other insurance or indemnity arrangements will apply (give details below)

Bangor University will meet the potential legal liability of the sponsor for harm to participants arising from the design of the research. Please see attached insurance certificate.

Please enclose a copy of relevant documents.

A76-3. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of investigators/collaborators arising from harm to participants in the conduct of the research?

Note: Where the participants are NHS patients, indemnity is provided through the NHS schemes or through professional indemnity. Indicate if this applies to the whole study (there is no need to provide documentary evidence). Where non-NHS sites are to be included in the research, including private practices, please describe the arrangements which will be made at these sites and provide evidence.

- ☒ NHS indemnity scheme or professional indemnity will apply (participants recruited at NHS sites only)
- ☐ Research includes non-NHS sites (give details of insurance/ indemnity arrangements for these sites below)

Bangor University will meet the potential legal liability of the sponsor for harm to participants arising from the conduct of the research. Please see attached insurance certificate.

Please enclose a copy of relevant documents.

PART C: Overview of research sites

Please enter details of the host organisations (Local Authority, NHS or other) in the UK that will be responsible for the research sites. For NHS sites, the host organisation is the Trust or Health Board. Where the research site is a primary care site, e.g. GP practice, please insert the host organisation (PCT or Health Board) in the Institution row and insert the research site (e.g. GP practice) in the Department row.

Research site		Investigator/ Collaborator/ Contact	
Institution name	Wales Probation Trust	Title	Ms
Department name	Public Protection and Service Development Team	First name/ Initials	Eleanor
Street address	33 Westgate Street	Surname	Worthington
Town/city	Cardiff		
Post Code	CF10 1JE		
Institution name	Betsi Cadwaladr University Health Board	Title	Dr
Department name	Ty Llywelyn Medium Secure Unit	First name/ Initials	Robin
Street address	Bryn y Neuadd Hospital	Surname	Owen
Town/city	Llanfairfechan		
Post Code	LL33 0HH		

PART D: Declarations

D1. Declaration by Chief Investigator

1. The information in this form is accurate to the best of my knowledge and belief and I take full responsibility for it.
2. I undertake to abide by the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research.
3. If the research is approved I undertake to adhere to the study protocol, the terms of the full application as approved and any conditions set out by review bodies in giving approval.
4. I undertake to notify review bodies of substantial amendments to the protocol or the terms of the approved application, and to seek a favourable opinion from the main REC before implementing the amendment.
5. I undertake to submit annual progress reports setting out the progress of the research, as required by review bodies.
6. I am aware of my responsibility to be up to date and comply with the requirements of the law and relevant guidelines relating to security and confidentiality of patient or other personal data, including the need to register when necessary with the appropriate Data Protection Officer. I understand that I am not permitted to disclose identifiable data to third parties unless the disclosure has the consent of the data subject or, in the case of patient data in England and Wales, the disclosure is covered by the terms of an approval under Section 251 of the NHS Act 2006.
7. I understand that research records/data may be subject to inspection by review bodies for audit purposes if required.
8. I understand that any personal data in this application will be held by review bodies and their operational managers and that this will be managed according to the principles established in the Data Protection Act 1998.
9. I understand that the information contained in this application, any supporting documentation and all correspondence with review bodies or their operational managers relating to the application:
 - Will be held by the REC (where applicable) until at least 3 years after the end of the study; and by NHS R&D offices (where the research requires NHS management permission) in accordance with the NHS Code of Practice on Records Management.
 - May be disclosed to the operational managers of review bodies, or the appointing authority for the REC (where applicable), in order to check that the application has been processed correctly or to investigate any complaint.
 - May be seen by auditors appointed to undertake accreditation of RECs (where applicable).
 - Will be subject to the provisions of the Freedom of Information Acts and may be disclosed in response to requests made under the Acts except where statutory exemptions apply.
 - May be sent by email to REC members.
10. I understand that information relating to this research, including the contact details on this application, may be held on national research information systems, and that this will be managed according to the principles established in the Data Protection Act 1998.
11. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named below. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.

Contact point for publication *(Not applicable for R&D Forms)*

NRES would like to include a contact point with the published summary of the study for those wishing to seek further information. We would be grateful if you would indicate one of the contact points below.

- ☒ Chief Investigator
- ☐ Sponsor

- ☐ Study co-ordinator
☐ Student
☐ Other – please give details
☐ None

Access to application for training purposes *(Not applicable for R&D Forms)*

Optional – please tick as appropriate:

☒ I would be content for members of other RECs to have access to the information in the application in confidence for training purposes. All personal identifiers and references to sponsors, funders and research units would be removed.

This section was signed electronically by Miss Emma Lloyd on 07/04/2014 18:22.

Job Title/Post: Trainee Clinical Psychologist
 Organisation: North Wales Clinical Psychology Programme
 Email: psp0da@bangor.ac.uk
 Signature:
 Print Name: Emma Lloyd
 Date: (dd/mm/yyyy)

D2. Declaration by the sponsor's representative

If there is more than one sponsor, this declaration should be signed on behalf of the co-sponsors by a representative of the lead sponsor named at A64-1.

I confirm that:

1. This research proposal has been discussed with the Chief Investigator and agreement in principle to sponsor the research is in place.
2. An appropriate process of scientific critique has demonstrated that this research proposal is worthwhile and of high scientific quality.
3. Any necessary indemnity or insurance arrangements, as described in question A76, will be in place before this research starts. Insurance or indemnity policies will be renewed for the duration of the study where necessary.
4. Arrangements will be in place before the study starts for the research team to access resources and support to deliver the research as proposed.
5. Arrangements to allocate responsibilities for the management, monitoring and reporting of the research will be in place before the research starts.
6. The duties of sponsors set out in the Research Governance Framework for Health and Social Care will be undertaken in relation to this research.
7. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named in this application. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.

This section was signed electronically by Mr Hefin Francis on 09/04/2014 17:32.

Job Title/Post:	School Manager for Psychology
Organisation:	Bangor University
Email:	h.francis@bangor.ac.uk

D3. Declaration for student projects by academic supervisor(s)

1. I have read and approved both the research proposal and this application. I am satisfied that the scientific content of the research is satisfactory for an educational qualification at this level.
2. I undertake to fulfil the responsibilities of the supervisor for this study as set out in the Research Governance Framework for Health and Social Care.
3. I take responsibility for ensuring that this study is conducted in accordance with the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research, in conjunction with clinical supervisors as appropriate.
4. I take responsibility for ensuring that the applicant is up to date and complies with the requirements of the law and relevant guidelines relating to security and confidentiality of patient and other personal data, in conjunction with clinical supervisors as appropriate.

Academic supervisor 1

This section was signed electronically by Dr Julia Wane on 09/04/2014 17:05.

Job Title/Post: Consultant Clinical Psychologist
 Organisation: BCUHB
 Email: julia.wane@wales.nhs.uk

Academic supervisor 2

This section was signed electronically by Dr James Lea on 08/04/2014 11:43.

Job Title/Post: Academic Tutor/Senior Clinical Psychologist
 Organisation: NWCPP
 Email: j.lea@bangor.ac.uk

Academic supervisor 3

This section was signed electronically by Dr Robin Owen on 08/04/2014 10:06.

Job Title/Post: Clinical Psychologist
 Organisation: NHS
 Email: robin.owen2@wales.nhs.uk

REC response letter- request for further information

Part of the research infrastructure for Wales funded by the National Institute for Social Care and Health Research, Welsh Government.
Yn rhan o seilwaith ymchwil Cymru a ariannir gan y Sefydliad Cenedlaethol ar gyfer Ymchwil Gofal Cymdeithasol ac Iechyd, Llywodraeth Cymru



Wales REC 3
Sixth Floor, Churchill House
17 Churchill Way
Cardiff CF10 2TW

Telephone : 029 2037 6829
Fax : 029 2037 6824
E-mail : corinne.scott@wales.nhs.uk
Website : www.hra.nhs.uk

13 May 2014

Miss Emma Lloyd
Trainee Clinical Psychologist
Betsi Cadwaladr University Health Board
North Wales Clinical Psychology Programme
School of Psychology,
43 College Road,
Bangor LL57 2DG

Dear Miss Lloyd

Study Title: People's experiences of living with a personality disorder
diagnosis: A perspective from individuals within the Probation
Service
REC reference: 14/WA/0144
IRAS project ID: 145859

The Research Ethics Committee reviewed the above application at the meeting held on 08 May 2014.

Documents reviewed

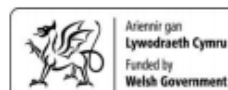
The documents reviewed at the meeting were:

Document	Version	Date
Evidence of insurance or indemnity	QBE certificate of insurance - Bangor University - expires 31 July 2014	
Evidence of insurance or indemnity	UMAL certificate of insurance - Bangor University - expires 31 July 2014	11 July 2013
Interview Schedules/Topic Guides	Semi structured interview schedule; version 2	03 March 2014
Investigator CV	Miss Lloyd	28 March 2014
Investigator CV	Dr James Lea	06 December 2013
Investigator CV	Dr Julia Warne	06 December 2013
Investigator CV	Dr Robin Owen	06 December 2013
Other: Letter of confirmation of access from Wales Probation	signed Ian Barrow	02 December 2013
Participant Consent Form	2	03 March 2014
Participant Information Sheet	1	04 February 2014
Protocol	1	15 July 2013
REC application	signed electronically by Miss Lloyd; electronically by	11 April 2014



Cynhelir Cydweithrediad Gwyddor Iechyd Academaidd y Sefydliad Cenedlaethol ar gyfer Ymchwil Gofal Cymdeithasol ac Iechyd gan Fwrdd Addysgu Iechyd Powys

The National Institute for Social Care and Health Research Academic Health Science Collaboration is hosted by Powys Teaching Health Board



	Hefin Francis, sponsor's representative; electronically by Dr Julia Wane, Dr James Lea and Dr Robin Owen, academic supervisors	
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Provisional opinion

The Committee would be content to give a favourable ethical opinion of the research, subject to receiving a complete response to the request for further information set out below.

Authority to consider your response and to confirm the Committee's final opinion has been delegated to the Chair.

Further information or clarification required

Recruitment process

- The Committee would like written clarification of the recruitment method, and copies of any letters to be used should be provided for review.

Information sheet

- The information sheet should be amended to make clear that any disclosure of criminal activity which has been committed but for which the participant has not been convicted and / or disclosure of intended criminal activity will be reported.

If you would find it helpful to discuss any of the matters raised above or seek further clarification from a member of the Committee, you are welcome to contact the Committee Manager, Dr. Corinne Scott whose contact details can be found at the header of this letter.

When submitting your response to the Committee, please send revised documentation where appropriate underlining or otherwise highlighting the changes you have made and giving revised version numbers and dates.

If the committee has asked for clarification or changes to any answers given in the application form, please do not submit a revised copy of the application form; these can be addressed in a covering letter to the REC.

The Committee will confirm the final ethical opinion within a maximum of 60 days from the date of initial receipt of the application, excluding the time taken by you to respond fully to the above points. A response should be submitted by no later than 12 June 2014.

Membership of the Committee

The members of the Committee who were present at the meeting are listed on the attached sheet.

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.

14/WA/0144	Please quote this number on all correspondence
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Yours sincerely

pp **Dr Pete Wall**
Chair

E-mail: corinne.scott@wales.nhs.uk

Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments.

Copy to: Mr Hefin Francis
Dr Rossela Roberts, Betsi Cadwaladr University Health Board

Wales REC 3
Attendance at Committee meeting on 08 May 2014

Committee Members:

<i>Name</i>	<i>Profession</i>	<i>Present</i>	<i>Notes</i>
Dr Gail Boniface	Occupational Therapist	No	
Dr Paul Brown	Radiographer	No	
Dr Maurice Buchalter	Vice Chair / Hospital Consultant (Cardiologist)	No	
Professor Kate Bullen	Psychologist	No	
Mrs Joy Darch	Nurse	Yes	
Mr Terry Eastham	Lay Plus member	Yes	
Mrs Monika Hare	Alternate Vice Chair / Lay member	Yes	
Ms Nicola Heales	Lay Plus member	No	
Mr HAO Hughes	Pharmacist	Yes	
Dr Meriel Jenney	Hospital consultant (Paediatric oncologist)	No	
Dr Andrea Longman	Lay member	Yes	
Dr V. Bapuji Rao	Hospital consultant (Psychiatrist)	Yes	
Ms Paula Strong	Nurse	No	
Mrs Wendy Turkie	Lay member	No	
Dr Richard Walker	Lay Plus member	Yes	
Dr Pete Wall	Chair / Clinical Physiologist	Yes	
Mr Stewart Williams	Lay Plus member	Yes	

Also in attendance:

<i>Name</i>	<i>Position (or reason for attending)</i>
Dr Corinne Scott	Co-ordinator
Mrs Helen Williams	Assistant Coordinator

Written comments – not regarding this application - received from:

<i>Name</i>	<i>Position</i>
Dr Meriel Jenney	Hospital consultant (Paediatric oncologist)

My response to request for further information



Research Committee
Wales REC 3
Sixth Floor, Churchill House
17 Churchill Way
Cardiff CF10 2TW

Miss Emma Lloyd
Trainee Clinical Psychologist
North Wales Clinical Psychology
Programme
School of Psychology
Bangor University
LL57 2DG

psp0da@bangor.ac.uk

30th May 2014

Dear Dr Wall

RE: Response to request for further information following REC Committee meeting on the 08/05/14

Study Title:	People's experiences of living with a personality disorder diagnosis: A perspective from individuals within the Probation Service
REC reference:	14/WA/0144
IRAS project ID:	145859

Thank you for your letter detailing the review for my proposed research project. Please find below the responses to the request for further information:

Recruitment process

The Committee would like written clarification of the recruitment method, and copies of any letters to be used should be provided for review.

