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Doctoral Thesis:

Psychiatric diagnosis: Learning from people who have been labeled and the

practitioners who work with them

Rebecca Hough

Doctorate in Clinical Psychology

Division of Health Research, Lancaster University

Word Count Statement

Thesis Section	Text	Tables, figures, references and appendices	Total
Abstract	290	0	290
Literature Review	7994	4895	12889
Research Paper	7995	4527	12522
Critical Appraisal	3999	517	4516
Ethics Section	4590	3735	8325
Totals	**24868**	**13674**	**38542**

Abstract

This thesis comprises a literature review, a research paper and a critical review of the research process.

In the literature review, a metasynthesis method was used to identify and synthesise 12 studies that explored experiences of psychiatric diagnosis. Four themes emerged; 'the diagnostic experience: problems with validity and utility'; 'reaction to diagnosis: devastation and hope'; 'personal experience: impact on self'; and 'interpersonal experience: relationships and identity'. Findings are discussed in terms of the impact of diagnosis on self and identity and suggest that there are both positive and negative aspects to diagnosis. Working with diagnosis and psychological formulation in mental health practice is considered, focusing on ameliorating the negative and preserving the positive aspects of diagnosis.

The study presented in the research paper used a grounded theory methodology, where ten participants who were practitioners in adult mental health services in the National Health Service in England were interviewed, to develop a theory that explained how diagnosis was used in practice. The core category 'needing a certain foundation for practice' was constructed from the data, with two further categories; 'holding and coping with inconsistent and differing views' and 'impact on practice: depersonalisation and not challenging diagnosis'. Findings suggest that diagnosis has survived because for some it provides a secure base for practice and for others the power dynamics inherent in working in a system predicated on diagnosis and the perceived lack of utility of diagnosis, make challenging it unappealing. Critical consideration of all frameworks used to understand distress is encouraged and findings are discussed in relation to attachment and cognitive theories.

The critical review discusses further findings about the role of psychology and power. Then, reflections are offered about epistemology, using grounded theory methodology and conducting research when practising clinically.

Declaration

This thesis records work undertaken for the Doctorate in Clinical Psychology at Lancaster

University's Division of Health Research between September 2014 and May 2015.

The work presented here is the author's own, except where due reference is made. The work

has not been submitted for the award of a higher degree elsewhere.

Name: Rebecca Hough

Signature:

Date

Acknowledgements

I am sincerely grateful to all participants for sharing their opinions and experiences with me and for giving me their time.

Thanks to my supervisors for continued encouragement and belief.

Finally, thanks to my friends and family, because without them nothing would be possible.

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Section One: Literature Review

How do people experience and make sense of psychiatric diagnoses attributed to

them? A Metasynthesis

Rebecca Hough

Doctorate in Clinical Psychology

Division of Health Research, Lancaster University

Correspondence should be addressed to:

Rebecca Hough

Department of Clinical Psychology,

Faculty of Health and Medicine,

Furness Building,

Lancaster University,

Lancaster,

Lancashire, UK.

LA14YW

Email: r.hough@lancaster.ac.uk

Tel: +44 1524 593378

Fax: +44 1524 592981

Prepared for submission to *Journal of Mental Health.* [1]

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[1] Please note this manuscript was prepared in line with author guidelines for the *Journal of Mental Health* (See Appendix 1-A). Where these guidelines have not been followed, Lancaster University thesis guidelines have been followed. The word count is also in line with University not *Journal* guidance.

Abstract

Background: There is debate about psychiatric diagnostic criteria and their applications for people who have been labeled using diagnosis. An accumulated body of qualitative research explores the experience of living with diagnosis.

Aims: The aim of this metasynthesis was to identify and synthesise that qualitative research.

Method: A systematic search of qualitative articles was conducted using five databases, identifying 12 studies that met the inclusion/exclusion criteria. These articles were synthesised according to the method of Noblit and Hare (1988).

Results: Four themes emerged from the metasynthesis*; the diagnostic experience: problems with validity and utility*; *reaction to diagnosis: devastation and hope*; *personal experience: impact on self*; and *interpersonal experience: relationships and identity*. These themes interact to make up the experience of diagnosis.

Conclusions: Diagnosis creates some positive and some negative experiences. Findings are discussed in terms of the impact of diagnosis on self and identity. Working with diagnosis and psychological formulation in mental health practice is considered, with a focus on ameliorating the negative and preserving the positive aspects of diagnosis.

Declaration of Interests: None.

Keywords: Psychiatric diagnosis; mental health.

The recent publication of the updated fifth edition of the Diagnostic and Statistical Manual of Mental Disorders ([DSM-5] American Psychiatric Association [APA], 2013) has sparked international debate in academic literature about the challenges of using psychiatric diagnosis in mental health practice (Bracken et al., 2012; Ben-Zeev, Young & Corrigan, 2010). Despite this controversy, in developed countries such as Australia (Commonwealth Government of Australia, 2013) and the United States of America ([USA] Probst, 2013) a diagnosis is required to gain access to funding for treatments and services. Prevalence rates suggest that 5.7% of the population in the USA (Kessler et al., 2005) and 3% in Australia (Fourth National Mental Health Plan Working Group, 2009) live with psychiatric diagnoses.

In the United Kingdom (UK), the Office of National Statistics (ONS) state that one in four people will experience a diagnosable mental health problem in any one year (ONS, 2001). In the UK, psychiatric diagnoses are made by mental health professionals, using the International Classification of Diseases 10 ([ICD-10], World Health Organization, 1992) and the DSM-5 (APA, 2013). Research into the reliability of the third edition of the DSM ([DSM-III]; APA, 1980), which analysed data collected from DSM-III field trials, has shown that experienced clinicians only agree on a broad diagnostic category 50% of the time (Kirk & Kutchins, 1994).

Diagnostic Debate

These diagnostic systems raise wide reaching debate and controversy, particularly in relation to the validity of psychiatric diagnosis (herein referred to simply as diagnosis), within psychiatry itself (Bracken et al., 2012) and beyond, particularly in psychology (Pilgrim, 2007) and service user movements (Weitz, 2013). However, research suggests that mental health professionals value diagnosis as a common language but acknowledge its contested validity and associated stigma (Stalker, Ferguson & Barclay, 2005). Mental health problems are stereotypically associated with stigmatising beliefs about weakness and

deviance, which can be internalised as beliefs about self that are consistent with such stigma (Warner, 1994).

Due to the pejorative effects of psychiatric labels, this paper will refer to 'people in receipt of a psychiatric diagnosis' (PRPD), to describe those who have been labeled using diagnostic systems. It is hoped that this term will avoid, as far as possible, assumptions about the internal worlds of those who participated in the synthesised research. This is also in line with British Psychological Society (BPS) publications, which attempt to "use terms which are as neutral as possible and do not imply a particular 'framework of understanding'", for example using the term 'people' instead of 'patients' (BPS, 2010, p. 10).

In 2013, the BPS Division of Clinical Psychology (DCP) released a statement about the shifting paradigm of diagnosis in mental health (BPS, 2013). This was in response to the publication of the latest version of the DSM-5 (APA, 2013) and states that rather than using reductive diagnostic categories as set out in the DSM-5, clinical psychologists (CPs) and other mental health professionals should develop a framework for understanding distress based on understanding human experience, moving beyond the disease model. They commissioned a working party to make recommendations about alternatives to diagnosis (still anticipated at the time of writing). Research by Evans et al. (2013) examining psychologists' views and practices regarding diagnostic systems, in 23 countries, showed that 60% used a formal classification system (ICD-10 or DSM-IV) in routine practice. These psychologists preferred more flexible diagnostic guidelines and used diagnosis to inform treatment decisions and facilitate communication with PRPD and other professionals. Psychologists outside Europe and the USA identified problems with applicability of criteria in other cultures.

Medical professionals are better represented than psychologists and other professions

in research examining views on and use of diagnostic systems. Mellsop and colleagues used the same survey method to analyse views of psychiatrists in New Zealand (Mellsop, Dutu, & Robinson, 2007), Brazil and Japan (Mellsop et al., 2007). The same survey method was used in the USA (Bell, Sowers, & Thompson, 2008), as well as with primary care physicians, psychiatrists and psychologists in New Zealand (Mellsop, Lutchman, Lillis, & Dutu, 2011). Consistently, clinicians used the DSM over other systems and valued diagnosis for offering a shared language and to aid care planning. When asked what they need from a classification system, participants reported that they would favour a more reliable system with fewer categories.

Other professional groups also report some issues working with these systems. Research suggests that nurses in New Zealand use diagnosis to inform treatment plans, communicate difficulties to PRPD and their families and for statistical monitoring for their service (Aitchison & Mellsop, 2010). However, they felt that diagnostic systems did not allow for cultural or alternative explanations of difficulties and that labelling hindered recovery, meaning diagnosis was not in line with nursing values. Social workers in the USA also reported feeling that their values and ethical practices were compromised working within diagnostic systems (Probst, 2013; Hitchens & Becker, 2014). Despite these professionals' views, diagnostic systems prevail in mental health practice.