Preliminary discussions with the Wales Probation Trust have identified Probation Officers in North Wales with caseloads of individuals diagnosed with a personality disorder. The research team will meet with the probation officers and provide details of the inclusion and exclusion criteria. Probation officers will identify and approach individuals based on these criteria. They will ask people who meet the criteria if they are interested in participating in research. If they demonstrate an interest in participating then they will be provided with a participant information sheet. If the individual would like to participate or would like to discuss the research further, they can verbally consent to their email address and/or phone number to be passed on to the researcher. Otherwise, the individual can choose to contact the researcher for further information through the email address provided on the information sheet.

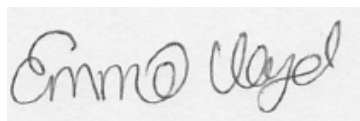
Information sheet

The information sheet should be amended to make clear that any disclosure of criminal activity which has been committed but for which the participant has not been convicted and / or disclosure of intended criminal activity will be reported.

Please find attached an amended version of the information sheet to incorporate the requested information (version 3 - dated 23.05.14). The added information has been underlined.

I hope you will find this information satisfactory. Please do not hesitate to contact me if you would like any further information.

Yours sincerely

A handwritten signature in cursive script, reading "Emma Lloyd". The signature is written in dark ink on a light-colored background.

Emma Lloyd

REC confirmation of ethical approval letter

Part of the research infrastructure for Wales funded by the National Institute for Social Care and Health Research, Welsh Government.
Yn rhan o seilwaith ymchwil Cymru a ariannir gan y Sefydliad Cenedlaethol ar gyfer Ymchwil Gofal Cymdeithasol ac Iechyd, Llywodraeth Cymru



Wales REC 3
Sixth Floor, Churchill House
17 Churchill Way
Cardiff CF10 2TW

Telephone : 029 2037 6829
Fax : 029 2037 6824
E-mail : corinne.scott@wales.nhs.uk
Website : www.hra.nhs.uk

03 June 2014

Miss Emma Lloyd
Trainee Clinical Psychologist
Betsi Cadwaladr University Health Board
North Wales Clinical Psychology Programme
School of Psychology
43 College Road,
Bangor
Gwynedd LL57 2DG

Dear Miss Lloyd

Study title: People's experiences of living with a personality disorder
diagnosis: A perspective from individuals within the Probation
Service
REC reference: 14/WA/0144
IRAS project ID: 145859

Thank you for your letter of 30 May 2014, responding to the Committee's request for further information on the above research and submitting revised documentation.

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

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Manager, Dr. Corinne Scott, corinne.scott@wales.nhs.uk.

Confirmation of ethical opinion

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

Conditions of the favourable opinion

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

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

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.



Cynhelir Cydweithrediad Gwyddor Iechyd Academaidd y Sefydliad Cenedlaethol ar gyfer Ymchwil Gofal Cymdeithasol ac Iechyd gan Fwrdd Addysgu Iechyd Powys

The National Institute for Social Care and Health Research Academic Health Science Collaboration is hosted by Powys Teaching Health Board



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

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

Sponsors are not required to notify the Committee of approvals from host organisations

Registration of Clinical Trials

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

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

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

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

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

Ethical review of research sites

NHS sites

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

Approved documents

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

<i>Document</i>	<i>Version</i>	<i>Date</i>
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only)	UMAL certificate of insurance - Bangor University - expires 31 July 2014	11 July 2013
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only)	QBE certificate of insurance - Bangor University - expires 31 July 2014	
Interview schedules or topic guides for participants	Semi structured interview schedule; version 2	03 March 2014
Other [Letter of confirmation of access from Wales Probation]	signed Ian Barrow	02 December 2013
Participant consent form	2	03 March 2014
Participant information sheet (PIS)	2	23 May 2014
REC Application Form	signed electronically by Miss Lloyd; electronically by Hefin Francis, sponsor's representative; electronically by Dr Julia Wane, Dr James Lea and Dr Robin Owen, academic supervisors	11 April 2014

Research protocol or project proposal	1	15 July 2013
Response to Request for Further Information [Letter signed Ms Lloyd]		30 May 2014
Summary CV for Chief Investigator (CI)	Miss Lloyd	28 March 2014
Summary CV for Chief Investigator (CI)	Dr Robin Owen	06 December 2013
Summary CV for Chief Investigator (CI)	Dr Julia Warne	06 December 2013
Summary CV for Chief Investigator (CI)	Dr James Lea	06 December 2013

Statement of compliance

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

After ethical review

Reporting requirements

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

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

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

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

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

14/WA/0144	Please quote this number on all correspondence
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With the Committee's best wishes for the success of this project.

Yours sincerely

Dr. Corinne Scott
NISCHR RES Manager

pp Mrs. Monika Hare
Alternate Vice Chair

E-mail: corinne.scott@wales.nhs.uk

Enclosures: "After ethical review – guidance for researchers"

Copy to: Mr Hefin Francis
Dr Rossela Roberts, Betsi Cadwaladr University Health Board

R&D response- request for further information



GIG
CYMRU
NHS
WALES

Bwrdd Iechyd Prifysgol
Betsi Cadwaladr
University Health Board

Panel Arolygu Mewnol Y&D R&D Internal Review Panel

Betsi Cadwaladr University Health Board
Ysbyty Gwynedd
Clinical Academic Office
Bangor, Gwynedd
LL57 2PW

Miss Emma Lloyd
Trainee Clinical Psychologist
North Wales Clinical Psychology Programme
School of Psychology
Bangor University
LL57 2DG

psp0da@bagor.ac.uk

Chairman/Cadeirydd – Dr Nefyn Williams PhD, FRCGP
Email: rossela.roberts@wales.nhs.uk
wendy.scrase2@wales.nhs.uk
sion.lewis@wales.nhs.uk
Tel/Fax: 01248 384 877

09 May 2014

Dear Miss Lloyd,

Re: Notification that local governance checks are not satisfied

Study Title People's experience of living with a personality disorder diagnosis: A perspective from individuals within the Probation Service
IRAS reference 145859

Thank you for submitting your R&D application and supporting documents.
The above study was reviewed by the BCUHB R&D Internal Review Panel in its meeting of the 08 May 2014

Below, please find a list of documents you have submitted for review:

Document:	Version	Date
R&D Checklist	-	-
R&D Form	-	07/04/2014
SSI Checklist	-	-
SSI Form	-	07/04/2014
Protocol	1	15/07/2013
Information Sheet	1	04/02/2014
Consent Form	2	03/03/2014
Interview Schedule	2	03/03/2014
REC Valid Application Letter	-	10/04/2014
Wales Probation Trust Approval Letter	-	02/12/2013
CV of CI/Student	-	28/03/2014

Unfortunately, we have been unable to satisfy all the local governance checks for your study.
Below are the details of the governance check(s) that we have been unable to satisfy:

Participant information & consent documents and process

The Panel requested that the contact details for Mr Francis (in the complaints section) are completed.

Emergency / Backup / Support arrangements

The Panel requested a clarification of the adequacy of the support mechanism for participants who may become distressed (is it sufficient that the researcher is able to help and the probation officer is present and able to assist, or should alternative arrangements be made?)

Compliance with Data Protection Act and data security issues

1. The Panel requested a clarification of whether the probation officer/care coordinator can give details to the researcher about potential participants, and what is the process in place to ensure that this is done with the individuals' consent.

2. A further clarification was requested regarding the encryption of audio-recordings: is the recorder a BU encrypted device or a process in place to encrypt individual mp3 files?
3. The Panel requested that the process to handle incidental disclosures is described in the protocol.

Research Ethics Committee favourable opinion

The REC favourable opinion letter should be submitted for the Panel's perusal.

Other regulatory approvals and authorizations

The approval letter from National Offender Management Service should be submitted for the Panel's perusal.

If you are able to provide additional information or further clarification to resolve these issues, we will review the relevant local governance checks again. If the committee has asked for clarification or changes to any answers given in the application form, please do not submit a revised copy of the application form; these can be addressed in a covering letter to the Committee

Authority to consider your response and to confirm the Panel's final opinion has been delegated to the Chairman.

The Panel will issue a final opinion on the application within a maximum of 60 days from the initial receipt of application, excluding the time taken by you to respond fully to the above points.

Please do not hesitate to contact us if you require any further information or assistance.

Yours sincerely,



Dr Nefyn Williams PhD, FRCGP
Associate Director of R&D
Chairman Internal Review Panel

Copy to:

Academic Supervisor:	Dr Robin Owen North Wales Forensic Psychiatry Bryn Y Neuadd Hospital LL33 0HH robin.owen2@wales.nhs.uk
Academic Supervisor:	Dr James Lea North Wales Clinical Psychology Programme School of Psychology Bangor University LL57 2DG j.lea@bangor.ac.uk
Academic Supervisor:	Dr Julie Wane North Wales Forensic Psychiatric Service Bryn y Neuadd Hospital LL33 0HH julia.wane@wales.nhs.uk

My response to the request for further information



R&D Internal review Panel
Betsi Cadwaladr University Health Board
Ysbyty Gwynedd
Clinical Academic Office
Bangor, Gwynedd
LL57 2PW

Miss Emma Lloyd
Trainee Clinical Psychologist
North Wales Clinical Psychology
Programme
School of Psychology
Bangor University
LL57 2DG

psp0da@bangor.ac.uk

30th May 2014

Dear Dr Williams

**RE: Response to request for further information following the R&D Internal
Review Panel on the 08/05/14.**

Study Title: People's experiences of living with a
personality disorder diagnosis: A
perspective from individuals within the
Probation Service

IRAS project ID: 145859

Thank you for your letter detailing the review for my proposed research project. Please find below a list of additional information as requested:

Participant information & consent documents and process

The Panel requested that the contact details for Mr Francis (in the complaints section) are completed.

Please find attached participant information sheet and consent form with the contact details for Mr Francis in the complaints section.

Emergency/ Backup/ Support arrangements

The Panel requested a clarification of the adequacy of the support mechanism for participants who may become distressed (is it sufficient that the researcher is able to help and the probation officer is present and able to assist, or should alternative arrangements be made?)

If a participant becomes distressed during the interview process they will be supported by the researcher. I am a trainee clinical psychologist with over eight years' experience of working in mental health services. The nature of the training I have received has equipped me with the skills necessary to work with individuals experiencing high levels of distress. If the participant appears to be distressed or expresses distress they will be encouraged to take a break from the interview. I will discuss with them the nature of their distress and remind them that they do not need to continue. If I feel that a participant is becoming too distressed I will terminate the interview. I can also provide participants with information of how to access mental health services if required and also signpost them to support services such as the CALL helpline.

There will be a probation officer within the vicinity of the interview room, who can assist if necessary, and arrange access to local services if deemed necessary.

Compliance with Data Protection Act and data security issues

- 1. Clarify whether the probation officer/care coordinator can give details to the researcher about potential participants, and what is the process in place to ensure that this is done with the individuals consent.**

The researcher will meet with the probation officers/care co-ordinators who will identify potential participants on their caseloads based on the inclusion/exclusion criteria specified. The probation officer/care co-ordinator will approach potential participants and discuss the research with them. If the individual expresses interest in the research then they will be provided with an information sheet to read. If they would like to participate then they can verbally consent to their contact details will be passed on to the researcher. The researcher will then contact the interested participant directly either by phone or email, depending upon the contact details the participant has consented to be passed on.

- 2. Clarify the encryption of audio recording: is the recorder a BU encrypted device or a process in place to encrypt individual MP3 files.**

After the interview has finished the audio recording will be immediately transferred to a password protected laptop. Each file will be anonymised and password protected. The interview will then be deleted from the audio recording device.

- 3. The Panel requested that the process to handle incidental disclosures is described in the protocol.**

If the participant makes any incidental disclosures relating to crimes committed for which they have not been prosecuted for and/or crimes they intend to commit, then this information will be passed on to the probation officer/care coordinator. The participant will be informed of this in the information sheet and also reminded of this prior to the interview commencing.

Research Ethics Committee favourable opinion

The REC favourable opinion letter should be submitted for the Panel's perusal.

I have submitted a response for a request for further information following the REC review held on the 8th May 2014, and I am awaiting their response. As soon as a favourable opinion letter is available, this will be submitted for the panel's perusal.

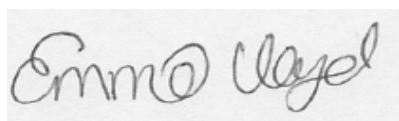
Other regulatory approvals and authorizations

The approval letter from National Offender Management Service should be submitted for the Panel's perusal.

I have received approval from the National Offender Management Service by email; however they have not provided an approval letter. Please find attached a copy of the email response received which confirms their approval of the research project.

I hope you will find these responses satisfactory. Please do not hesitate to contact me if you require further information.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Emma Lloyd', written in a cursive style.

Emma Lloyd

R&D approval letter



**GIG
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Betsi Cadwaladr
University Health Board

Panel Arolygu Mewnol Y&D R&D Internal Review Panel

Betsi Cadwaladr University Health Board
Ysbyty Gwynedd
Clinical Academic Office
Bangor, Gwynedd
LL57 2PW

Miss Emma Lloyd
Trainee Clinical Psychologist
North Wales Clinical Psychology Programme
School of Psychology
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psp0da@bagor.ac.uk

Chairman/Cadeirydd – Dr Nefyn Williams PhD, FRCGP
Email: rossela.roberts@wales.nhs.uk
wendy.scrase2@wales.nhs.uk
sion.lewis@wales.nhs.uk
Tel/Fax: 01248 384 877

13 June 2014

Dear Miss Lloyd,

Re: Confirmation that R&D governance checks are complete / R&D approval granted

Study Title People's experience of living with a personality disorder diagnosis: A perspective from individuals within the Probation Service
IRAS reference 145859

The above research project was reviewed at the meeting of the BCUHB R&D Internal Review Panel

The Committee is satisfied with the scientific validity of the project, the risk assessment, the review of the NHS cost and resource implications and all other research management issues pertaining to the revised application.

Thank you for responding to the Committee's request for further information. The R&D office considered the response on behalf of the Committee and is satisfied with the scientific validity of the project, the risk assessment, the review of the NHS cost and resource implications and all other research management issues pertaining to the revised application.

Please note that this approval does not automatically confer the right to access primary care sites; it allows you to approach individual GP practices and seek permission to conduct your research.

The Internal Review Panel is pleased to confirm that all governance checks are now complete and to grant approval to proceed at Betsi Cadwaladr University Health Board sites as described in the application.

The documents reviewed and approved are listed below:

Documents Reviewed:	Version	Date
R&D Checklist	-	-
R&D Form	-	07/04/2014
SSI Checklist	-	-
SSI Form	-	07/04/2014
Protocol	1	15/07/2013
Information Sheet	2	23/05/2014
Consent Form	3	23/05/2014
Interview Schedule	2	03/03/2014
REC Valid Application Letter	-	10/04/2014
Wales Probation Trust Approval Letter	-	02/12/2013
CV of CI/Student	-	28/03/2014
Response to R&D	-	30/05/2014
REC Furth Information Approval	-	03/06/2014

All research conducted at the Betsi Cadwaladr University Health Board sites must comply with the Research Governance Framework for Health and Social Care in Wales (2009).
An electronic link to this document is provided on the BCUHB R&D WebPages.
Alternatively, you may obtain a paper copy of this document via the R&D Office.

Attached you will find a set of approval conditions outlining your responsibilities during the course of this research. Failure to comply with the approval conditions will result in the withdrawal of the approval to conduct this research in the Betsi Cadwaladr University Health Board.

If your study is adopted onto the NISCHR Clinical Research Portfolio (CRP), it will be a condition of this NHS research permission, that the Chief Investigator will be required to regularly upload recruitment data onto the portfolio database.

To apply for adoption onto the NISCHR CRP, please go to:

<http://www.wales.nhs.uk/sites3/page.cfm?orgid=580&pid=31979>.

Once adopted, NISCHR CRP studies may be eligible for additional support through the NISCHR Clinical Research Centre. Further information can be found

at: <http://www.wales.nhs.uk/sites3/page.cfm?orgid=580&pid=28571> and/or from your NHS R&D office colleagues.

To upload recruitment data, please follow this link:

http://www.crnc.nihr.ac.uk/about_us/processes/portfolio/p_recruitment.

Uploading recruitment data will enable NISCHR to monitor research activity within NHS organizations, leading to NHS R&D allocations which are activity driven. Uploading of recruitment data will be monitored by your colleagues in the R&D office.

If you need any support in uploading this data, please contact wendy.scrase2@wales.nhs.uk or sion.lewis@wales.nhs.uk

If you would like further information on any other points covered by this letter please do not hesitate to contact me.

On behalf of the Committee, may I take this opportunity to wish you every success with your research.

Yours sincerely,



Dr Nefyn Williams PhD, FRCGP
Associate Director of R&D
Chairman Internal Review Panel

Copy to:

Academic Supervisor:	Dr Robin Owen North Wales Forensic Psychiatry Bryn Y Neuadd Hospital LL33 0HH robin.owen2@wales.nhs.uk
Academic Supervisor:	Dr James Lea North Wales Clinical Psychology Programme School of Psychology Bangor University LL57 2DG j.lea@bangor.ac.uk
Academic Supervisor:	Dr Julie Wane North Wales Forensic Psychiatric Service Bryn y Neuadd Hospital LL33 0HH julia.wane@wales.nhs.uk

NOMS Application form

Welcome to the Integrated Research Application System

IRAS Project Filter

The integrated dataset required for your project will be created from the answers you give to the following questions. The system will generate only those questions and sections which (a) apply to your study type and (b) are required by the bodies reviewing your study. Please ensure you answer all the questions before proceeding with your applications.

Please enter a short title for this project (maximum 70 characters)

People's experiences of living with a personality disorder diagnosis

1. Is your project research?

☒ Yes ☐ No

2. Select one category from the list below:

- ☐ Clinical trial of an investigational medicinal product
- ☐ Clinical investigation or other study of a medical device
- ☐ Combined trial of an investigational medicinal product and an investigational medical device
- ☐ Other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice
- ☐ Basic science study involving procedures with human participants
- ☐ Study administering questionnaires/interviews for quantitative analysis, or using mixed quantitative/qualitative methodology
- ☒ Study involving qualitative methods only
- ☐ Study limited to working with human tissue samples (or other human biological samples) and data (specific project only)
- ☐ Study limited to working with data (specific project only)
- ☐ Research tissue bank
- ☐ Research database

If your work does not fit any of these categories, select the option below:

☐ Other study

2a. Please answer the following question(s):

- a) Does the study involve the use of any ionising radiation? ☐ Yes ☒ No
- b) Will you be taking new human tissue samples (or other human biological samples)? ☐ Yes ☒ No
- c) Will you be using existing human tissue samples (or other human biological samples)? ☐ Yes ☒ No

3. In which countries of the UK will the research sites be located? (Tick all that apply)

- ☐ England
- ☐ Scotland
- ☒ Wales
- ☐ Northern Ireland

3a. In which country of the UK will the lead NHS R&D office be located:

- ☐ England
☐ Scotland
☒ Wales
☐ Northern Ireland
☐ This study does not involve the NHS

4. Which review bodies are you applying to?

- ☒ NHS/HSC Research and Development offices
☐ Social Care Research Ethics Committee
☒ Research Ethics Committee
☐ National Information Governance Board for Health and Social Care (NIGB)
☒ National Offender Management Service (NOMS) (Prisons & Probation)

For NHS/HSC R&D offices, the CI must create Site-Specific Information Forms for each site, in addition to the study-wide forms, and transfer them to the PIs or local collaborators.

5. Will any research sites in this study be NHS organisations?

- ☒ Yes ☐ No

6. Do you plan to include any participants who are children?

- ☐ Yes ☒ No

7. Do you plan at any stage of the project to undertake intrusive research involving adults lacking capacity to consent for themselves?

- ☐ Yes ☒ No

Answer Yes if you plan to recruit living participants aged 16 or over who lack capacity, or to retain them in the study following loss of capacity. Intrusive research means any research with the living requiring consent in law. This includes use of identifiable tissue samples or personal information, except where application is being made to the NIGB Ethics and Confidentiality Committee to set aside the common law duty of confidentiality in England and Wales. Please consult the guidance notes for further information on the legal frameworks for research involving adults lacking capacity in the UK.

8. Do you plan to include any participants who are prisoners or young offenders in the custody of HM Prison Service or who are offenders supervised by the probation service in England or Wales?

- ☒ Yes ☐ No

9. Is the study or any part of it being undertaken as an educational project?

- ☒ Yes ☐ No

Please describe briefly the involvement of the student(s):

This research is being undertaken as part of the researcher's Doctorate in Clinical Psychology at the North Wales Clinical Psychology Programme.

9a. Is the project being undertaken in part fulfilment of a PhD or other doctorate?

- ☒ Yes ☐ No

10. Will this research be financially supported by the United States Department of Health and Human Services or any of

its divisions, agencies or programs?

☐ Yes ☒ No

11. Will identifiable patient data be accessed outside the care team without prior consent at any stage of the project (including identification of potential participants)?

☐ Yes ☒ No



Ministry of JUSTICE

National Offender
Management Service

APPLICATION FORM TO UNDERTAKE RESEARCH ACROSS NOMS

1. Full title of the research:

People's experiences of living with a personality disorder diagnosis: A perspective from individuals within the Probation Service

3. Date of request:

4. The following categories are the NOMS Research Strategic Priorities.

Please tick the one that best applies to the research you are requesting:

- ☐ Decency
- ☐ Diversity & Equality
- ☐ Organisational Effectiveness
- ☐ Public Protection
- ☐ Offender Management and Reducing Re-offending
- ☐ Security
- ☐ Maintaining Order and Control
- ☐ Physical Health
- ☒ Mental Health

4. Are you targeting specific groups?

☒ Yes ☐ No

If yes please specify which groups you are targeting and specify approximate numbers for each

group: Number

- | | | |
|---|-------------------------------------|----|
| Women | <input type="checkbox"/> | |
| Male | <input type="checkbox"/> | |
| Young People (under 18) | <input type="checkbox"/> | |
| Young Offenders (18-21) | <input type="checkbox"/> | |
| Sex Offenders | <input type="checkbox"/> | |
| Violent Offenders | <input type="checkbox"/> | |
| Self Harm | <input type="checkbox"/> | |
| Domestic Violence | <input type="checkbox"/> | |
| Extremism* / Radicalism | <input type="checkbox"/> | |
| Staff | <input type="checkbox"/> | |
| Religious Groups | <input type="checkbox"/> | |
| <i>Please identify which religious group(s)</i> | | |
| Other | <input checked="" type="checkbox"/> | 10 |

Please specify:

Individuals with a diagnosis of personality disorder

* If you are targeting Extremist Offenders please refer to the NOMS policy on access to extremist offenders before submitting

your application.

5. Chief Investigator:

	Title	Forename/Initials	Surname
	Miss	Emma	Lloyd
Post	Trainee Clinical Psychologist		
Qualifications	BSc (Hons) Psychology and Criminology		
Employer	Betsi Cadwaladr University Health Board		
Work Address	North Wales Clinical Psychology Programme School of Psychology, 43 College Road, Bangor, Gwynedd		
Post Code	LL57 2DG		
Work E-mail	psp0da@bangor.ac.uk		
* Personal E-mail			
Work Telephone	07792104873		
* Personal Telephone/Mobile			
Fax			

6. Other key investigators/collaborators. Please include all grant co-applicants, protocol co-authors and other key members of the Chief Investigator's team, including non-doctoral student researchers.

	Title	Forename/Initials	Surname
	Dr	Robin	Owen
Post	Clinical Psychologist		
Qualifications	D.Clin.Psy		
Employer	Betsi Cadwaladr University Health Board		
Work Address	North Wales Forensic Psychiatric Service Ty Llywelyn MSU Bryn y Neuadd Hospital, Llanfairfechan		
Post Code	LL33 0HH		
Telephone	01248 682 133		
Fax			
Mobile			
Work Email	Robin.Owen2@wales.nhs.uk		

	Title	Forename/Initials	Surname
	Dr	James	Lea
Post	Clinical Psychologist		
Qualifications	D.Clin.Psy		
Employer	North Wales Clinical Psychology Programme		
Work Address	North Wales Clinical Psychology Programme School of Psychology, Bangor University Bangor, Gwynedd		
Post Code	LL57 2DG		
Telephone	01248383890		
Fax			
Mobile			
Work Email	j.lea@bangor.ac.uk		

	Title Forename/Initials Surname
	Dr Julia Wane
Post	Consultant Clinical Psychologist
Qualifications	D.Clin.Psy
Employer	Betsi Cadwaladr University Health Board
Work Address	North Wales Forensic Psychiatric Service
	Ty Llywelyn MSU
	Bryn y Neuadd Hospital, Llanfairfechan
Post Code	LL33 0HH
Telephone	01248682133
Fax	
Mobile	
Work Email	Julia.Wane@wales.nhs.uk

7. Student (please refer to the Prison Service Order for information on students eligible to apply).

Educational projects

Name and contact details of student(s):

Student 1

	Title Forename/Initials Surname
	Miss Emma Lloyd
Address	North Wales Clinical Psychology Programme
	School of Psychology, 43 College Road,
	Bangor, Gwynedd
Post Code	LL57 2DG
E-mail	psp0da@bangor.ac.uk
Telephone	07792104873
Fax	

Give details of the educational course or degree for which this research is being undertaken:

Name and level of course/ degree:

This research is being undertaken as part of a Doctorate in Clinical Psychology (D.Clin.Psy).

Name of educational establishment:

North Wales Clinical Psychology Programme.

Name and contact details of academic supervisor(s):

Academic supervisor 1

	Title Forename/Initials Surname
	Dr Robin Owen
Address	North Wales Forensic Psychiatric Service
	Ty Llywelyn MSU
	Bryn y Neuadd Hospital, Llanfairfechan
Post Code	LL33 0HH
E-mail	Robin.Owen2@wales.nhs.uk
Telephone	01248 682 133

Fax

Academic supervisor 2

Title Forename/Initials Surname
 Dr James Lea
 Address North Wales Clinical Psychology Programme
 School of Psychology, Bangor University
 Bangor, Gwynedd
 Post Code LL57 2DG
 E-mail j.lea@bangor.ac.uk
 Telephone 01248 383890
 Fax

Academic supervisor 3

Title Forename/Initials Surname
 Dr Julia Wane
 Address North Wales Forensic Psychiatric Service
 Ty Llywelyn MSU
 Bryn y Neuadd Hospital, Llanfairfechan
 Post Code LL33 0HH
 E-mail Julia.Wane@wales.nhs.uk
 Telephone 01248682133
 Fax

Please state which academic supervisor(s) has responsibility for which student(s):

Please click "Save now" before completing this table. This will ensure that all of the student and academic supervisor details are shown correctly.