Existing Qualitative Research

Qualitative research gathering the experiences of individuals who have been diagnosed is particularly important given the lack of voice they have within the mental health system; for example PRPD are not consulted on revisions of the DSM series (Frese, 2010).

Some lived experience research contributes to debates about the utility of diagnosis for PRPD and how well diagnosis explains participants' experiences. For example, Castillo

(2000) explored the experiences of people who have been diagnosed with personality

disorder and found that 86% conceptualised their difficulties in terms of anxiety, depression

or both, suggesting their experience of distress differs from its diagnostic description. Sayre

(2000), in a grounded theory exploration of how individuals diagnosed with schizophrenia

view their situations, found that participants who were in hospital rejected the psychiatric

definition of their distress.

Often, qualitative research aiming to explore the experiences of PRPD includes

findings relating to the experience of living with a diagnosis. For example, Lilja and Hellzén

(2008) qualitatively explored experiences of psychiatric care in Sweden and found their

participants regretted the permanency of diagnosis when they were no longer experiencing

distress. LaFrance (2007), in a study of participants' accounts of depression, found that

diagnosis offered validation. A Canadian study of women who had recovered from

psychosis found that diagnosis was destructive for the individual, given the lack of hope for

recovery associated with diagnostic labels (Hagen & Nixon, 2011). A UK based interpretive

phenomenological analysis study of service users' experiences of early intervention in

psychosis services found that service users developed their own framework for

understanding their distress beyond that offered by the service, which reflected a

psychosocial understanding (Harris, Collinson & das Nair, 2012). While these are useful

findings, they represent findings of larger qualitative studies whose aims were to explore

experiences of distress and not diagnosis.

A smaller body of literature has focused on the experience of being labeled using

psychiatric diagnosis and subsequently living with a diagnosis, attempting to separate out

the effects of living with distress and living with a label (e.g. Howe, Tickle & Brown, 2014;

Black, Thornicroft & Murray, 2013). Giles and Newbold (2011) explored the use of

diagnosis in online mental health communities, finding that diagnosis was desired to allow

forum users to feel part of the group identity of individuals with the same diagnosis and was

used as proof of their distress. As Hayne (2003) asserts, it is important to recognise "the

distinctness of diagnosis as a phenomenon of the illness experience" (p. 722). It is this body

of literature that is the focus of this metasynthesis.

The Current Metasynthesis

Metasynthesis is an interpretative analysis of qualitative studies, which creates a

synthesis of those studies, grounded in empirical data (Shaw, 2012). The aim is to increase

the utility of the findings of the studies featured and the stories told by their participants.

With the established body of qualitative research investigating experience of diagnosis for

PRPD and the controversy surrounding the use of diagnosis in policy and practice,

metasynthesis seemed timely and useful. The aim was to create a synthesised understanding

of the experience of diagnosis from multiple studies.

Noblit and Hare's (1988) metaethnographic method is the most commonly cited

approach to metasynthesis used in published metasyntheses (Bondas & Hall, 2007) and was

used in this metasynthesis. This method was selected because it was considered to meet the

aim, which was to explore the contribution of the collection of studies as a whole and

produce higher order themes, preserving the interpretations of participants' original

accounts. The metaethnography process achieves this through comparison of the findings of

original studies, allowing similarities and differences in findings to be explored.

This metasynthesis is conducted from a social constructionist stance, acknowledging

that the themes found are the author's construction of participants' experiences of diagnosis,

based on the research findings of the studies included in the metasynthesis, and there is no

ultimate truth to be uncovered (Creswell & Miller, 2000).

Methodology

Diagnosis and Research

As discussed, the DCP made a recent statement questioning the validity of diagnosis and suggesting that CPs use less stigmatising frameworks for understanding human experience (BPS, 2013). However, most qualitative research exploring the experiences of PRPD is predicated on diagnosis, for example, studies that claim to explore the experience of participants diagnosed with obsessive compulsive disorder (Murphy & Perera-Delcourt, 2012) and bipolar disorder (Inder et al., 2008). The majority of papers in this metasynthesis can also be characterised in this way, however this metasynthesis explores the experience of diagnosis as a construct and does not just explore the experience of those who are considered to fall into a single diagnostic category. This is because the aim of this metasynthesis is to explore the phenomenon of diagnosis; regardless of the category ascribed to participants. However, the influence of individual diagnostic categories was not ignored in the process of synthesis.

Inclusion/Exclusion Criteria

Articles that met the following criteria were included in the metasynthesis: used adult participants and focused on the experience of adults; explored the experience of psychiatric diagnosis; used qualitative methods and reported qualitative data; published in a peer-reviewed journal to give an initial judgment of quality; included data from PRPD and where data were included from, for example, service providers or carers, data and themes from PRPD were clearly distinguished; published in English (to avoid the prohibitive cost of translation); provided analysis of first-hand experiences of PRPD with participant quotations included in the article; offered interpretive, inductive analysis.

Given the lack of research in this area and this metasynthesis being the first attempt to review this literature, the decision was made to include articles that used a range of

methodologies and epistemologies, where an inductive, interpretive method was used, to allow a full representation of qualitative research in the area. Papers that did not use an inductive approach were excluded. For example, a study by Giles and Newbold (2011) was excluded, after the full paper was read, because although it explored diagnosis in online communities it did not take an inductive approach. Using conversation analysis, data were analysed according to themes that were pre-determined from previous research, which was a deductive approach.

Search Terms

Literature searches took place up to 9th January 2015. The search terms in Table 1 were generated from the APA and EBSCO host thesauruses and were used to search the databases, in the quest for a high recall and high precision search strategy (Buckland & Gey, 1994).

TABLE 1 HERE

Databases Searched

Five databases were searched with the terms mentioned above. No date restrictions were imposed. *PsychInfo* was searched using advanced search option, 'Boolean search' and 'peer-reviewed journals' selected. *PubMed*, *CINAHL*, *Web of Science*, and *Academic Search Complete* were also searched, with similar search strategies. Figure 1 shows a flowchart of article selection (adapted from Cairns, 2014). When narrowing down the search, duplicates were removed and then titles of all papers yielded by the search were read. The majority of these papers were quantitative and this was clear from the title. Where it was not clear from the title whether the paper was relevant or not, usually in the case of qualitative papers in the search, the abstract was read to determine relevance. For example, it was unclear from the title whether a paper by Rogers and Dunne (2011) explored the experience of having a diagnosis of 'personality disorder', however on reading the abstract it was clear that the

focus of the paper was inpatient experience. The author is confident that all relevant papers were retrieved, given that the search strategy was developed using comprehensive thesauri, with the support of a specialist librarian. It was also clear from hand searching reference lists of included studies that there were no references discovered, other than that indicated in Figure 1, in addition to the systematic searches of databases.

FIGURE 1 HERE

Characteristics of Studies

Twelve articles met the inclusion/exclusion criteria; see Table 2 for a summary of their characteristics. Six studies took place in the UK, three in New Zealand, two in Australia, one in Canada and one in the USA. There were 207 participants across the studies. The participant age range was 23-79 years. Participants were recruited from a range of sources: research networks, doctors' surgeries and mental health, forensic and inpatient services.

TABLE 2 HERE

Evaluating Quality

The Critical Appraisal Skills Programme (CASP) tool (Public Health Research Unit [PHRU], 2006) was used to evaluate the reporting quality of the articles (see Table 3 for scores). This evaluation was used to allow for critical consideration of the reporting quality of the articles, not to exclude them based on scores, because there is no consensus on markers of quality in qualitative research (Sandelowski & Barroso, 2003) and limits on what is reported can be imposed, for example by journal guidelines.

CASP was used with a four point rating scale, adapted from that used by Duggleby et al. (2010) and by Murray and Forshaw (2013). The first two questions of the CASP are for screening purposes, asking that there is a clear statement of aims for the research and that a qualitative methodology is appropriate; all articles met these screening criteria. In this

framework zero points were awarded where a particular issue was not reported on, one point where there was little explanation, two points where some explanation was given but not elaborated (for example it mentions ethical approval was granted but does not elaborate) and three points were awarded where full explanation was given. A sample of articles and CASP scores were audited by a peer to consider consistency in the application of the CASP tool and where there were inconsistencies, scores were negotiated to come to consensus.

TABLE 3 HERE

Analysis and Synthesis

The method followed the steps of Noblit and Hare (1988). The first two stages have been described above; identifying a research question and carrying out literature searches.

Step three- first reading of articles. Articles were read, recording contextual details such as sample and settings, to collate Table 2 and allow comparison. The articles were analysed by order of publication, with awareness that the order in which articles are read can influence the analysis (Noblit & Hare, 1988). Themes, subthemes and quotations illuminating the themes, which were relevant to the research question, were selected from each article and written on Post-It notes.

Step four- deciding how the studies are related to each other. This involved understanding the themes drawn out of each article and making initial judgments about how these were related to those from the other articles. The Post-It notes were placed on flipchart paper (Appendix 1-B), moving them around throughout the second reading to group them into emerging themes.