Student(s)	Academic supervisor(s)
Student 1 Miss Emma Lloyd	<input checked="" type="checkbox"/> Dr Robin Owen <input checked="" type="checkbox"/> Dr James Lea <input checked="" type="checkbox"/> Dr Julia Wane

Please attach a CV for all researchers.

8. Has external funding for the research been secured?

- ☐ Funding secured from one or more funders
☐ External funding application to one or more funders in progress
☒ No application for external funding will be made

What type of research project is this?

- ☒ Standalone project
☐ Project that is part of a programme grant
☐ Project that is part of a Centre grant
☐ Project that is part of a fellowship/ personal award/ research training award
☐ Other

Other – please state:

9. Does your research cover:

- ☐ Prisons
- ☒ Probation
- ☐ Both Prisons & Probation

10. Please select each region and then select the establishments / offices within those regions where you wish to conduct the research:

- ☐ North West
- ☐ North East
- ☐ East Midlands
- ☐ East of England
- ☐ Greater London
- ☐ Kent & Sussex
- ☐ South Central
- ☐ Yorkshire & Humberside
- ☐ South West
- ☐ West Midlands
- ☐ High Security
- ☒ Wales ☒ Wales Probation Trust
- ☐ Establishment(s) / Office(s) not known at this stage

11. Please advise when the outcomes are required by (and whether there are any critical deadlines when information from this research is required):

It is hoped that data collection will begin in the spring/summer of 2014, to allow sufficient time for data analysis and write-up. The deadline for the completion of the research is June 2015, where it will be submitted to the North Wales Clinical Psychology Programme.

12. How long do you expect the study to last in the UK?

Planned start date: 03/03/2014

Planned end date: 30/06/2015

Total duration:

Years: 1 Months: 3 Days: 28

Research Aims & Objectives

13. Summary of the study. Please provide a brief summary of the research (maximum 300 words) using language easily understood by lay reviewers and members of the public. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, this summary will be published on the website of the National Research Ethics Service following the ethical review.

Personality disorders are controversial diagnoses, provoking heated debate among people with personal experience of these diagnoses, mental health staff, researchers and policy makers. The debate surrounding psychiatric diagnosis has recently been highlighted in a position statement released by the British Psychological Society, Division of Clinical Psychology (DCP, BPS, 2013). They argue that functional psychiatric diagnoses, including personality

disorders, have limited reliability and questionable validity, and serve to medicalise distress. Psychiatric diagnoses can have negative implications for service users, such as stigma, discrimination and low self esteem, therefore it is important to explore how service users experience living with the diagnostic label of 'personality disorder'. However, qualitative studies investigating the experiences of individuals diagnosed with personality disorder are limited, and only one study has explored the experiences of individuals with forensic histories. There has been no such research undertaken with individuals under the management of the probation service, or in rural areas such as North Wales.

The present study aims to contribute to the literature, giving a voice to a group of people who experience particular difficulties and discrimination. It is important to understand how individuals experience these labels, in order to develop ways of offering support. It will hope to gain an in-depth account of how a diagnosis of personality disorder has impacted on the individual's identity, relationships, and behaviour in the context of living in a rural area.

14. What is the scientific justification for the research? *Please put this in language comprehensible to a lay person.*

The debate surrounding psychiatric diagnosis has been highlighted in a recent position statement released by the Division of Clinical Psychology (DCP, BPS, 2013). It is argued that functional psychiatric diagnoses, including personality disorders, have limited reliability and questionable validity, and medicalise distress. Their report highlights the significant impact of psychiatric diagnoses on service users' lives. This can be through discrimination due to negative social attitudes towards those with a psychiatric diagnosis, which can create and compound social exclusion. A further issue is that of stigmatisation and negative impact on identity, in that the language of disorder and deficit can negatively shape a person's outlook on life, and their identity and self-esteem. Due to the negative implications of psychiatric diagnoses for service users, it is important to explore how service users experience living with the diagnostic label of 'personality disorder'.

Previous research:

Qualitative studies investigating the experiences of individuals living with personality disorder are limited, and none has been undertaken in individuals under the management of probation services. Four studies have been identified that have explored people's experiences of living with a personality disorder diagnosis (Nehls, 1999; Ramon, Castillo and Morant, 2001; Stalker, Ferguson and Barclay, 2005; Horn, Johnstone & Brooke, 2007). These studies interviewed individual's without a history of offending behaviours. One recent study has explored experience of having a personality disorder diagnosis within the context of forensic secure and community services (Black, Thornicroft & Murray, 2012).

Proposed research:

The present study aims to contribute to the growing literature, giving a voice to a group of people who experience particular difficulties and discrimination. It is important to understand how individuals experience these labels, in order to develop ways of offering support. This research will focus on the experiences of individuals who have a personality disorder diagnosis living in the community, who are under the management of probation services. Research has not been undertaken in this population previously. This is important to explore as research has indicated that about half of individuals under the management of probation services meet the criteria for a diagnosis of a personality disorder (Brooker et al, 2012). People with personality disorder are discriminated against with access to services often denied, because they are stigmatised and regarded as a more difficult group with whom to work (Newton-Howes, 2008). The failure to focus appropriately on issues relating to personality disorder is a barrier to the NHS and National Offender Management Service meeting its objectives of health improvement and public protection (Department of Health, 2010).

This research will also differ from previous research in that participants will be living in rural Welsh communities. It will hope to gain an in depth account of how a diagnosis of personality disorder has impacted on their identity and relationships, in the context of living in a rural area.

15. What is the principal research question/objective? *Please put this in language comprehensible to a lay person.*

What are the experiences of people who have been diagnosed with a 'personality disorder'?

16. What are the secondary research questions/objectives if applicable? *Please put this in language comprehensible to a lay person.*

5. How have people made sense of the diagnosis?

6. How has this diagnosis impacted on their relationships, identity, understanding of their behaviour, and opportunities in life?

17. What are the potential benefits of the research?

To NOMS:

To gain a detailed understanding of the experiences of individual's diagnosed with a personality disorder diagnosis under the management of the probation service in Wales. This could inform the development of future practices in relation to this group of people.

To academic knowledge in the field of study:

This aims to contribute to the growing literature in this field, giving a voice to a group of people who experience particular difficulties and discrimination. As a stigmatised and marginalised group of people, it is important to understand how individuals' experience these labels in order to develop ways of supporting this group.

Research Plan & Methodology

18. Broadly speaking, what type of methodology do you intend to use in order to deliver this research:

- ☐ Literature review
- ☐ Rapid evidence assessment / systematic review
- ☐ Secondary data analysis
- ☐ Primary quantitative approach
- ☒ Primary qualitative approach
- ☐ Experimental / quasi-experimental
- ☐ Economic analysis
- ☐ Other

19. Please summarise your design and methodology. *It should be clear exactly what will happen to the research participant, how many times and in what order. Please complete this section in language comprehensible to the lay person. Do not simply reproduce or refer to the protocol. Further guidance is available in the guidance notes.*

Participant recruitment:

Participants will be people aged between 25 and 50 years who have been formally diagnosed with a personality disorder, and have lived with this diagnosis for at least two years. They will be currently under the management of the probation service in North Wales. If not enough participants can be recruited through the probation service, then participants will be recruited from the forensic outpatient service at Ty Llywelyn Medium Secure Unit.

The individual's probation officer or care coordinator will inform the potential participant about the study. Information sheets will then be sent to people who wish to know more. They will be provided with the opportunity to contact the researcher to discuss the research. The person will be given up to 2 weeks to decide about whether to participate.

Design and procedures:

A qualitative research design has been selected, as it will capture the richness of the lived experience of participants. Qualitative research has been recognised as an important contributor to empirical evidence bases (Dixon Woods & Fitzpatrick, 2001). There are a number of different methods within qualitative designs but interpretive phenomenological analysis (IPA) has been selected as it focuses on the lived experience of individuals and how they make sense of a given phenomenon (Smith, Flowers, & Larkin, 2010) and is therefore the most relevant to answering the research questions.

A semi-structured interview will be conducted with participants, focusing on their experience of living with a diagnosis of personality disorder. It is anticipated these interviews will last up to an hour. Interviews will take place in either the probation services offices or Ty Llywelyn Medium Secure Unit. Interviews will take place with the participant and researcher alone to ensure participants feel safe to discuss their experiences freely. Interviews will be digitally recorded, immediately transferred to a password protected laptop and transcribed by the researcher. Once transcribed the data will be anonymised.

Measures

The semi-structured interview schedule will be drawn up with the research supervisors: Dr Robin Owen, Dr James Lea and Dr Julia Wane. The interview will begin with collecting demographic data including participants' age, gender, ethnicity, diagnosis, and time since diagnosis.

The interview will then cover themes of experience of living with diagnosis, relationships with family and friends, and identity. The interview will be flexible, open, and participant led to facilitate the collection of rich data.

Data management and analysis

Digital recordings will be immediately transferred to a password protected laptop where the anonymised transcriptions will also be stored. Interpretive phenomenological analysis (IPA; Smith, Flowers, and Larkin, 2010) has been selected as the qualitative research method as it captures the lived experience of individuals and how they make sense of particular phenomena, such as a diagnosis of personality disorder. IPA also allows the interview schedule to be used flexibly, which will mean the data collected will capture the richest and most important aspects of the participant's lived experience.

The researcher will transcribe the interviews verbatim to aid the analysis process. Transcripts will be analysed using guidelines by Smith, Flowers, and Larkin, 2010.

20. Please select the following as appropriate, and give as much detail about data collection methods as possible. (Where relevant, attach references for instruments or drafts of questionnaires etc.)

- ☐ Case records
- ☐ Interviews
- ☐ Observation

Questionnaires (please tick the type below and complete further details)

- ☐ Self completion
- ☐ Administration by researcher
- ☐ Postal
- ☐ Web based
- ☐ Other

Research Analysis & Dissemination

21. Please describe the methods of analysis (statistical or other appropriate methods, e.g. for qualitative research) by which the data will be evaluated to meet the study objectives.

The present study aims to better understand and explore people's experiences of living with a personality disorder diagnosis using Interpretive Phenomenological Analysis (IPA; Smith, Flowers, and Larkin, 2010). IPA is a qualitative methodology which explores in detail 'personal lived experience and how participants make sense of that experience'. Each interview will be audio recorded and then transcribed. IPA allows the interview schedule to be used flexibly, which will mean the data collected will capture the richest and most important aspects of the participant's lived experiences. Analysis will involve careful examination of these transcripts, and themes will be generated from the text. Theme generation will focus on capturing the essence of each individual participant's personal experience, in relation to their personality disorder diagnosis. When each transcript has been considered individually and themes generated, comparisons will be made between the themes of each of the transcripts.

22. Will the research include a reconviction study? (If yes please state how this will be conducted)

- ☐ Yes ☒ No

NB. The body reviewing an application, which includes a reconviction element, should forward it to the Re-offending and

Criminal Career Statistics team in OMS Analytical Services in the Ministry of Justice.

23. For how long will you store research data generated by the study?

Years: 5

Months:

24-1. How do you intend to report and disseminate the results of the study? Tick as appropriate:

- ☒ Peer reviewed scientific journals
- ☐ Internal report
- ☒ Conference presentation
- ☐ Publication on website
- ☐ Other publication
- ☐ Submission to regulatory authorities
- ☐ Access to raw data and right to publish freely by all investigators in study or by Independent Steering Committee on behalf of all investigators
- ☐ No plans to report or disseminate the results
- ☐ Other (please specify)

24-2. Please state how the results will be made available for NOMS:

A copy of the final report will be made available.

Research Ethics

25. Summary of main issues. *Please summarise the main ethical and design issues arising from the study and say how you have addressed them.*

During the interview process, participants may describe difficult life experiences. As such there is the potential for the participants to become distressed during interview. The researcher will be sensitive to the emotional state of the participant at all times during the project and be flexible in taking breaks or stopping the interview completely if the participant becomes distressed. The researcher is a trainee clinical psychologist and has the skills necessary to manage high levels of emotion or distress. Participants will be fully debriefed following the interview and encouraged to seek support from their probation officer or care coordinator if they require further support.

To ensure that participants do not have unrealistic expectations of the research, they will be informed that despite the research being undertaken by a trainee clinical psychologist, the aim of the interview is not to provide therapy.

Participants will be under the management of the probation service or forensic service, therefore will have a history of offending behaviours. It is possible that individuals' may disclose criminal behaviour for which they have not been prosecuted. Prior to the interview commencing, the limits of confidentiality will be explained to the participant. They will be informed that if they do disclose such information then the researcher has a duty to pass this on to their probation officer or care coordinator.

A small monetary thank you will be provided to participants to recognise the time given to the research. Grant and Sugarman (2004) suggest that incentives become ethically inappropriate if they unduly influence the decision to participate, act as a coercive inducement, or compromise the dignity of participants. It is also felt that it is ethically questionable not to recognise participation in a time consuming project. A £10 voucher is deemed an appropriate amount as it is small enough to not be coercive, will be explained in the information sheet that it is a thank you for participation to ensure no loss of dignity, and is in line with BCUHB policy.

26. Details of REC application

Name of REC	REC for Wales
Address	Sixth Floor, Churchill House 17 Churchill Way, Cardiff, CF10 2TW
E-mail	corinne.scott@wales.nhs.uk
REC Reference number	
Copy of REC opinion	<input type="radio"/> Enclosed <input checked="" type="radio"/> To follow

27. I confirm that the research will comply with the Statement of Professional Principles as detailed in relevant Prison Service Orders and Prison Service Instructions (<http://www.hmprisonservice.gov.uk/resourcecentre/psispsos/>) and that only one application will be sent to the National Offender Management System.