Step five- translating studies into one another. This step was a continuation of working toward interpreting themes within and between articles, "translating the interpretations of one study into the interpretations of another" (Noblit & Hare, 1988, p. 32). Crucial to this was checking that the themes and concepts represented the themes of the

original articles and these themes were similar enough to be included in the same synthesised themes. Post-Its were moved around the flipchart to gather a sense of the story or process represented in each theme.

Step six- synthesising themes into higher order themes that preserve and represent the meaning in the individual studies. Concepts were examined for how well they captured the original themes within each article. Table 4 was created to allow tracking of theme development and checking that the overall themes represented the authors' original themes.

Step seven- expressing the synthesis. This article was created to write up the findings. Preferred Reporting Items for Systematic reviews and Meta-Analyses ([PRISMA] Moher, Liberat, Tetzlaff, Altman, 2009) guidelines were referred to when writing up this study, to consider quality of reporting, given that no such guidelines exist for reporting metasyntheses. For example, including a flow chart to show the screening process in the literature searches (Figure 1).

<div align="center">

Findings

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Across 12 articles, four themes were identified to represent the experience of diagnosis for PRPD. Each theme contains subthemes, describing how diagnosis operates within these themes. Interactions between themes and subthemes are discussed throughout. Participant quotations are provided to illuminate the findings; where provided, pseudonyms used in original studies are reported. Table 4 shows which themes from the original articles were synthesised into the themes presented here and Figure 2 gives a diagrammatic representation of themes.

TABLE 4 HERE

FIGURE 2 HERE

The Diagnostic Experience: Questioning Validity and Utility

The first theme represents the experience of the diagnostic process. Participants were mostly critical of this process, many struggling to identify their own experience in the diagnostic categories attributed to them and finding a lack of transparency and explanation from professionals. Most papers recounted experiences of multiple diagnoses being given or changes made to diagnoses. These experiences often led participants to question how valid and useful diagnoses were.

Lack of fit and lack of utility. Participants described how diagnosis was presented to them by professionals as fact; Andrea was told "this is definitely what you have, we are 100% sure" (Horn, Johnstone, & Brooke, 2007, p. 261) with little transparency about how diagnoses were reached; "I don't know how they diagnosed me" (Paul in Howe et al., 2014, p. 151). Carol could not see the relevance of diagnosis to her own personal experience ("it was just a name, it didn't really mean much", Horn et al., 2007, p. 261). The labels themselves were associated with derogation; "it's a horrible term for someone", says Sandra about personality disorder, and Margaret suggests the personality disorder label does not accurately describe her distress; "I think it should be changed to something to do with feelings and emotions" (Stalker et al., 2005, p. 365).

This lack of personal resonance, which other participants noted, led them to question the utility of a label imposed by others; for example one participant stated "I don't think it gave me anything constructive" (Hayne, 2003, p. 726). Conversely, Robert expressed that for him diagnosis was an accurate naming that did not cause distress; "I don't see any problem because that is exactly what I suffer from" (Stalker et al., 2005, p. 365).

Professionals were reported to consider PRPD not seeing the personal significance of diagnosis as denial or lack of insight but one participant in Moeke-Maxwell, Wells and Mellsop (2008, p. 10) suggested that education about how diagnosis fits personally can

encourage ownership of it; "if you feel like you own it, then you're going to accept it".

However there was some suggestion that professionals were inconsistent in their

explanations of diagnoses ("they think it's some kind of chemical imbalance in the brain

[…] but they can't explain it"; Howe et al., 2014, p. 156). There was also a sense that those

fitting the "textbook" definitions of diagnoses received better treatment, because

professionals felt more confident dealing with those people (Gary in Horn et al., 2007, p.

262).

Questions about the applicability of the diagnosis were ongoing, with one participant

stating "when I'm normal that's when I find it hard to accept that I've got it" (Inder et al.,

2010 p.101), suggesting that absence of symptoms causes confusion about the permanency

of diagnosis. Barbara also expressed this confusion by saying, "it is a permanent thing. But I

actually find that sometimes I am better" (Stalker et al., 2005, p.363).

Multiple and changing diagnoses. Participants spoke about diagnoses being

changed by professionals over time; this "flip flopping between" (Milton & Mullan, 2014, p.

5) understandably caused confusion and led to questioning the validity of these diagnoses

(whether they accurately represented their distress), losing faith in services and the

diagnostic system; "it comes to the point where you think, 'ok I'm not going to believe in

your diagnosis'" (Moeke-Maxwell et al., 2008, p. 10). The distress caused by changing a

diagnosis was clear; one participant discussed how new diagnoses and new medications

came with new psychiatrists and how those changes "tore my world apart" (Moeke-

Maxwell et al., 2008, p. 10).

Reaction to Receiving the Diagnosis: Devastation and Hope

This theme describes participants' initial reactions to receiving a diagnosis, which

was in some ways devastating but also instilled some hope and offered a sense of relief.

Legitimisation and containment. A strong subtheme was an initial feeling that diagnosis legitimises the distress experienced by PRPD as medical, real and not their fault (Pitt, Kilbride, Welford, Nothard & Morrison, 2009), which feels containing for them because they then feel like those problems can be treated with medication. One participant described their initial response to diagnosis; "yes I know what's wrong with me. Now I might be able to fix it" (Moeke-Maxwell et al., 2008, p. 3). It was a process of making their illness evident, validating their previous experiences or symptoms as not normal, and allowing the treatment phase to begin. Having a name for their difficulties was important; "if you can name it, you can claim it, you can tame it" (Hayne, 2003, p. 727). Those who identified with the diagnosis felt that it offered a useful framework for explaining their distress, indicating an interaction with the *lack of fit and utility* subtheme; where diagnosis did not fit with experience it offered less opportunity for *legitimisation and containment*.

This reaction was mostly evident for people who had struggled to access services and diagnosis, with one participant explaining that it was "a relief" to finally know what was wrong (Pitt et al., 2009, p. 421). For some participants relief came when they were able to access services due to diagnosis. However, as the next subtheme attests, diagnosis providing a means of access to services was not straightforward.

Hope that diagnosis was a means to access services. Diagnosis creating a means to access services was dependent on diagnostic category. For some, particularly those diagnosed with psychosis, it gave them access to services, which had often been denied pre-diagnosis; Paul said "it's nice to get [the diagnosis] because then you get help" (Howe et al., 2014, p. 157).

However, for those diagnosed with personality disorders, a diagnosis often meant exclusion from services. During the reading of papers, it was hypothesised that for the UK studies, this would be a finding of older studies, published before the release of the National

Institute of Mental Health's (2003) paper insisting that people diagnosed with personality disorder should no longer be excluded from mental health services, aiming to improve outcomes and quality of life. However, experiencing exclusion and stigma as a result of this diagnosis continued to be evident in papers as late as Black et al. (2013).

Unfortunately, for those diagnosed with personality disorders, the diagnosis was pejorative and felt like "being labeled and judged versus diagnosed and treated" (Nehls, 1999, p. 288). One participant felt like a "burden to everyone" (Brenda, Horn et al., 2007, p. 261), suggesting that this rejection is internalised. This subtheme indicates that the individual perception of hope after diagnosis can interact with the more negative social and service context.

Devastation, hopelessness and shame. Many participants spoke about feeling distress, in addition to and separate from the distress linked to their mental health issues, in response to diagnosis. Where participants spoke about their reactions to diagnosis, the language used was emotive; one participant spoke about feeling "devastated" (Moeke-Maxwell et al., 2008, p. 9). A participant in Nehls' (1999) study spoke about being given a diagnosis as "like a knife to the heart", leaving a feeling that "life as I knew it just had completely ended" (p. 725). Being given a diagnosis with a lack of information further increased hopelessness.

Some participants had internalised societal narratives about people with mental health problems, which meant that they applied those narratives to themselves when the diagnosis was made; "I just thought schizophrenic people go around murdering and raping people […] I'm not schizophrenic, you know what I mean" (Pitt et al., 2009, p. 421). Lack of opportunity to discuss diagnosis increased reliance on already internalised narratives; Maureen stated "no one has ever explained it [her diagnosis] to me" (Stalker et al., 2005, p. 365) and one participant spoke of an "increasing reluctance to use names of diseases"

(Milton & Mullen, 2014, p. 4), which seemed to contribute to the lack of discussion about diagnosis. Lack of discussion about how diagnosis fits with personal experience was identified as a problem in the *lack of fit and lack of utility* subtheme; it seems here that not understanding how diagnosis fits with their experiences led some participants to react negatively to it and experience it as destroying a sense of hope.

Personal Experience: Impact on Self

This theme explores the impact of diagnosis on the sense of self and later the *identity and diagnosis* subtheme explores its impact on identity. Although these concepts are difficult to define, here, the self is considered a cognitive and affective (Heatherton, Krendl, Macrae & Kelley, 2007) "representation or set of representations about oneself, parallel to the representations people have of other individuals" (Swann & Bosson, 2010, p. 591). The self holds the representation of one's identity, which is formed through identifications with significant others (caregivers, groups) who we might positively identify with and aspire to be like, or wish to disassociate from (Weinrich, 2003). Therefore self is our internal representation of who we are and identity is our understanding and subjective experience of how the self operates in a social context, in relation to others. The metasynthesis revealed that, for some, diagnosis caused the loss of an established sense of self, with the subsequent rebuilding of narratives about self.

Losing who I am. Some participants described how diagnosis assaulted their established sense of self; as Kevin described "it was like breaking a glass" (Hayne. 2003, p. 725), leaving participants feeling that they no longer knew themselves and yearning for their sense of self pre-diagnosis. One participant described "coming to terms with the loss of who I am, and that I sometimes feel I cannot be the person I once thought I was" (Proudfoot et al., 2009, p. 125). This sense of deconstruction was palpable and emotive, with Irene describing feeling "like a newborn child" (Hayne, 2003, p. 726). This loss of self seemed to

be in response to the naming of distress using diagnosis; "when they name the mental illness it denies you a being" (Irene, Hayne, 2003, p. 726). For Sandra, diagnosis of personality disorder suggested a fundamental flaw in her representation of herself; "there is something wrong with my personality and it is disordered in some way" (Stalker et al., 2005, p. 363).

Rebuilding narrative: past and present. As a response to diagnosis, some participants had to reattribute their history and their past sense of self, according to their label. There were similarities here to the subtheme *legitimisation and containment*; participants felt that the label helped them make sense of previous difficulties; "I can see now with my money problems and the way I sort of behaved in the past. Definitely not normal" (Inder et al., 2010, p. 160). This went beyond legitimising and finding explanations for past experiences and behaviours; there was a sense that some participants reframed their entire lives through the lens of diagnosis, internalising it as an explanation. For example, a participant in the Delmas, Proudfoot, Parker and Manicavasagar study described this as "[…] like a totally new framework, like you had always been speaking English and now you will be speaking Chinese […] It's always been Chinese you just thought you spoke English. I've had to recode all my past experiences" (2011, p. 921).

Rebuilding the narrative of the past seemed to be a positive experience for some participants but led to a negative narrative about self in the present. A participant spoke about developing a persistent acceptance that they would never be normal, always "defective" (Delmas et al., 2011, p. 137) and disliking their new self; "I hate the person I've become" (Proudfoot et al., 2009, p. 126). The perceived "permanency" (Danielle in Milton & Mullan, 2014, p. 263) of diagnosis suggests that this change in self is permanent. Belief in a part of the self that was not about their distress was protective for one participant; Ben attests "I'm pretty normal in most ways" (Howe et al., 2014, p. 156).

Interpersonal Experience: Relationships and Identity

Many participants discussed how others reacted to them, often applying stigmatising beliefs, resulting in them learning not to disclose their diagnosis, which led to isolation. Here, stigma is considered to be a social construction, which defines and devalues people according to certain characteristics, for example experiencing distress (Dovidio, Major & Crocker, 2000). As noted earlier, participants felt shame based on their internalised views about mental health difficulties. This theme explores how participants felt shame based on others' reactions to them and their diagnosis, how these experiences impacted on their identity and the way they communicated their distress to others.

Stigma, non-disclosure and isolation. One participant spoke of feeling stigmatised as incompetent and "subnormal" (Janet in Howe et al., 2014, p. 156). There was some difference according to diagnosis, with PRPD diagnosed with personality disorders feeling judged as dependent, overly emotional and manipulative (e.g. Horn et al., 2007; Nehls, 1999), and people diagnosed with psychosis feeling judged as violent (e.g. Howe et al., 1999). Because of this stigma, many participants did not wish to disclose their diagnosis to friends, family members, employers, members of the public and sometimes mental health professionals; "I've learned from experience not to give that diagnosis […] because it just has a lot of negative ramifications" (Nehls, 1999, p. 288). This fear of stigma led to non-disclosure, which led to isolation and not getting the help they needed. One participant had learned this the hard way after disclosing their diagnosis; "I lost all my friends… yes I lost them all" (Pitt et al., 2009, p. 421).

Identity and diagnosis. Where participants spoke about how they project themselves into the world, accepting diagnosis as a part of their identity and not its totality seemed to have positive consequences; "I always say schizophrenia, not 'a schizophrenic', you happen to have schizophrenia, but you're a human being first, with a life and dreams

and goals" (Milton & Mullan, 2014). Some participants hoped that others would also view

them in this way; Carol expressed a preference for others to "treat you as a person, rather

than a diagnosis" (Horn et al., 2007, p. 203). Participants preferred to be treated holistically

by professionals; "some would treat the illness, some would treat the person, and the ones

that treated the person would have better outcomes" (Milton & Mullen, 2014, p. 4).

Allowing the label to define identity (being a "schizophrenic", Pitt et al., 2009, p. 421)

hindered recovery.

Summary of themes

The themes above indicate that the experience of being diagnosed, as explored in the

diagnostic experience theme, caused some participants to question how much their

diagnosis applied to them and therefore question the utility of their diagnosis (*lack of fit and*

lack of utility). Having a diagnosis changed (*multiple and changing diagnoses*) led to further

questioning of fit and utility and left some participants feeling confused and questioning the

utility of diagnosis. The emotional response to diagnosis was explored in the *reaction to*

receiving the diagnosis theme, which suggested that for some, diagnosis offered

legitimisation and containment because it offered a name for their distress and a framework

within which to understand and manage it. Some of this containment came from the hope

that diagnosis was a *means to access services*, however this was not a straightforward

process for all participants. A very different emotional reaction reported by some

participants was *devastation, hopelessness and shame*, often because diagnosis activated

internalised, negative societal narratives associated with their diagnosis.

The *personal experience: impact on self* theme indicated that some participants felt

that they lost an established sense of self (*losing who I am*), and some went through a

process of *rebuilding the narrative* of their life, through the lens of their diagnosis, making

alternative attributions and explanations for some life events and difficulties. This rebuilding

of the *past* led to incorporating diagnosis into their sense of self in the *present*, which was overwhelmingly negative.

Participants' *interpersonal experience* of diagnosis incorporated their relationships and identity. In the *stigma, non-disclosure and isolation* subtheme, participants discussed experiencing stigma as a result of their diagnosis, or at least perceiving stigma, which resulted in non-disclosure of their diagnosis and sometimes their difficulties, leading to isolation and not getting appropriate support. The *identity and diagnosis* subtheme suggests that some participants accepted diagnosis as part but not all of their identity and wished to be seen holistically.

It is important to note that a linear process cannot be derived from this metasynthesis, for example it cannot be determined that all participants went through an experience of losing their established self (*losing who I am*) and then started to rebuild that sense of self (*rebuilding self*). Rather, the findings indicate that the experiences denoted in the themes were pertinent for some participants and indicate potential reactions to diagnosis and how that diagnosis might operate in personal and interpersonal domains.

Discussion

The aim was to synthesise qualitative research exploring the experience of diagnosis. The understandings about diagnosis found in this metasynthesis are elaborated on in this discussion, suggesting ways to move towards an approach that preserves the positive consequences of diagnosis and compensates for its negative impact.

The Self and Identity

Research suggests that sense of self is shattered when distress is experienced and the rebuilding of an enduring sense of self is an important part of recovery (Davidson & Strauss, 1992; Young & Ensing, 1999). Other research suggests that an enduring sense of self is reshaped, rather than shattered, when an individual experiences distress (Romano, McCay,

Goering, Boydell & Zipursky, 2010). In this reshaping or rebuilding, developing a perspective that distress is simply one part of the self promotes recovery (Davidson, O'Connell, Tondora, Lawless, Evans, 2005). However, current findings suggest an overwhelmingly negative impact of diagnosis on self.

The findings of this metasynthesis suggest that the naming of distress (diagnosis) could impact on sense of self, separate to the experience of distress. Sense of self is shattered as a result of diagnosis (*losing who I am* subtheme) and sense of self in both the past and present must be rebuilt according to diagnosis (*rebuilding the narrative*). Inder et al. (2008) suggest that, for people diagnosed with bipolar disorder, incorporating bipolar disorder into their sense of self was vital in terms of moving on and accepting their 'illness'. However, these results (*rebuilding the narrative*) suggest that this can be a negative process, as rebuilding a sense of self based on diagnosis led to a negative sense of self.

Research suggests that experiencing distress impacts on identity and leads to the re-development of that identity, but no clear model about how this happens exists (Wisdom, Bruce, Saedi, Weis & Green, 2008). These findings show that identity was sometimes altered to include diagnosis as part of it and this was a positive process for some (*identity and diagnosis*), when others also accepted it as only part of that person's identity.

This suggests that diagnosis has a negative impact when it is incorporated into an individual's sense of self, but it can be positive when incorporated into identity. Distinctions between self and identity in the literature seem blurred but these findings can be best understood within systemic theorising about self. Systemic theory considers self to be relational, fluid and bought into existence by the narratives used to describe it, with self being limited by the opportunities and social environment of the individual (Flaskas, 2002). Identity is created by the constancy of these narratives (Anderson, 1997) and therefore it makes sense that a change in these narratives, for example introducing diagnosis, would

impact self (by offering alternative narratives for understanding past behaviour and present self) and identity (by challenging the constancy of existing narratives).