This section was signed electronically by Miss Emma Lloyd on 07/04/2014 18:30.

Job Title/Post:	Trainee Clinical Psychologist
Organisation:	North Wales Clinical Psychology Programme
Email:	psp0da@bangor.ac.uk

Email confirming approval from NOMS

Received on the 09.05.14

Good morning

I can confirm that we have reviewed the project proposal and are in a position to support this project.

Kind regards

Eleanor

Eleanor Worthington
Research and Evaluation Officer
Public Protection and Service Development (PPSD) Team
Wales Probation Trust
33 Westgate Street
Cardiff
CF10 1JE
Mob:07794 240560

Unless otherwise stated, the contents of this email are classified as RESTRICTED

NOMS confirmation of access letter

FE DDARPARWN EIN GWASANAETH I CHI YN EICH DEWIS IAITH
 WE WILL PROVIDE OUR SERVICE IN THE LANGUAGE OF YOUR CHOICE

33 HEOL Y PORTH / 33 WESTGATE ST
 CAERDYDD / CARDIFF
 CF10 1JE
 FFON / TEL: 02920 785015

Prawf Cymru
Wales Probation

**CYFYNGEDIG / RESTRICTED**

Our Ref: IB/EW

2nd December 2013

Dear Dr Robin Owen

Thank-you for your application to undertake Personality Disorder research with us.

I have now had the opportunity to review the relevant instructions regarding research applications. I am pleased to advise that we are happy to accept your proposal.

The Practice and Performance Committee meets on a quarterly basis and there would be an expectation that you provide updates to the committee regarding the progress of your research. Wales Probation Trust also requires that the scope of the research is not altered without prior agreement through the Practice and Performance Committee.

If you have any queries then please don't hesitate to contact our Research and Evaluation Officer, Eleanor Worthington. Her contact details are eleanor.worthington@wales.probation.gsi.gov.uk, 07794 240 560.

Yours sincerely

Ian Barrow
Director of Operations

Ethics Amendment 1

After being granted ethical approval in June of 2014, I attempted to recruit participants from within the probation service. However, by November of 2014 on only two people had been identified and agreed to participate. It was therefore decided by the research team that the inclusion criteria would need to be widened to recruit a sufficient number of participants. The amendment sought to recruit people from within Community Mental Health Teams and Community Rehabilitation Teams who had previously been in receipt of forensic services or probation services.

Amendment 1: Approval email from University Ethics

Received on 16.10.14

Dear Emma Laura Catherine,

2013-11884-A12207 Amendment to People's experiences of living with a personality disorder diagnosis in the Probation Service.

Your research proposal number 2013-11884-A12207 has been reviewed by the School of Psychology Ethics and Research Committee and the committee are now able to confirm ethical and governance approval for the above research on the basis described in the application form, protocol and supporting documentation. This approval lasts for a maximum of three years from this date.

Ethical approval is granted for the study as it was explicitly described in the application

If you wish to make any non-trivial modifications to the research project, please submit an amendment form to the committee, and copies of any of the original documents reviewed which have been altered as a result of the amendment. Please also inform the committee immediately if participants experience any unanticipated harm as a result of taking part in your research, or if any adverse reactions are reported in subsequent literature using the same technique elsewhere.

Governance approval is granted for the study as it was explicitly described in the application and we are happy to confirm that this study is now covered by the University's indemnity policy.

If any new researchers join the study, or any changes are made to the way the study is funded, or changes that alter the risks associated with the study, then please submit an amendment form to the committee.

Yours sincerely

Everil McQuarrie

Amendment 1: IRAS form

Notice of Amendment

IRAS Version 3.5

Welcome to the Integrated Research Application System
IRAS Project Filter
<p>The integrated dataset required for your project will be created from the answers you give to the following questions. The system will generate only those questions and sections which (a) apply to your study type and (b) are required by the bodies reviewing your study. Please ensure you answer all the questions before proceeding with your applications.</p>
<p>Please enter a short title for this project (maximum 70 characters) People's experiences of living with a personality disorder diagnosis</p>
<p>1. Is your project research?</p> <p><input checked="" type="radio"/> Yes <input type="radio"/> No</p>
<p>2. Select one category from the list below:</p> <p> <input type="radio"/> Clinical trial of an investigational medicinal product <input type="radio"/> Clinical investigation or other study of a medical device <input type="radio"/> Combined trial of an investigational medicinal product and an investigational medical device <input type="radio"/> Other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice <input type="radio"/> Basic science study involving procedures with human participants <input type="radio"/> Study administering questionnaires/interviews for quantitative analysis, or using mixed quantitative/qualitative methodology <input checked="" type="radio"/> Study involving qualitative methods only <input type="radio"/> Study limited to working with human tissue samples (or other human biological samples) and data (specific project only) <input type="radio"/> Study limited to working with data (specific project only) <input type="radio"/> Research tissue bank <input type="radio"/> Research database </p> <p>If your work does not fit any of these categories, select the option below:</p> <p><input type="radio"/> Other study</p>
<p>2a. Please answer the following question(s):</p> <p> a) Does the study involve the use of any ionising radiation? <input type="radio"/> Yes <input checked="" type="radio"/> No b) Will you be taking new human tissue samples (or other human biological samples)? <input type="radio"/> Yes <input checked="" type="radio"/> No c) Will you be using existing human tissue samples (or other human biological samples)? <input type="radio"/> Yes <input checked="" type="radio"/> No </p>
<p>3. In which countries of the UK will the research sites be located? <i>(Tick all that apply)</i></p> <p> <input type="checkbox"/> England <input type="checkbox"/> Scotland <input checked="" type="checkbox"/> Wales <input type="checkbox"/> Northern Ireland </p> <p>3a. In which country of the UK will the lead NHS R&D office be located:</p>

Notice of Amendment

IRAS Version 3.5

- ☐ England
☐ Scotland
☒ Wales
☐ Northern Ireland
☐ This study does not involve the NHS

4. Which review bodies are you applying to?

- ☒ NHS/HSC Research and Development offices
☐ Social Care Research Ethics Committee
☒ Research Ethics Committee
☐ National Information Governance Board for Health and Social Care (NIGB)
☒ National Offender Management Service (NOMS) (Prisons & Probation)

For NHS/HSC R&D offices, the CI must create Site-Specific Information Forms for each site, in addition to the study-wide forms, and transfer them to the PIs or local collaborators.

5. Will any research sites in this study be NHS organisations?

- ☒ Yes ☐ No

6. Do you plan to include any participants who are children?

- ☐ Yes ☒ No

7. Do you plan at any stage of the project to undertake intrusive research involving adults lacking capacity to consent for themselves?

- ☐ Yes ☒ No

Answer Yes if you plan to recruit living participants aged 16 or over who lack capacity, or to retain them in the study following loss of capacity. Intrusive research means any research with the living requiring consent in law. This includes use of identifiable tissue samples or personal information, except where application is being made to the NIGB Ethics and Confidentiality Committee to set aside the common law duty of confidentiality in England and Wales. Please consult the guidance notes for further information on the legal frameworks for research involving adults lacking capacity in the UK.

8. Do you plan to include any participants who are prisoners or young offenders in the custody of HM Prison Service or who are offenders supervised by the probation service in England or Wales?

- ☒ Yes ☐ No

9. Is the study or any part of it being undertaken as an educational project?

- ☒ Yes ☐ No

Please describe briefly the involvement of the student(s):
 This research is being undertaken as part of the researcher's Doctorate in Clinical Psychology at the North Wales Clinical Psychology Programme.

9a. Is the project being undertaken in part fulfilment of a PhD or other doctorate?

- ☒ Yes ☐ No

10. Will this research be financially supported by the United States Department of Health and Human Services or any of

Notice of Amendment

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its divisions, agencies or programs?

☐ Yes ☒ No

11. Will identifiable patient data be accessed outside the care team without prior consent at any stage of the project (including identification of potential participants)?

☐ Yes ☒ No

NOTICE OF SUBSTANTIAL AMENDMENT

Please use this form to notify the main REC of substantial amendments to all research other than clinical trials of investigational medicinal products (CTIMPs).

The form should be completed by the Chief Investigator using language comprehensible to a lay person.

Details of Chief Investigator:

	Title Forename/Initials Surname
	Miss Emma Lloyd
Work Address	North Wales Clinical Psychology Programme School of Psychology, 43 College Road, Bangor, Gwynedd
PostCode	LL57 2DG
Email	psp0da@bangor.ac.uk
Telephone	07792104873
Fax	

Full title of study:	People's experiences of living with a personality disorder diagnosis: A perspective from individuals within the Probation Service
Lead sponsor:	Bangor University School of Psychology
Name of REC:	Wales REC 3
REC reference number:	14/WA/0144
Name of lead R&D office:	Betsi Cadwaladr University Health Board
Date study commenced:	13.06.14
Protocol reference (if applicable), current version and date:	
Amendment number and date:	Amendment number 1 14.10.14

Type of amendment

(a) Amendment to information previously given in IRAS

☒ Yes ☐ No

If yes, please refer to relevant sections of IRAS in the "summary of changes" below.

(b) Amendment to the protocol

☐ Yes ☒ No

If yes, please submit either the revised protocol with a new version number and date, highlighting changes in bold, or a document listing the changes and giving both the previous and revised text.

(c) Amendment to the information sheet(s) and consent form(s) for participants, or to any other supporting

documentation for the study

☐ Yes ☒ No

If yes, please submit all revised documents with new version numbers and dates, highlighting new text in bold.

Is this a modified version of an amendment previously notified and not approved?

☐ Yes ☒ No

Summary of changes

Briefly summarise the main changes proposed in this amendment. Explain the purpose of the changes and their significance for the study.

If this is a modified amendment, please explain how the modifications address the concerns raised previously by the ethics committee.

If the amendment significantly alters the research design or methodology, or could otherwise affect the scientific value of the study, supporting scientific information should be given (or enclosed separately). Indicate whether or not additional scientific critique has been obtained.

Since gaining ethical approval for my research in June of this year, I have been attempting to recruit participants from the North Wales Probation Service. Despite numerous emails, phone calls and meetings with probation officers it has not been possible to identify any participants who meet the criteria, as most people under their management have been identified as having a Personality Disorder however do not have a formal diagnosis. The other group of participants for which I received ethical approval for recruitment is people within the North Wales Forensic Outpatient Service. At present there are only two people who have been identified within this service who meet the criteria. I am currently approaching these individuals to see if they would like to participate. However, there are not enough individuals within this service to fulfil my requirement for 6-8 participants.

My research supervisor Dr Robin Owen (Clinical Psychologist, North Wales Forensic Psychology Service) has identified potential participants from within community services who have previously been the recipients of forensic services. These individuals are currently within Community Mental Health Teams and within Community Rehabilitation Teams across North Wales. Preliminary discussions with individuals from within these services (CRT managers) have identified approximately 15 potential participants to date who meet the criteria.

I am requesting that my ethical approval is extended to include people from within these populations. In doing this my sample will continue to consist of people with a diagnosis of a personality disorder with a forensic history living in the community, and therefore will not have an impact on my research question. There has only been one previous study exploring the impact of a personality disorder diagnosis on individuals with a forensic history (Black, Thornicroft & Murray, 2013) however this sample largely consisted of individuals within a medium secure unit. This study will focus on people within the community and therefore will aim to offer a different insight into the experiences of individuals with a personality disorder diagnosis and forensic history. The recruitment process will remain the same: the individual will be identified by their care-coordinator or key worker. They will approach the individual with details of the research and if the person is interested in participating they can be provided with a participant information sheet and can contact me through the details provided. If they would rather be contacted by me then they can consent to their care coordinator or key worker passing on their contact details. We can then discuss the research further and arrange an interview. Depending on the participant's location, an appropriate location will be identified to conduct an interview such as the Community Rehabilitation Team base or Community Mental Health Team Building.

Any other relevant information

Applicants may indicate any specific issues relating to the amendment, on which the opinion of a reviewing body is sought.

List of enclosed documents

Document	Version	Date
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Declaration by Chief Investigator

1. I confirm that the information in this form is accurate to the best of my knowledge and I take full responsibility

Notice of Amendment

IRAS Version 3.5

- for it.
2. *I consider that it would be reasonable for the proposed amendment to be implemented.*

This section was signed electronically by Miss Emma Lloyd on 24/10/2014 13:06.

Job Title/Post: Trainee Clinical PSychologist
 Organisation: NWCPP
 Email: psp0da@bangor.ac.uk

Declaration by the sponsor's representative

I confirm the sponsor's support for this substantial amendment.

This section was signed electronically by Mr Hefin Francis on 24/10/2014 14:29.

Job Title/Post: Manager of School of Psychology
 Organisation: Bangor University
 Email: h.francis@bangor.ac.uk

Amendment 1: REC validation letter

Part of the research infrastructure for Wales funded by the National Institute for Social Care and Health Research, Welsh Government.
Yn rhan o seilwaith ymchwil Cymru a ariannir gan y Sefydliad Cenedlaethol ar gyfer Ymchwil Gofal Cymdeithasol ac Iechyd, Llywodraeth Cymru



Wales REC 3
Sixth Floor, Churchill House
17 Churchill Way
Cardiff CF10 2TW

Telephone : 029 2037 6829
Fax : 029 2037 6824
E-mail : corinne.scott@wales.nhs.uk
Website : www.hra.nhs.uk

18 November 2014

Miss Emma Lloyd
Trainee Clinical Psychologist
Betsi Cadwaladr University Health Board
North Wales Clinical Psychology Programme
School of Psychology, 43 College Road,
Bangor LL57 2DG

Dear Miss Lloyd

Study title: People's experiences of living with a personality disorder
diagnosis: A perspective from individuals within the Probation
Service
REC reference: 14/WA/0144
Amendment number: 1
Amendment date: 14 October 2014
IRAS project ID: 145859

The above amendment was reviewed at the meeting of the Committee held on 13 November 2014.