The key difference in the findings about self and the findings about identity was that participants seemed to enter into the process of rebuilding the narratives about self alone, accessing internal narratives, whereas changes in identity were about interactions with others. Therefore, here, when a person understands self individually, diagnosis has an overwhelmingly negative impact. However, when they start to consider their identity, in relation to and with others, where others support them to see diagnosis as only part of that identity, this is a positive experience. Therefore the interpersonal experience of diagnosis is important.

Implications for Practice. If diagnosis leads to questioning sense of self (*losing who I am*), *rebuilding the narrative* of life and trying to incorporate diagnosis into identity, it is pertinent to think about approaches that might facilitate this as a positive process. One approach that would allow understanding of experiences without imposing frameworks is narrative therapy (Morgan, 2000), where the practitioner sits in the 'not-knowing' position (Anderson & Goulishian, 1992) and shows curiosity about the life story of the client. The use of a narrative approach for PRPD has been discussed previously (Kirkpatrick, 2008) and could offer a way for PRPD to understand their experiences within a framework they have co-created with a therapist, which would not exclude medical frameworks.

It is important for practitioners to be aware of a person's reaction to their diagnosis and how they make sense of it. Cognitive Analytic Therapy ([CAT], Ryle, 1997) makes use of Vygotsky's (1978) concept, zone of proximal development (ZPD), which suggests that new learning can only take place when new information or skills to be learned are close enough to but different enough from a person's current perceptions. This highlights the importance of understanding the views of PRPD so that any work with their understanding

of distress is within their ZPD (which may include diagnosis and medical understandings) and is palatable for them.

All professionals should be aware of the impact of diagnosis on self and identity so that PRPD are supported to think about the meaning of diagnosis to them. Participants feeling like they lost their established sense of self (*losing who I am*) and rebuilding it according to diagnosis was an overwhelmingly negative experience, which could be mediated by communicating diagnosis as a name or an explanation for distress and working on a richer narrative, rather than diagnosis being something that has to be incorporated into sense of self, which is advocated elsewhere (Inder et al., 2008).

Using Diagnosis and Formulation

This metasynthesis suggests that diagnosis does have purpose for clients (for example offering *legitimisation and containment*); therefore it is important to think about how diagnosis can be used with psychological approaches. DCP guidance (BPS, 2014) urges services not to insist that PRPD adopt an illness representation of distress, in fact it insists that no overarching framework should be adopted. These discourses already exist in mental health policy and practice, with recovery-oriented practice in the UK emphasising the importance of shared meanings (Shepherd, Boardman & Slade, 2008; Turton et al., 2011).

Psychological formulation is "a *hypothesis about a person's difficulties*, which *draws from psychological theory*" and is co-constructed by a therapist and their client (Johnstone & Dallos, 2006, p. 4, original emphasis). In this metasynthesis, some participants felt shame about their diagnosis because they had internalised negative societal beliefs (*devastation, hopelessness and shame*) and experienced stigma from others (*stigma, non-disclosure and isolation*). PRPD internalising stigmatising beliefs that the general public hold is documented elsewhere (Read & Harré, 2001), which is not surprising given that they are part of the general public. Participants also spoke about a lack of information and discussion

about diagnosis (*lack of fit and lack of utility*), perhaps reinforcing the idea that diagnosis is shameful and so should not be discussed, increasing reliance on already held beliefs. Having an understanding of a personal formulation, rather than, or as well as, a label that comes with stereotypes, could be a less shaming experience.

It can be argued that although formulation is not a panacea, it offers the opportunity for sense making without a pejorative label. As Pilgrim suggests, "[l]ike diagnoses, formulations are fallible, but they are more plausible and more respectful of human complexity and the patient's right to recognition" (2015, p. 7). Qualitative research shows that formulation can be a difficult and emotional process for PRPD, with biological explanations sometimes preferred because they are validating, socially acceptable and less blaming of PRPD and others (Leeming, Boyle & MacDonald 2009). This is in line with findings from this metasynthesis about diagnosis offering legitimisation for the reality of participants' distress (*legitimisation and containment*), as well as access to services for some (*hope that diagnosis was a means to access services*). However it was also linked to stigma and hopelessness in the Leeming et al. (2009) study, as it was in the current metasynthesis (*devastation, hopelessness and stigma*). Leeming et al. (2009) suggest working with clients to develop resources for explaining their difficulties to others in a way they feel is comfortable for them. This could come from formulation, with the explanations developed for the individual being shared with others, however other explanations might sit alongside formulation.

Implications for using diagnosis and formulation in practice. Formulation should be done in a collaborative, person-specific not problem-specific and collaborative way, according to guidance (DCP, 2011). This needs to take account of and explore personal meanings attached to distress, including diagnosis and medical models of understanding. Perhaps then, to have utility for PRPD, within mental health services and societal

discourses, formulation has to move beyond the individual, to allow real biopsychosocial meanings to be shared, away from what Pilgrim describes as "psychological reductionism" (2014, p. 297). If diagnosis offers *legitimisation and containment*, those positive outcomes need to be preserved and perhaps heightened by offering explanation about the relevance of diagnosis to that person, not simply dismissing it outright.

As Pilgrim suggested, "there are good reasons to move towards a clearer position regarding the roles of diagnosis and formulation" (2010, p. 449). The DCP position statement (BPS, 2013) goes some way towards this. Perhaps guidance is needed about how to implement alternative approaches in a diagnostically driven environment. Developing shared meanings with PRPD about their difficulties is indicated here, which would include open discussions about diagnosis and how it might or might not fit for that individual (as indicated in the *lack of fit and lack of utility* subtheme). Developing truly collaborative understandings of distress would be in line with health policy in England that strives for PRPD and professionals working in partnership (Department of Health, 2006).

Limitations

It must be noted that the studies were conducted internationally and therefore in a range of cultures, policy and healthcare systems, which may influence the results. However, despite these diverse circumstances, there was greater similarity than difference in participants' experiences of diagnosis.

Separating out the experience and impact of diagnosis and the experience and impact of distress is not a simple task. For example, in subthemes *losing who I am* and *rebuilding self*, it is difficult to know how much of those processes are about diagnosis and how much are about the underlying distress, which is perhaps difficult for participants and researchers to disentangle. However, with the *personal experience* theme, participants seemed clear that the trigger to these issues with self was the point of diagnosis, even though they had often

been living with their distress for years. The complexity and interconnectedness of these experiences should be noted.

The CASP (PHRU, 2006) scores (Table 3) indicated that reporting quality of many of the studies could be improved. It is important to note that the contribution that each study is able to make to a metasynthesis depends on reporting quality, particularly in terms of how findings are reported. Findings of the studies of greater quality and those that provided more detail and insight into participants' experience of diagnosis (e.g. Horn et al., 2007) are reflected within the findings of this metasynthesis more than articles of poorer reporting quality and that explored other experiences in addition to diagnosis (e.g. Inder et al., 2010).

Future Research

The decision not to include findings about diagnosis in qualitative research that explored other aspects of living with distress was justified in the methodology section. However, some valuable insights into the experience of diagnosis, which are included in that literature base, may have been missed. This could make an interesting topic for a further metasynthesis.

Given that this metasynthesis found participants to have had similar experiences across diagnoses, it is interesting that a lot of research chooses to sample participants based on diagnosis, for example Inder et al. (2008) studied the impact of a diagnosis of bipolar disorder on the development of self, as discussed previously. This metasynthesis has found that the impact of diagnosis on self is similar across diagnoses, which suggests that Inder et al.'s (2008) findings could also be relevant for other PRPD who have not been diagnosed in the same way. Researchers perhaps need to grapple with these issues in order to maximise the utility of their findings.

Conclusion

This metasynthesis has explored the experience of being diagnosed with a mental health problem and has shown that diagnosis is a largely problematic phenomenon but it does have value for PRPD. There are other approaches to enabling PRPD to understand their distress and difficulties, particularly narrative approaches and psychological formulation. Diagnosis can helpfully form part of those approaches, which are not unproblematic themselves. Because diagnosis remains an influential framework for understanding distress, suggestions have been made about using diagnosis more constructively, perhaps minimising some of its negative effects. It seems there is a need to engage with the complexity of human experience (sometimes labeled as distress, mental health or illness) but also with the complexity of the impact of our existing frameworks for understanding distress. This may involve diverting attention and resources from the formulation versus diagnosis debate, towards achieving a better understanding of the underpinning ideas in both these constructs that support people to understand distress.

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    with psychiatric disabilities. *Psychiatric Rehabilitation Journal*, 22, 219–31.

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*Studies are included in the metasynthesis

Figure 1

Flow Diagram for Inclusion of Articles in the Metasynthesis

Number articles retrieved in initial search
PsychInfo- 3184
Academic Search Complete- 1674
CINAHL- 1282
Web of Science- 1255
International Bibliography of the Social Sciences- 153

Total titles read for initial consideration- 7548

Total abstracts read for further clarification- 44

Total initially meeting inclusion criteria- 18

Excluded due to
- Not qualitative research- 2
- Findings unhelpful for current research question- 4
- Not inductive approach- 1

Hand search identified- 1
(Stalker, Ferguson &
Barclay, 2010)

Included in the metasynthesis- 12

Figure 2

Themes Diagram

Table 1

Search Terms

Search Term	AND	AND	AND
("Mental Disorders" OR "Affective Disorders" OR "Alexithymia" OR "Anxiety Disorders" OR "Chronic Mental Illness" OR "Dissociative Disorders" OR "Eating Disorders" OR "Impulse Control Disorders" OR "Mental Disorders due to General Medical Conditions" OR "Neurosis" OR "Paraphilias" OR "Personality Disorders" OR "Psychosis" OR "Schizoaffective Disorder" OR "depression" OR "obsessive compulsive disorder" OR "bipolar")	(Diagnosis OR "psychiatric classification")	(questionnaire* OR survey* OR interview* OR "focus group*" OR "case stud*" OR observ* OR "grounded theory" OR narrative OR thematic OR experienc* OR "content analysis" OR ethnolog* OR Qualitative OR hermeneutic OR "interpretive phenomenological")	(label* OR stigma OR experience OR individual)

Table 2

Summary of Articles

Article	Research question/ aim	Methodology: method of data collection and analysis	Participants: setting, diagnosis, age range (years), sample size, gender [a]
Nehls (1999)	Explore the experience of living with a diagnosis of borderline personality disorder.	Individual interviews; Interpretive phenomenological analysis (IPA)	USA; recruited from a crisis intervention service, outpatient mental health clinic and an acute psychiatric unit; identified by clinicians as meeting the DSM-III-R or DSM-IV criteria for Borderline personality disorder (BPD); 30 adult female participants.
Hayne (2003)	Explore diagnosis as a distinct part of the mental illness experience.	Individual interviews; hermeneutic phenomenological study; thematic analysis	Canada; 14 participants from local mental health association and consumer network; all diagnoses (severe and enduring mental illness); persons with diagnosis and understanding of diagnosis.
Stalker et al. (2005)	Understanding service user and provider perspectives on personality disorder.	Individual interviews; grounded theory	UK; community adult mental health services; personality disorder; 10 service users (8 women, 2 men; White British; 27-52); 9 staff.
Horn et al. (2007)	Explore service user perspectives on diagnosis of borderline personality disorder.	Individual interviews, IPA	UK; BPD diagnosed by a mental health professional and have used mental health services in the last 6 months and have had 2 or more years contact with services; 5 participants (4 women and 1 man, age 23-44).

Moeke- Maxwell et al. (2008)	Explore consumer perspectives on current psychiatric classification systems.	Thematic analysis of focus group data	New Zealand; all diagnoses; 70 participants (32 men and 38 women; age range 26-68; 43 European/Pakeha; 11 Māori; 7 Māori /Pakeha; 1 Australian; 4 Samoan; 2 Cook Island Māori).
Proudfoot et al. (2009)	Explore the experience and difficulties faced by patients after they have received a diagnosis of bipolar disorder.	Email interviews with expert patients; Phenomenology and Lived Experience framework	Australia, bipolar; 26 participants recruited online through Black Dog Institute website, community mental health organisations, media, GPs and psychiatrists (diagnosed in last 12 months; age 18+; currently accessing services; scored 22+ on the Mood Swings Questionnaire).
Pitt et al. (2009)	Explore the impact of a diagnosis of psychosis.	Individual interviews; IPA	UK; service users with a diagnosis of psychosis (bipolar, schizoaffective, schizophrenia, personality disorder) who have used mental health services; 8 participants (6 male; 2 female, aged 18-65; 6 white British; 2 African-Caribbean).

Inder, Crowe, Joyce, Moor, Carter & Luty (2010)	Understand the process patients use to make sense of a diagnosis of a bipolar.	Thematic analysis of therapy sessions conducted as part of the research	New Zealand; bipolar; 15 participants from mental health services, GPs, bipolar support network and self-referral.
Delmas et al. (2011)	Explore the views and experiences of patients and family members about receiving a diagnosis of	Phenomenology and lived experience framework	New Zealand; bipolar; 17 participants with bipolar; 9 family members; 71% female; 28-62 years

bipolar disorder.

Black et al. (2013)	Explore the experience of having a personality disorder within the context of forensic secure and community services.	Individual interviews; IPA	UK; personality disorder; forensic community and secure settings; 10 participants (eight men and two women); awareness of their personality disorder diagnosis and significant experience of forensic services.
Milton & Mullan (2014)	Explore service users' views of communicating news of diagnosis to inform protocol development.	Individual, semi-structured interviews; thematic analysis	Australia; all diagnoses; 45 participants (21 female; age range 25-79 years).
Howe et al. (2014)	Explore the experience of receiving a diagnosis of schizophrenia and the stigma associated with the diagnostic label.	Individual interviews; IPA	UK; community mental health team; 7 participants with a diagnosis of schizophrenia (3 male; 4 female); mean age 44 years.

[a] Where information is not given it was not included in the article.

Table 3

CASP Scores

Article[a]	Design	Sampling	Data Collection	Reflexivity	Ethical Issues	Data Analysis	Findings	Value	Total
Nehls (1999)	3	2	2	0	0	2	2	3	14
Hayne (2003)	3	1	2	2	1	2	2	2	15
Stalker et al. (2005)	3	3	2	2	3	1	3	3	20
Horn et al. (2007)	3	2	2	3	0	2	3	3	18
Moeke-Maxwell et al. (2008)	3	2	1	0	0	1	2	2	11
Proudfoot et al. (2009)	2	2	1	0	1	2	3	2	13
Pitt et al. (2009)	2	1	2	0	0	2	2	3	12
Inder et al. (2010)	2	2	1	0	0	1	2	2	10
Delmas et al. (2011)	2	2	2	0	1	1	3	2	13
Black et al. (2013)	3	2	1	1	1	1	2	2	13
Milton & Mullan (2014)	2	2	1	0	1	2	2	2	12
Howe at al. (2014)	2	1	1	0	1	2	2	2	11

[a] Articles in chronological order; the order in which they were reviewed

Table 4

Themes Synthesised from Individual Articles

Article[a]	The diagnostic experience	Reaction to receiving the diagnosis	Personal experience	Interpersonal experience
Nehls (1999)	Living with a label Living with self-destructive behaviour perceived as manipulation	Living with a label Living with limited access to care		Living with a label Living with self-destructive behaviour perceived as manipulation
Hayne (2003)	A knowledge that knows	A knowledge that knows Knowledge made knowledgeable Making visible the invisible	A knowledge that knows Destructive (gift) of difference Knowledge made knowledgeable Making visible the invisible	Destructive (gift) of difference
Stalker et al. (2005)	Perceived helpfulness of diagnosis Understandings of personality disorder	Perceived helpfulness of diagnosis	Understandings of personality disorder	
Horn et al. (2007)	Uncertainty about what diagnosis meant Diagnosis is about not fitting Knowledge as power	Diagnosis as rejection Knowledge as power Uncertainty about what diagnosis meant	Hope and possibility of change	Uncertainty about what diagnosis meant Avoidance of the diagnosis of schizophrenia Hope and possibility of change
Moeke-Maxwell et al. (2008)	Improvements to classification systems Impact of receiving a variety of diagnoses	Confusion, disappointment and disillusionment Relief and hope		Improvements to classification systems Confusion, disappointment and disillusionment Relief and hope Improvements to classification system

Proudfoot et al. (2009)	Positive and negative reactions to diagnosis	Positive and negative reactions to diagnosis	Questions of identity: who am I? Uncertainty about the future	The image and effect of stigma
Pitt et al. (2009)		Means of access Labeling the person Cause of disempowerment Naming the problem	Labeling the person	Cause of social exclusion
Inder et al. (2010)	Experiencing treatment Making sense of Symptoms		Making sense of symptoms	
Delmas et al. (2011)	Accepting the diagnosis Misdiagnosis and growing awareness	Accepting the diagnosis	Accepting the diagnosis Misdiagnosis and growing awareness	Accepting the diagnosis
Black et al. (2013)	A difficult diagnosis	A difficult diagnosis	How I am, how I was A difficult diagnosis	How I am, how I was
Milton & Mullan (2014)	Recognising the dynamic nature of diagnosis.	Information sharing and knowledge building Realistic hope for the future Recognising the dynamic nature of diagnosis.	Stigma reduction	Stigma reduction Information sharing and knowledge building
Howe at al. (2014)	Lack of understanding of schizophrenia Stigma and diagnostic labels	Being schizophrenic	Being schizophrenic Managing stigma to maintain normality Lack of understanding of schizophrenia	Stigma and diagnostic Labels Managing stigma to maintain normality Being schizophrenic Lack of understanding of schizophrenia

[a] Articles in chronological order; the order in which they were reviewed

Appendix 1-A

Authors' notes for the *Journal of Mental Health*

Journal of Mental Heath
Instructions for Authors

Aims and Scope

The Journal of Mental Health is an international forum for the latest research in the mental health field. Reaching over 65 countries, the journal reports on the best in evidence-based practice around the world and provides a channel of communication between the many disciplines involved in mental health research and practice.

The journal encourages multi-disciplinary research and welcomes contributions that have involved the users of mental health services.