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Notice of Substantial Amendment (non-CTIMP)	1	14 October 2014

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

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 <http://www.hra.nhs.uk/hra-training/>

14/WA/0144: Please quote this number on all correspondence



Cynhelir Cylweithrediad Gwyddor Iechyd Academiaidd y Sefydliad Cenedlaethol ar gyfer Ymchwil Gofal Cymdeithasol ac Iechyd gan Fwrdd Addysgu Iechyd Powys
The National Institute for Social Care and Health Research Academic Health Science
Collaboration is hosted by Powys Teaching Health Board



Yours sincerely



pp **Dr Pete Wall**
Chair

E-mail: corinne.scott@wales.nhs.uk

Enclosures: List of names and professions of members who took part in the review

Copy to: Dr Rossela Roberts, Betsi Cadwaladr University Health Board
Mr Hefin Francis

Wales REC 3

Attendance at Committee meeting on 13 November 2014

Committee Members:

Name	Profession	Present	Notes
Dr Gail Boniface	Occupational Therapist	Yes	
Professor Kate Bullen	Psychologist	Yes	
Mrs Joy Darch	Nurse	Yes	
Mr Terry Eastham	Lay Plus member	Yes	
Ms Nicola Heales	Lay Plus member	Yes	
Mr HAO Hughes	Pharmacist	Yes	
Ms Paula Strong	Nurse	Yes	
Mrs Wendy Turkie	Retired nurse	Yes	
Dr Richard Walker	Lay Plus member	Yes	
Dr Pete Wall	Chair / Clinical Physiologist	Yes	
Mr Stewart Williams	Lay Plus member	Yes	

Also in attendance:

Name	Position (or reason for attending)
Dr Corinne Scott	NISCHR RES Manager
Mrs Helen Williams	NISCHR REC Coordinator

Written comments – not regarding this amendment - received from:

Name	Position
Dr Meriel Jenney	Hospital consultant (Paediatric oncologist)

Amendment 1: R&D validation letter



Bwrdd Iechyd Prifysgol
Betsi Cadwaladr
University Health Board

Panel Arolygu Mewnol Y&D R&D Internal Review Panel

Betsi Cadwaladr University Health Board
Ysbyty Gwynedd
Clinical Academic Office
Bangor, Gwynedd
LL57 2PW

Miss Emma Lloyd
Trainee Clinical Psychologist
North Wales Clinical Psychology Programme
School of Psychology
Bangor University
LL57 2DG

psp0da@bangor.ac.uk

Chairman/Cadeirydd - Dr. Nefyn Williams PhD, FRCGP
Email: rossela.roberts@wales.nhs.uk
wendy.scrase2@wales.nhs.uk
sion.lewis@wales.nhs.uk
Tel/Fax: 01248 384 877

18 November 2014

Dear Miss Lloyd,

Re: Minor Amendment 1 dated 14 October 2014

Study Title People's experiences of living with a personality disorder diagnosis: A perspective from individuals within the Probation Service
R&D reference 145859

The Panel does not consider this to be a "substantial amendment" as defined in the Research Governance Framework.
The amendment does not therefore require an opinion from the Panel and may be implemented immediately, as it does not affect the R&D approval previously given to this research.

The documents received were as follows:

Documents reviewed:	Version	Date
Notice of Amendment Form	-	-
REC Acknowledgment of Minor Amendment	-	18/11/2014

All research conducted at the Betsi Cadwaladr University Health Board sites must comply with the Research Governance Framework for Health and Social Care in Wales (August 2009).
An electronic link to this document is provided on the BCUHB R&D WebPages. Alternatively, you may obtain a paper copy of this document via the R&D Office.

On behalf of the Panel, may I take this opportunity to wish you every success with your research.

Yours sincerely,

Dr. Rossela Roberts, MICR, CSci
Clinical Governance Officer (R&D/Ethics)

Copy to:

Academic Supervisor: Dr Robin Owen
North Wales Forensic Psychiatry
Bryn Y Neuadd Hospital
LL33 0HH robin.owen2@wales.nhs.uk

Academic Supervisor: Dr James Lea
North Wales Clinical Psychology Programme
School of Psychology
Bangor University
LL57 2DG j.lea@bangor.ac.uk

Academic Supervisor: Dr Julie Wane
North Wales Forensic Psychiatric Service
Bryn y Neuadd Hospital
LL33 0HH julia.wane@wales.nhs.uk

Amendment 2:

Recruitment of participants continued to prove difficult; therefore it was decided by the research team to widen the inclusion criteria. This would include a wider age range (20-65), less time since diagnosis (12 months), and to recruit those with a history of contact with the criminal justice system, such as being arrested, rather than focus on those who had been involved in forensic mental health or probation services.

Please note; whilst the amendment requested to recruit from Ty Llywelyn, Medium Secure unit, this was not required as a sufficient number of participants were recruited through the widening of the other criteria. Therefore, NOMS approval was not sought.

Amendment 2: Approval email from University Ethics

Received on the 21.11.14

Dear Emma Laura Catherine,

2013-11884-A12543 Amendment to People's experiences of living with a personality disorder diagnosis in the Probation Service.

Your research proposal number 2013-11884-A12543 has been reviewed by the School of Psychology Ethics and Research Committee and the committee are now able to confirm ethical and governance approval for the above research on the basis described in the application form, protocol and supporting documentation. This approval lasts for a maximum of three years from this date.

Ethical approval is granted for the study as it was explicitly described in the application

If you wish to make any non-trivial modifications to the research project, please submit an amendment form to the committee, and copies of any of the original documents reviewed which have been altered as a result of the amendment. Please also inform the committee immediately if participants experience any unanticipated harm as a result of taking part in your research, or if any adverse reactions are reported in subsequent literature using the same technique elsewhere.

Governance approval is granted for the study as it was explicitly described in the application and we are happy to confirm that this study is now covered by the University's indemnity policy.

If any new researchers join the study, or any changes are made to the way the study is funded, or changes that alter the risks associated with the study, then please submit an amendment form to the committee.

Yours sincerely

Everil McQuarrie

Amendment 2: IRAS form

Notice of Amendment

IRAS Version 3.5

Welcome to the Integrated Research Application System

IRAS Project Filter

The integrated dataset required for your project will be created from the answers you give to the following questions. The system will generate only those questions and sections which (a) apply to your study type and (b) are required by the bodies reviewing your study. Please ensure you answer all the questions before proceeding with your applications.

Please enter a short title for this project (maximum 70 characters)
People's experiences of living with a personality disorder diagnosis

1. Is your project research?

☒ Yes ☐ No

2. Select one category from the list below:

- ☐ Clinical trial of an investigational medicinal product
- ☐ Clinical investigation or other study of a medical device
- ☐ Combined trial of an investigational medicinal product and an investigational medical device
- ☐ Other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice
- ☐ Basic science study involving procedures with human participants
- ☐ Study administering questionnaires/interviews for quantitative analysis, or using mixed quantitative/qualitative methodology
- ☒ Study involving qualitative methods only
- ☐ Study limited to working with human tissue samples (or other human biological samples) and data (specific project only)
- ☐ Study limited to working with data (specific project only)
- ☐ Research tissue bank
- ☐ Research database

If your work does not fit any of these categories, select the option below:

☐ Other study

2a. Please answer the following question(s):

- a) Does the study involve the use of any ionising radiation? ☐ Yes ☒ No
- b) Will you be taking new human tissue samples (or other human biological samples)? ☐ Yes ☒ No
- c) Will you be using existing human tissue samples (or other human biological samples)? ☐ Yes ☒ No

3. In which countries of the UK will the research sites be located? (Tick all that apply)

- ☐ England
- ☐ Scotland
- ☒ Wales
- ☐ Northern Ireland

3a. In which country of the UK will the lead NHS R&D office be located:

Notice of Amendment

IRAS Version 3.5

- ☐ England
☐ Scotland
☒ Wales
☐ Northern Ireland
☐ This study does not involve the NHS

4. Which review bodies are you applying to?

- ☒ NHS/HSC Research and Development offices
☐ Social Care Research Ethics Committee
☒ Research Ethics Committee
☐ National Information Governance Board for Health and Social Care (NIGB)
☒ National Offender Management Service (NOMS) (Prisons & Probation)

For NHS/HSC R&D offices, the CI must create Site-Specific Information Forms for each site, in addition to the study-wide forms, and transfer them to the PIs or local collaborators.

5. Will any research sites in this study be NHS organisations?

- ☒ Yes ☐ No

6. Do you plan to include any participants who are children?

- ☐ Yes ☒ No

7. Do you plan at any stage of the project to undertake intrusive research involving adults lacking capacity to consent for themselves?

- ☐ Yes ☒ No

Answer Yes if you plan to recruit living participants aged 16 or over who lack capacity, or to retain them in the study following loss of capacity. Intrusive research means any research with the living requiring consent in law. This includes use of identifiable tissue samples or personal information, except where application is being made to the NIGB Ethics and Confidentiality Committee to set aside the common law duty of confidentiality in England and Wales. Please consult the guidance notes for further information on the legal frameworks for research involving adults lacking capacity in the UK.

8. Do you plan to include any participants who are prisoners or young offenders in the custody of HM Prison Service or who are offenders supervised by the probation service in England or Wales?

- ☒ Yes ☐ No

9. Is the study or any part of it being undertaken as an educational project?

- ☒ Yes ☐ No

Please describe briefly the involvement of the student(s):
 This research is being undertaken as part of the researcher's Doctorate in Clinical Psychology at the North Wales Clinical Psychology Programme.

9a. Is the project being undertaken in part fulfilment of a PhD or other doctorate?

- ☒ Yes ☐ No

10. Will this research be financially supported by the United States Department of Health and Human Services or any of

Notice of Amendment

IRAS Version 3.5

its divisions, agencies or programs?

☐ Yes ☒ No

11. Will identifiable patient data be accessed outside the care team without prior consent at any stage of the project (including identification of potential participants)?

☐ Yes ☒ No

NOTICE OF SUBSTANTIAL AMENDMENT

Please use this form to notify the main REC of substantial amendments to all research other than clinical trials of investigational medicinal products (CTIMPs).

The form should be completed by the Chief Investigator using language comprehensible to a lay person.

Details of Chief Investigator:

	Title Forename/Initials Surname
	Miss Emma Lloyd
Work Address	North Wales Clinical Psychology Programme School of Psychology, 43 College Road, Bangor, Gwynedd
PostCode	LL57 2DG
Email	psp0da@bangor.ac.uk
Telephone	07792104873
Fax	

Full title of study:	People's experiences of living with a personality disorder diagnosis: A perspective from individuals within the Probation Service
Lead sponsor:	Bangor University School of Psychology
Name of REC:	Wales REC 3
REC reference number:	14/WA/0144
Name of lead R&D office:	Betsi Cadwaladr University Health Board
Date study commenced:	30.06.14
Protocol reference (if applicable), current version and date:	
Amendment number and date:	Amendment number 2 24.11.14

Type of amendment

(a) Amendment to information previously given in IRAS

☒ Yes ☐ No

If yes, please refer to relevant sections of IRAS in the "summary of changes" below.

(b) Amendment to the protocol

☐ Yes ☒ No

If yes, please submit either the revised protocol with a new version number and date, highlighting changes in bold, or a document listing the changes and giving both the previous and revised text.

(c) Amendment to the information sheet(s) and consent form(s) for participants, or to any other supporting documentation for the study

☐ Yes ☒ No

If yes, please submit all revised documents with new version numbers and dates, highlighting new text in bold.

Is this a modified version of an amendment previously notified and not approved?

☐ Yes ☒ No

Summary of changes

Briefly summarise the main changes proposed in this amendment. Explain the purpose of the changes and their significance for the study.

If this is a modified amendment, please explain how the modifications address the concerns raised previously by the ethics committee.

If the amendment significantly alters the research design or methodology, or could otherwise affect the scientific value of the study, supporting scientific information should be given (or enclosed separately). Indicate whether or not additional scientific critique has been obtained.

Since receiving ethical approval for our research in June of this year, it has not been possible to recruit any participants from the probation or forensic service who meet the inclusion criteria for the research. An amendment has been approved to allow for recruitment from within Community Mental Health Teams and Community Rehabilitation Teams in North Wales. However, following discussion with the research team it was decided that the inclusion criteria should be modified to allow for the recruitment from a larger pool of participants. These changes have been carefully chosen and we believe they do not result in any significant ethical issues, nor impact on the research question or recruitment method. They are solely to widen the inclusion criteria. These amendments have received approval from the Bangor University School of Psychology Ethics Committee. We would like to request the following changes to the inclusion criteria-

- 1) To change the age range of participants from 25-50 years to 20-65 years.
- 2) To change the length of time the participant has lived with a personality disorder diagnosis from a minimum of two years to a minimum of 12 months.
- 3) To include participants with a history of offending (as identified by their care coordinator) rather than only those who have been involved with the forensic service or probation service.
- 4) To invite participants from within secure units, including Ty Llywelyn Medium Secure Unit, Llanfairfechan to take part.

Any other relevant information

Applicants may indicate any specific issues relating to the amendment, on which the opinion of a reviewing body is sought.

List of enclosed documents

Document	Version	Date
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Declaration by Chief Investigator

1. I confirm that the information in this form is accurate to the best of my knowledge and I take full responsibility for it.
2. I consider that it would be reasonable for the proposed amendment to be implemented.