The international editorial team are committed to seeking out excellent work from a range of sources and theoretical perspectives. The journal not only reflects current good practice but also aims to influence policy by reporting on innovations that challenge traditional ways of working. We are committed to publishing high-quality, thought-provoking work that will have a direct impact on service provision and clinical practice.

The Journal of Mental Health features original research papers on important developments in the treatment and care in the field of mental health. Theoretical papers, reviews and commentaries are also accepted if they contribute substantially to current knowledge.

Submissions

All submissions, including book reviews, should be made online at Journal of Mental Health's Manuscript Central site at http://mc.manuscriptcentral.com/cjmh

New users should first create an account. Once a user is logged onto the site submissions should be made via the Author Centre. Please note that submissions missing reviewer suggestions are likely to be un-submitted and authors asked to add this information before resubmitting. Authors will be asked to add this information in section 4 of the on-line submission process.

Manuscripts will be dealt with by the Executive Editor. It is essential that authors pay attention to the guidelines to avoid unnecessary delays in the evaluation process.

The names of authors should not be displayed on figures, tables or footnotes to facilitate blind reviewing.

Word Count

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

Book Reviews

All books for reviewing should be sent directly to Martin Guha, Book Reviews Editor, Information Services & Systems, Institute of Psychiatry, KCL, De Crespigny Park, PO Box 18, London, SE5 8AF.

Manuscript Style

Manuscripts should be typed double-spaced (including references), with margins of at least 2.5cm (1 inch). The cover page (uploaded separately from the main manuscript) should show the full title of the paper, a short title not exceeding 45 characters (to be used as a running title at the head of each page), the full names, the exact word length of the paper and affiliations of authors and the address where the work was carried out. The corresponding author should be identified, giving full postal address, telephone, fax number and email address if available. To expedite blind reviewing, no other pages in the manuscript should identify the authors. All pages should be numbered.

Abstracts: The first page of the main manuscript should also show the title, together with a

structured abstract of no more than 200 words, using the following headings: Background, Aims, Method, Results, Conclusions, Declaration of interest. The declaration of interest should acknowledge all financial support and any financial relationship that may pose a conflict of interest. Acknowledgement of individuals should be confined to those who contributed to the article's intellectual or technical content.

Keywords: Authors will be asked to submit key words with their article, one taken from the pick-list provided to specify subject of study, and at least one other of their own choice.

Text: Follow this order when typing manuscripts: Title, Authors, Affiliations, Abstract, Keywords, Main text, Appendix, References, Figures, Tables. Footnotes should be avoided where possible. The total word count for review articles should be no more than 6000 words. Original articles should be no more than a total of 4000 words. We do not include the abstract, tables and references in this word count. Language should be in the style of the APA (see Publication Manual of the American Psychological Association, Fifth Edition, 2001).

Style and References: Manuscripts should be carefully prepared using the aforementioned Publication Manual of the American Psychological Association, and all references listed must be mentioned in the text. Within the text references should be indicated by the author's name and year of publication in parentheses, e.g. (Hodgson, 1992) or (Grey & Mathews 2000), or if there are more than two authors (Wykes et al. ., 1997). Where several references are quoted consecutively, or within a single year, the order should be alphabetical within the text, e.g. (Craig, 1999; Mawson, 1992; Parry & Watts, 1989; Rachman, 1998). If more than one paper from the same author(s) a year are listed, the date should be followed by (a), (b), etc., e.g. (Marks, 1991a).

The reference list should begin on a separate page, in alphabetical order by author (showing the names of all authors), in the following standard forms, capitalisation and punctuation:

a) For journal articles (titles of journals should not be abbreviated):

Grey, S.J., Price, G. & Mathews, A. (2000). Reduction of anxiety during MR imaging: A controlled trial. *Magnetic Resonance Imaging, 18,* 351–355.

b) For books:

Powell, T.J. & Enright, S.J. (1990) *Anxiety and Stress management*. London: Routledge

c) For chapters within multi-authored books:

Hodgson, R.J. & Rollnick, S. (1989) More fun less stress: How to survive in research. In G.Parry & F. Watts (Eds.), *A Handbook of Skills and Methods in Mental Health Research* (pp. 75–89). London:Lawrence Erlbaum.

Illustrations: should not be inserted in the text. All photographs, graphs and diagrams should be referred to as 'Figures' and should be numbered consecutively in the text in Arabic numerals (e.g. Figure 3). The appropriate position of each illustration should be indicated in the text. A list of captions for the figures should be submitted on a separate page, or caption should be entered where prompted on submission, and should make interpretation possible without reference to the text. Captions should include keys to symbols. It would help ensure greater accuracy in the reproduction of figures if the values used to generate them were supplied.

Tables: should be typed on separate pages and their approximate position in the text should be indicated. Units should appear in parentheses in the column heading but not in the body of the table. Words and numerals should be repeated on successive lines; 'ditto' or 'do' should not be used.

Proofs

Page proofs are sent to the designated corresponding author. They must be carefully checked and returned within 48 hours of receipt. Please note that in the proof stage, only typographical errors, printer's errors and errors of scientific fact can be corrected. No substantial author's changes will be made.

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abstracts, to Shadowfax Publishing and Informa Healthcare. Transfer of copyright enables the

publishers to ensure full copyright protection and to disseminate the article and journal to the

widest possible readership in print and electronic forms.

Appendix 1-B

Example of analysis on flipchart paper
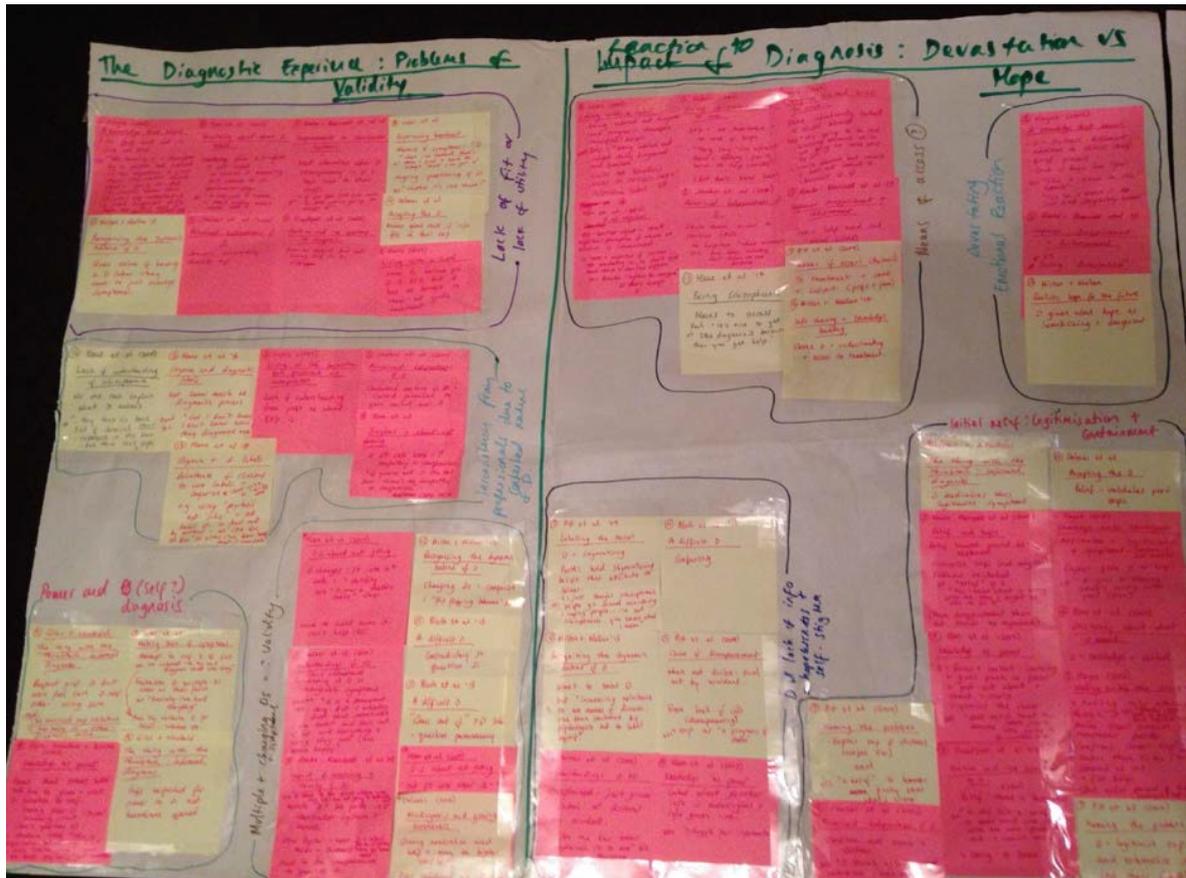
Section Two: Research Paper

Using psychiatric diagnosis in practice: A grounded theory drawing on practitioner

views and experiences

Rebecca Hough

Doctorate in Clinical Psychology

Division of Health Research, Lancaster University

Correspondence should be addressed to:

Rebecca Hough

Department of Clinical Psychology,

Faculty of Health and Medicine,

Furness Building,

Lancaster University,

Lancaster,

Lancashire, UK.