This section was signed electronically by Miss Emma Lloyd on 24/11/2014 16:05.

Notice of Amendment

IRAS Version 3.5

Job Title/Post:	Trainee Clinical Psychologist
Organisation:	North Wales Clinical Psychology Programme
Email:	psp0da@bangor.ac.uk

Declaration by the sponsor's representative

I confirm the sponsor's support for this substantial amendment.

This section was signed electronically by Mr Hefin Francis on 24/11/2014 16:51.

Job Title/Post:	School Manager Psychology
Organisation:	Bangor University
Email:	h.francis@bangor.ac.uk

Amendment 2: REC validation letter

Part of the research infrastructure for Wales funded by the National Institute for Social Care and Health Research, Welsh Government.
Yn rhan o seilwaith ymchwil Cymru a ariannir gan y Sefydliad Cenedlaethol ar gyfer Ymchwil Gofal Cymdeithasol ac Iechyd, Llywodraeth Cymru



16 December 2014

Miss Emma Lloyd
Trainee Clinical Psychologist
Betsi Cadwaladr University Health Board
North Wales Clinical Psychology Programme
School of Psychology, 43 College Road,
Bangor, Gwynedd
LL57 2DG

Wales REC 3
Sixth Floor, Churchill House
17 Churchill Way
Cardiff CF10 2TW

Telephone : 029 2037 6829
Fax : 029 2037 6824
E-mail : corinne.scott@wales.nhs.uk
Website : www.hra.nhs.uk

Dear Miss Lloyd

Study title: People's experiences of living with a personality disorder
diagnosis: A perspective from individuals within the Probation
Service
REC reference: 14/WA/0144
Amendment number: 2
Amendment date: 24 November 2014
IRAS project ID: 145859

The above amendment was reviewed at the meeting of the Committee held on 11 December 2014.

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Members however suggest that Miss Lloyd take advice from NOMS with regard to any possible approvals needed from them, although their favourable opinion of the amendment is not contingent upon this.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Notice of Substantial Amendment (non-CTIMP)	2	24 November 2014

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

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 <http://www.hra.nhs.uk/hra-training/>



Cynhelir Cylweithrediad Gwyddor Iechyd Academaidd y Sefydliad Cenedlaethol ar gyfer Ymchwil Gofal Cymdeithasol ac Iechyd gan Fwrdd Addysgu Iechyd Powys

The National Institute for Social Care and Health Research Academic Health Science Collaboration is hosted by Powys Teaching Health Board



14/WA/0144:	Please quote this number on all correspondence
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Yours sincerely



pp **Dr Pete Wall**
 Chair

E-mail: corinne.scott@wales.nhs.uk

Enclosures: List of names and professions of members who took part in the review

Copy to: Dr Rossela Roberts, Betsi Cadwaladr University Health Board
 Mr Hefin Francis

Amendment 2: R&D Validation letter

Chairman/Cadeirydd - Dr. Nefyn Williams Phd, FRCGP

Email: rossela.roberts@wales.nhs.ukdebra.slater@wales.nhs.uksion.lewis@wales.nhs.uk

Tel/Fax: 01248 384 877

Dear Miss Lloyd,

Re: Substantial Amendment: SA02 dated 24/11/2014

Study Title People's experiences of living with a personality disorder diagnosis: a
Perspective from individuals within the Probation Service

R&D reference 145859

The above amendment was reviewed by the R&D Office on the 09 February 2015
on behalf of the Internal Review Panel.

Documents reviewed:	Version	Date
Notice of Substantial Amendment Form	SA02	24/11/2014
REC Favourable Opinion of Amendment	-	16/12/2014

The R&D Office have no objection and is able to support the amendment based on the information provided. The amendment does not affect local management approval previously given to this research.

As part of the regular monitoring undertaken by the Internal Review Panel you will be required to complete a short progress report. This will be requested on a 6 monthly basis. However, please contact me sooner should you need to report any particular successes or problems concerning your research. Whilst BCUHB is keen to reduce the burden of paperwork for researchers failure to produce a report may result in withdrawal of approval.

All research conducted at the Betsi Cadwaladr University Health Board sites must comply with the Research Governance Framework for Health and Social Care in Wales (August 2009). An electronic link to this document is provided on the BCUHB R&D WebPages. Alternatively, you may obtain a paper copy of this document via the R&D Office.

The decision is sent to you in electronic format only – please let me know whether you will be requiring a formal letter.

On behalf of BCUHB, we would like to wish you every success with your research.

Best wishes

Mr Sion Lewis

Cynorthwydd Rheolaeth ac Ymchwil

Research & Development Assistant

Ymchwil a Datblygu

Research and Development

Bwrdd Iechyd Prifysgol

Betsi Cadwaladr

University Health Board

Ysbyty Gwynedd Hospital

Bangor

Gwynedd

LL57 2PW

Tel: (01248) 384877 - Ext: 4877

Email: Sion.Lewis@wales.nhs.uk

Bwrdd Iechyd Prifysgol Betsi Cadwaladr yw enw gweithredol Bwrdd Iechyd Lleol Prifysgol Betsi Cadwaladr

Betsi Cadwaladr University Health Board is the operational name of Betsi Cadwaladr University Local Health Board



Participant Information Sheet

People's experiences of living with a personality disorder diagnosis.

Invitation

You are invited to take part in a research study that is being conducted through Bangor University. The study will contribute towards the researcher, Emma Lloyd's educational qualification (Doctorate in Clinical Psychology).

Purpose of the Study

Personality disorders are controversial diagnoses, provoking heated debate among people with personal experience of these diagnoses, mental health staff, researchers and policy makers. The purpose of this research is to explore the experiences of people living with a diagnosis of a personality disorder. The outcomes may help professionals to develop a more thorough understanding of people's lived experience of a personality disorder diagnosis, and may help to develop improved clinical services and practices in the future.

Why have I been chosen?

You have been identified by your Care Coordinator/ Probation Officer as having received a diagnosis of a personality disorder at least two years ago.

Do I have to take part?

Taking part is entirely voluntary. It is up to you whether or not you decide to take part. If you choose to take part, you will be given this information sheet to keep and will be asked to sign a consent form. If you decide to take part, you can withdraw at any time.

What is involved in taking part?

The research will involve being interviewed by the researcher. You will be invited to talk about your experiences of living with a personality disorder diagnosis. This interview will be recorded and will take no more than an hour. You will be given a £10 gift voucher for taking the time to participate in this research.

Are there any potential risks involved in taking part?

The interviews are not intended to cause any distress, however you may find that talking about any difficult experiences may cause you to feel upset. If this happens you will be supported by the researcher. You can also stop at any time. The researcher can provide you with information about helplines to use for support, and you can access further support from your Care Coordinator/ Probation Officer.

What are the possible benefits of taking part?

By taking part in this research you will be providing important information regarding how people experience living with a personality disorder. This may help to develop ways of offering support to people diagnosed with a personality disorder in the future.

Will the information I provide be confidential?

The information you provide will be confidential unless you disclose something that suggests that you or another person is at risk of significant harm. In this instance, I, the researcher, will be duty bound to break confidentiality, and pass the information on to a relevant agency. If you disclose any criminal activity which you have committed but have not been convicted for and / or disclose any intended criminal activity then I will also be duty bound to report this information to your Care Coordinator/ Probation Officer.

What will happen to the results of the research study?

Unless you choose not to, you will receive a letter summarising the results of the study. The authors also intend to publish this information in a research journal, in order to share the findings with other clinicians and researchers interested in this area. **Under no circumstances will personal identifying information be published.** Pseudonyms will be assigned to all participants, however direct quotations will be used in the write-up of the research. There is a section on the consent form which asks if you consent to direct quotations from your interview being used.

Consent

If, after reading this information sheet, you decide to take part in this research, please read and sign the consent form provided.

The research team would like to keep the anonymised data from this research for 48 months following the completion of this study, with the possibility of it being used in future research. There is a section of the consent form requesting your consent to this.

Please make sure that you have understood the information. Feel free to ask the researcher any other questions you may have regarding the study.

Contact details

Should you require further information about the study please contact:

Emma Lloyd – email: psp0da@bangor.ac.uk

What if there is a problem?

In the event of any complaints concerning the conduct of this research that cannot be resolved with the researcher, you may contact:

Mr Hefin Francis, School Manager, School of Psychology, Brigantia Building, Penrallt Road, Bangor University, Bangor, Gwynedd, LL57 2DG.

Tel: 01248 388339, Email: h.francis@bangor.ac.uk



Taflen wybodaeth i gyfranogwyr

Profiadau pobl o fyw gyda diagnosis anhwylder personoliaeth.

Gwahoddiad

Rydym yn eich gwahodd i gymryd rhan mewn astudiaeth ymchwil a gynhelir drwy Brifysgol Bangor. Bydd yr astudiaeth yn cyfrannu tuag at gymhwyster addysgol yr ymchwilydd, Emma Lloyd (Doethuriaeth mewn Seicoleg Glinigol).

Pwrpas yr astudiaeth

Mae anhwylderau personoliaeth yn ddiagnosau dadlennol, gan arwain at drafod a dadlau brwd ymysg pobl sydd â phrofiad personol o'r diagnosau hyn, staff iechyd meddwl, ymchwilwyr a gwneuthurwyr polisi. Diben yr ymchwil hon yw edrych ar brofiadau pobl sy'n byw gyda diagnosis o anhwylder personoliaeth. Gall y canlyniadau helpu gweithwyr proffesiynol i ddatblygu dealltwriaeth fwy trylwyr o brofiadau pobl o fyw gyda diagnosis anhwylder personoliaeth, a gall helpu i ddatblygu gwell gwasanaethau clinigol yn y dyfodol.

Pam ydw i wedi cael fy newis?

Mae eich Cydlynnydd Gofal / Swyddog Profiannaeth wedi nodi eich bod wedi cael diagnosis anhwylder personoliaeth o leiaf ddwy flynedd yn ôl.

Oes rhaid imi gymryd rhan?

Mae cymryd rhan yn gwbl wirfoddol. Chi sydd i benderfynu a ydych am gymryd rhan ai peidio. Os penderfynwch gymryd rhan, cewch y daflen wybodaeth hon i'w chadw, a gofynnir ichi lofnodi ffurflen gydsynio. Os ydych yn penderfynu cymryd rhan, mae gennych hawl i dynnu'n ôl ar unrhyw adeg.

Beth fydd yn digwydd os byddaf yn cymryd rhan?

Bydd yr ymchwil yn ymwneud â chael cyfweiliad gan yr ymchwilydd. Fe'ch gwahoddir i siarad am eich profiadau o fyw gyda diagnosis anhwylder personoliaeth. Caiff y cyfweiliad hwn ei recordio ac ni fydd yn cymryd mwy nag awr. Byddwch yn cael tocyn anrheg £10 am gymryd rhan yn yr ymchwil.

Oes yna unrhyw beryglon tebygol wrth gymryd rhan?

Ni fwriedir i'r cyfweiliadau achosi unrhyw drallod; fodd bynnag, efallai y gwelwch y bydd siarad am unrhyw brofiadau anodd yn eich cynhyrfu. Os bydd hynny'n digwydd bydd yr ymchwilydd yn rhoi cefnogaeth i chi. Gellwch stopio ar unrhyw adeg hefyd. Gall yr ymchwilydd roi gwybodaeth i chi am linellau cymorth i'w defnyddio am gefnogaeth, a gellwch gael cefnogaeth bellach gan eich Cydlynnydd Gofal / Swyddog Profiannaeth.

Beth yw'r manteision posib o gymryd rhan?

Trwy gymryd rhan yn yr astudiaeth hon, byddwch yn darparu gwybodaeth bwysig ynghylch sut mae pobl yn byw gydag anhwylder personoliaeth. Gall hyn helpu i ddatblygu ffyrdd o gynnig cefnogaeth yn y dyfodol i bobl sydd wedi cael diagnosis anhwylder personoliaeth.

A fydd y wybodaeth yr ydych yn ei darparu'n gyfrinachol?

Bydd y wybodaeth yr ydych yn ei darparu'n gyfrinachol oni bai eich bod yn datgelu rhywbeth sy'n awgrymu eich bod chi neu rywun arall mewn peryg o niwed sylweddol. Os felly, bydd yn ddyletswydd arnaf i , yr ymchwilydd, i dorri cyfrinachedd, a rhoi'r wybodaeth i asiantaeth berthnasol. Os byddwch yn datgelu unrhyw weithgaredd troseddol rydych wedi'i gyflawni ond na chafwyd chi'n euog ohono ac /neu'n datgelu unrhyw weithgaredd troseddol y bwriadwch ei gyflawni, yna bydd yn ddyletswydd arnaf hefyd i roi gwybod am hyn i'ch Cydlynnydd Gofal / Swyddog Profiannaeth.

Beth fydd yn digwydd i ganlyniadau'r astudiaeth ymchwil?

Byddwch yn derbyn llythyr yn crynhoi canlyniadau'r astudiaeth, oni bai eich bod yn dewis peidio ei gael. Mae'r awduron hefyd yn bwriadu cyhoeddi'r wybodaeth hon mewn cyfnodolyn ymchwil, er mwyn rhannu eu canfyddiadau gyda chlinigwyr ac ymchwilwyr eraill sydd â diddordeb yn y maes hwn. **Ni chyhoeddir dan unrhyw amgylchiadau wybodaeth a all ddatgelu pwy ydych.** Bydd pawb fydd yn cymryd rhan yn cael ffugenwau; fodd bynnag, defnyddir dyfyniadau ganddynt wrth ysgrifennu adroddiad yr astudiaeth. Mae adran ar y ffurflen gydsynio sy'n gofyn a ydych yn cydsynio i ddyfyniadau o'ch cyfweiliad gael eu defnyddio.

Cydsynio

Os penderfynwch gymryd rhan yn yr ymchwil hon ar ôl darllen y daflen wybodaeth hon, darllenwch a llofnodwch y ffurflen gydsynio a ddarperir.

Hoffai'r tîm ymchwil gadw'r data dienw o'r ymchwil hon am 48 mis ar ôl cwblhau'r astudiaeth hon, ac mae'n bosibl y byddant yn cael eu defnyddio mewn ymchwil yn y dyfodol. Mae adran ar y ffurflen gydsynio sy'n gofyn a ydych yn cydsynio i hynny.

Gwnewch yn siŵr eich bod wedi deall y wybodaeth. Mae pob croeso i chi ofyn i'r ymchwilydd unrhyw gwestiynau eraill sydd gennych ynghylch yr astudiaeth.

Manylion cyswllt

Os oes angen rhagor o wybodaeth arnoch am yr astudiaeth, yna cysylltwch â:

Emma Lloyd – e-bost: psp0da@bangor.ac.uk

Beth os bydd problem yn codi?

Os oes gennych unrhyw gwynion ynglŷn â'r modd y gwneir yr ymchwil na ellwch eu datrys gyda'r ymchwilydd, gellwch gysylltu â:

Hefin Francis, Rheolwr yr Ysgol Seicoleg, Adeilad Brigantia, Ffordd Penrallt, Prifysgol Bangor, Bangor, Gwynedd, LL57 2DG.

Ffôn: 01248 388339, E-bost: h.francis@bangor.ac.uk

Consent Form- English Version

**Consent Form****People's experiences of living with a personality disorder diagnosis.****Researcher:** Emma Lloyd, Trainee Clinical Psychologist

The information you provide will not be released or disclosed without your separate consent as required by law. **The published results will not contain any personal identifiers.** Pseudonyms will be assigned to each participant to ensure anonymity.

If you have any questions about this research, or your involvement in the research you can contact the researcher, Emma Lloyd, who will answer any questions or concerns you may have (see contact details below).

You will have been given the opportunity to read this form carefully and to keep a copy for your own records.

Please read the statements below. If you are happy with each statement, please initial or sign in the relevant box:

1. I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason. ☐
3. I agree for my interview to be recorded. ☐
4. I agree for direct quotations from my interview to be used in the write-up of this research. These will be anonymous. ☐
5. I agree for my anonymised data to be kept by the research team for a period of 48 months after the research has been completed, for possible use in future research. ☐
6. I have read and understood the limits of confidentiality. ☐

7. I agree to take part in the study.

☐

Name of Participant

Date

Signature

Name of person taking consent

Date

Signature

Should you require further information about the study please contact:
Emma Lloyd – email: psp0da@bangor.ac.uk.

In the event of any complaints concerning the conduct of this research that cannot be resolved with the researcher, you may contact: Mr Hefin Francis, School Manager, School of Psychology, Brigantia Building, Penrallt Road, Bangor University, Bangor, Gwynedd, LL57 2DG. Tel: 01248 388339, Email: h.francis@bangor.ac.uk

Consent Form- Welsh Version

**Ffurflen Gydsynio**

Profiadau pobl o fyw gyda diagnosis anhwylder personoliaeth.

Ymchwilydd: Emma Lloyd, Seicolegydd Clinigol dan Hyfforddiant

Ni chaiff unrhyw wybodaeth a roddir gennych ei rhyddhau neu ei datgelu heb eich cydsyniad unigol yn ôl gofynion y gyfraith. **Ni fydd y canlyniadau a gyhoeddir yn cynnwys unrhyw wybodaeth a allai ddangos pwy yw rhywun.** Rhoddir ffugenw i bawb fydd yn cymryd rhan er mwyn sicrhau na ellir gwybod pwy ydych.

Os oes gennych unrhyw gwestiynau am yr ymchwil hon, neu am eich ymwneud â'r ymchwil, cysylltwch â'r ymchwilydd, Emma Lloyd, a fydd yn ateb unrhyw gwestiynau neu bryderon a allai fod gennych (gweler manylion cyswllt isod).

Byddwch wedi cael y cyfle i ddarllen y ffurflen hon yn ofalus ac i gadw copi yn eich cofnodion personol eich hun.

Darllenwch y gosodiadau isod. Os ydych yn fodlon ar bob gosodiad, llofnodwch y bocs perthnasol:

1. Rwyf yn cadarnhau fy mod wedi darllen a deall y daflen wybodaeth am yr astudiaeth uchod. Rwyf wedi cael cyfle i ystyried y wybodaeth a gofyn cwestiynau ac wedi cael atebion boddhaol iddynt. ☐
2. Rwy'n deall fy mod yn cymryd rhan yn wirfoddol ac y gallaf dynnu'n ôl unrhyw bryd, heb roi rheswm. ☐
3. Rwy'n cytuno i'm cyfweiliad gael ei recordio. ☐
4. Rwy'n caniatáu i ddyfyniadau o'm cyfweiliad gael eu defnyddio mewn adroddiad ymchwil hon. Bydd y rhain yn ddienw. ☐
5. Rwy'n cytuno i'r tîm ymchwil gadw fy nata dienw am gyfnod o 48 mis ar ôl i'r ymchwil gael ei gorffen, rhag ofn y bydd eu hangen ar gyfer ymchwil yn y dyfodol. ☐

6. Rwyf wedi darllen a deall y cyfyngiadau ar gyfrinachedd.

☐

7. Rwy'n cytuno i gymryd rhan yn yr astudiaeth.

☐

Enw'r Cyfranogwr

Dyddiad

Llofnod

Enw'r sawl sy'n derbyn y cydsyniad

Dyddiad

Llofnod

Os oes angen rhagor o wybodaeth arnoch am yr astudiaeth, yna cysylltwch â:
Emma Lloyd – e-bost: psp0da@bangor.ac.uk

Os oes gennych unrhyw gwynion ynghylch y modd y gwneir yr ymchwil na ellwch eu datrys gyda'r ymchwilydd, gellwch gysylltu â: Hefin Francis, Rheolwr yr Ysgol Seicoleg, Adeilad Brigantia, Ffordd Penrallt, Prifysgol Bangor, Bangor, Gwynedd, LL57 2DG. Ffôn: 01248 388339, E-bost: h.francis@bangor.ac.uk

General Appendix

General Appendix 1: Semi-structured interview schedule

Semi-Structured Interview Schedule

Prior to the interview, demographic data will be collected- name, age, when diagnosed, where diagnosed, and by whom.

1. Can you tell me about how you came to receive a personality disorder diagnosis?

2. What does this diagnosis mean to you?

3. Has the diagnosis influenced your life?

Possible prompts: identity, relationships with family and friends, employment,
offending, community.

4. Has this diagnosis influenced how other people relate to you?

Possible prompts: family, friends, community, professionals.

5. Has the diagnosis changed the way you think or feel about yourself?

Possible prompts: Do you see yourself differently now than before you had the
diagnosis?

In what ways?

6. Has the diagnosis been helpful in understanding yourself?

Possible prompts: behaviour, relationships.

7. How important has this diagnosis been for you?

General Appendix 2: Example of data analysis using transcript extract.

This table offers an example of how raw transcripts (middle column) were initially analysed. Initial ideas were noted down as an immediate reaction to the data. Exploratory comments (right column) consisted of three processes with different focuses:

1. Descriptive comments which focused on describing the content of what the participant has said, the subject of the talk within the text (normal text).
2. Linguistic comments which focused upon exploring the specific use of language by the participant (*italic text*).
3. Conceptual comments focused on engaging at a more interrogative and conceptual level (underlined comments).

This then led to ideas being encapsulated in the emergent themes (left hand column).

Emergent Themes	Original Transcript	Exploratory Comments
<p>Questioning the diagnosis.</p> <p>Decided by others.</p> <p>Difficulties stem from trauma.</p>	<p>As regards this borderline personality disorder, I don't know where they've got it from. Plus they say I'm post-traumatic stress disorder.... which I can understand that one because when the nurse worked it out, post which is the past, the traumas you've been through in the past, stress disorder, which, that sort of registers with me really. I think that's what it is. It stems from your childhood I think. I really do think it comes from your childhood as to how you act in life.</p> <p>I: so, what does the borderline personality disorder diagnosis mean to you?</p>	<p>Questioning the diagnosis. <i>Use of the pronoun they – something decided by another and applied to her.</i></p> <p>Has received multiple diagnoses. <u>PTSD is something that she can relate to-placing her difficulties in the context of past traumas.</u></p> <p>It registers with her- <u>fits with her reality and experiences in life, making sense as opposed to the BPD diagnosis.</u></p> <p>Emphasising the importance of childhood experiences</p>

<p>Negative impact on sense of self.</p> <p>Loss of normality.</p> <p>Silenced by the diagnosis.</p> <p>Power and control.</p> <p>Rejecting the diagnosis</p> <p>Difficulties related to alcohol use</p> <p>Coping with loss</p>	<p>P: It makes me feel horrible. It doesn't make me feel normal because.... I don't think I've got a personality problem. I think they just label people with these things just to sort of either shut them up or.....I've known a lot of people who've been labelled with things and they've found out they've labelled them wrong. But it used to worry me but it doesn't worry me so much now. Because I just know I've not got a personality problem...if I don't drink...and I don't. I gave up drink for 14 years and then when I lost my daughter (name) (number) years ago I started slipping and sliding again...but at the moment I'm not drinking. But on the television they're showing drink all the time and drink all the time and it just makes you feel....you only get the buzz for an hour and then the melancholy sets in. Do you understand what I mean?</p> <p>I: yeah</p> <p>P: So, I don't bother about this personality problem anymore. Too old to bother about it.</p> <p>I: yeah. So, has the diagnosis influenced your life?</p> <p>P: yes it has. 'Cos I think you over power yourself with people because you want them to like you but not everybody likes everybody, I've learnt that in life but I wanted everybody to like me and ...I'm genuine with people, I've helped people in the past. I can't count on one hand how many people have come in this house that I've helped over the years...and it affects me that.... I've asked people do you think I've got personality problems? 'no', you know people I've known for years 'no I don't think you've got a</p>	<p>Diagnosis makes her feel horrible and not normal. <u>Impact on sense of self and self-esteem. The loss of normality</u></p> <p>Rejecting the diagnosis. <u>It is not how she makes sense of her difficulties. They label people- something that is done to you.</u> Being diagnosed to shut them up- <u>diagnosis as a way of silencing people.</u> <u>Issues of power and control in services?</u> Being labelled wrong- sees the diagnosis as a label which can be incorrectly applied.</p> <p>It used to worry her <u>Diagnosis as something negative which has added to her difficulties.</u> Sees her difficulties as being associated with alcohol use- <u>Using alcohol to cope with traumatic and loss. Rejecting the diagnosis</u></p> <p>Struggling with abstinence from alcohol, <u>struggling to cope.</u> <i>Use of the word melancholy to emphasise her sadness.</i></p> <p>Doesn't bother thinking about this diagnosis now <u>a sense that there are more important things in life, it's not important enough to take up anymore of her time.</u></p> <p>She has made extra efforts in her social relationships as a result of this diagnosis. <u>Needing to prove that it was not true, a fundamental attack on her sense of self</u></p> <p>Emphasising how she is genuine and helps others. <u>In contrast to her experiences with mental health services? Diagnosis does not fit with her view of herself. Deep implications of questioning herself</u></p> <p>Seeking reassurance from others who know her well- they don't believe the diagnosis to be true. <u>Challenging the diagnosis, needing to know that it does not fit with others and her own view of herself</u></p>
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A label without meaning	personality problem. Many a person has said that to me. So I don't know where it's come from. What does it mean?...	Feeling frustrated with the diagnosis. Asking what does it mean? <u>The diagnosis is meaningless to her.</u>
	I: so, it's had an effect on how you feel about yourself?	
Impact on self-esteem.	P: yeah, I felt really low and not normal, not normal. You know, thinking that I had this personality problem. I think I over powered myself to make sure that I haven't got a personality problem. I get on with everybody. So why are they saying this about me? Oh, and I'm bipolar, they've diagnosed me with bipolar....and manic depressive, they've diagnosed me with that in the past. But I just don't understand where they're coming from.	Impact on her mood and self-esteem. <i>Repetition of not normal to emphasise the negative effect of the diagnosis.</i> <u>Diagnosis transforms you into something abnormal?</u> Feels she has needed to prove the diagnosis as wrong. <i>Use of they to signify that it is others who think this.</i> <u>Feeling persecuted by others who have attached this label? An attack on her sense of self.</u> Other diagnoses have been applied to her. <u>Others have labelled her, rather than understanding her? Adding to her evidence that the BPD label is not helpful?</u> Doesn't understand it- confusion.
Loss of normality		
Diagnosis as an attack on the self		

General Appendix 3: Word Count Statement.**Word Count Statement**

Thesis Component	Word Count
Title	4
Thesis abstract	282
Empirical study	6963
Empirical study references	691
Literature review	6199
Literature review references	1088
Contributions to theory and clinical practice	4696
Contributions to theory and clinical practice references	1033
Word count excluding tables, figures, reference lists and appendices:	18144
Literature review appendix:	
Appendix 1- Literature search process	141
Appendix 2- Table of literature review studies	1434
Research paper appendix:	
Appendix 1- Table of demographic information	76
Appendix 2- Table of themes	198
General appendix	
Interview schedule (research paper)	136
Example of Analysed Transcript (research paper)	1104
Appendices including figures, tables and reference lists, excluding ethics appendix:	5901

Total word count: 24045