LA14YW

Email: r.hough@lancaster.ac.uk

Tel: +44 1524 593378

Fax: +44 1524 592981

Prepared for submission to *Journal of Mental Health*. [1]

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[1] Please note this manuscript was prepared in line with author guidelines for the *Journal of Mental Health* (See Appendix 2-A). Where these guidelines have not been followed, Lancaster University thesis guidelines have been followed. The word count is also in line with University not *Journal* guidance.

Abstract

Background: There is debate surrounding the use of psychiatric diagnosis in mental health practice, however little is known about how it is used by practitioners and why its use is sustained, when concerns about its validity and impact on those it labels are well documented.

Aims: To develop a grounded theory (GT) that explains how diagnosis is used in adult mental health practice in the National Health Service in England.

Method: GT methodology was used, interviewing ten participants from complex care and treatment teams.

Results: The core category *needing a certain foundation for practice* was constructed from the data, with two further categories; *holding and coping with inconsistent and differing views* and *impact on practice: depersonalisation and not challenging diagnosis*. Findings are discussed in relation to previous research, and to attachment and cognitive theories.

Conclusions: Results suggest diagnosis has survived because it provides, for some, a secure base for practice. For others, the power dynamics inherent in working in a system predicated on diagnosis and the perceived lack of utility of diagnosis, make challenging it unappealing. Suggestions are made to encourage critical consideration of all frameworks used to understand distress.

Declaration of Interests: None.

Keywords: Grounded theory, staff, diagnosis.

Debates about the validity, reliability and utility of classifying distress according to

psychiatric diagnosis (herein referred to as diagnosis) have raged since the 19th century

(Johnstone, 2014). There are two diagnostic classification systems, the *International*

Classification of Diseases (ICD), now in its tenth edition (World Health Organization, 1992)

and the *Diagnostic and Statistical Manual of Mental Disorders* (DSM), now in its fifth

edition (American Psychiatric Association [APA], 2013). Concerns about reliability are

empirically supported by research demonstrating that psychiatrists frequently disagree about

the most accurate diagnosis (e.g. Bentall, 2003, 2009). Comorbidity studies show people who

meet the criteria for one diagnosis most likely meet the criteria for at least one other (e.g.

Boyle, 2002; Timimi, 2011a), raising concerns about validity.

The stigma attached to diagnosis has also been found to have a negative impact on

those it labels (Ben-Zeev, Young & Corrigan, 2010). As justified in section one of this thesis,

in an attempt to use language that does not make assumptions about inner experiences, the

term 'people in receipt of a psychiatric diagnosis' (PRPD) will be used to refer to those who

have been labeled using diagnosis.

This debate has heightened and become more public in recent years, due to the

publication of the updated DSM-5 (APA, 2013). Some believe that the diagnostic system is

inherently flawed ("unreliable and invalid") because categorising distress in this way implies

biological causation, which is not evidenced (The Midlands Psychology Group, 2012, p.7).

The Critical Psychiatry Network in the UK have suggested, in academic literature, that

psychiatry should move away from biological reductionism towards openness to different

systems of meaning (e.g. Bracken et al., 2012).

Fairly new to the debate, in 2013, the British Psychological Society's (BPS) Division

of Clinical Psychology (DCP) released a position statement, in response to the publication of

DSM-V, calling for a "paradigm shift" away from a diagnostic, medical understanding of

distress (BPS, 2013). It suggested that less stigmatising frameworks are needed for a richer

understanding of distress as human experience.

As discussed in the literature review of this thesis, qualitative research with people

who have been diagnosed reveals mixed views and experiences. For some, diagnosis offers a

validating explanation for their distress and a treatment pathway (Leeming, Boyle &

MacDonald, 2009). Diagnosis has also been described as legitimising the problems

experienced by PRPD as medical, real and not their fault (Pitt, Kilbride, Welford, Nothard &

Morrison, 2009). Other PRPD experience it as hopeless when it is delivered without hope for

recovery and its potential personal relevance is not explored (Horn, Johnstone & Brooke,

2007). It has also been suggested that the perceived benefits of diagnosis are compromised by

its lack of validity and reliability (The Midlands Psychology Group, 2012). Therefore,

diagnosis has been shown to have utility for PRPD, but this is potentially compromised by its

questionable validity, reliability and the way it is communicated. Perhaps then, a better

understanding of how diagnostic and other frameworks of understanding are used in practice

is needed.

Existing Research: Practitioners and Diagnosis

There is a small body of research exploring mental health practitioners' views on and

use of diagnosis in practice. Probst (2012) qualitatively explored how social workers (SWs)

in the USA navigate using diagnosis in practice, finding that SWs walked a metaphorical

tightrope needing to exaggerate problems, or fit them into overlapping, ill-fitting categories,

to hastily access services and insurance on behalf of PRPD. However they also felt a pull to

minimise pathologising what they saw as problems of living, so as not to compromise their

ethical values. Diagnosis compromising esteemed professional values was echoed by nurses

in New Zealand in a questionnaire study (Aitchison & Mellsop, 2010); they used diagnosis to

inform treatment plans, communicate difficulties to PRPD and their families and for

admission and discharge thresholds, but believed diagnosis squeezed out alternative

explanations of difficulties and hindered recovery. In the UK, Stalker, Ferguson and Barclay

(2005) explored practitioner views about personality disorder diagnosis. Their participants

felt that diagnosis provided access to some services and a common language for

understanding distress but were concerned about stigma.

A larger scale study with psychologists in 23 countries (Evans et al., 2013) showed

that 60% used a formal classification system (ICD-10 or DSM-IV) in practice to inform

treatment decisions and support communication with PRPD and other professionals, but most

used systems as flexible guidelines rather than strict criteria. A further large-scale

questionnaire study with psychiatrists in Brazil, Japan and New Zealand (Mellsop et al.,

2007), suggested most believed diagnostic systems were important for communication with

other professionals but some felt diagnosis had limited utility in informing treatment plans,

those in Japan and New Zealand questioned cross cultural applicability and most wanted a

simpler and more reliable system.

Therefore, existing research suggests there are sections within all clinical groups

working with PRPD that are critical of diagnosis, however they continue to use diagnostic

systems to communicate and describe the needs of PRPD. As there are for PRPD living with

diagnosis, for staff too there are positive and negative aspects to this paradigm.

Psychology in Mental Health Settings

Formulation in psychology has been considered by some to offer a more

individualised approach to care in contrast to the standardised approaches that can result from

diagnostic categories (Aston, 2009). Psychological formulation has been defined as "a

hypothesis about a person's difficulties, which *draws from psychological theory*" (Johnstone

& Dallos, 2006, p. 4, original emphasis). Formulation developed, arguably, in behaviourism

in the 1950s in the USA, as functional analysis, which developed into case formulation, as an

attempt to establish credibility in relation to psychiatry on the basis that it offered a clearer

pathway to intervention and did not rely on the unobservable mind (it relied on observable

behaviour), like diagnosis did (Eells, 1997). Approaches to formulation based on other

psychological models have been developed since and debate about the respective uses of

formulation and diagnosis has grown (Johnstone, 2006). As Pilgrim and Carey (2010) have

suggested, the divergence of clinical psychology (CP) away from diagnosis and towards

formulation became "a rallying point for a distinctive professional identity" (p. 312) and

some psychologists argue that formulation and diagnosis are fundamentally incompatible

because of the link between diagnosis and biological causation of distress (Vanheule, 2012).

It could be argued that there are advantages for CPs in discrediting diagnosis and

encouraging the use of formulation as the preferred alternative, galvanising their own

professional identity and utility, as distinct from other mental health professionals.

        In the UK, formulation is a core competency for CPs (DCP, 2010). Formulation is

also a core competency for CPs in Australia (Page, Werner, Stritzke & McLean, 2008), and

psychologists in the USA, who are expected to formulate *and* diagnose (American

Psychological Association, 2006). Formulation is not only the domain of CPs in the UK; it is

a competency of practitioner psychologists (Health and Care Professions Council [HCPC],

2012). The DCP (2011) and the HCPC (2012) encourage formulation to be done with teams

(constructing shared understandings of difficulties), and training and supervision of other

professionals to support them to formulate. The Department of Health (DH) too advises

working from shared formulation to guide care in teams (DH, 1999).

        Research about formulation in teams is limited (Johnstone & Dallos, 2006). One

qualitative study found that staff working with adults on an inpatient recovery unit believed

team formulation aided understanding of the individuals they were working with and their

distress but also found differences in participants' views, with some seeing formulation as

'fact', leading to treatment pathways and others seeing it as offering provisional hypotheses to be reflected on (Summers, 2006). Dexter-Smith (2010) found that team formulation helped emotional containment of staff working in stressful jobs.

Rationale for Current Study

As Pilgrim (2014) suggests, it would be useful to move away from considering what is wrong with diagnosis towards considering why alternatives to it have not had a similar impact. If, as the DCP (BPS, 2013) suggest, a new framework is needed for practice, an understanding is needed about why diagnosis has survived for so long, with widespread concern about its validity and impact on PRPD, because this has not been explained by existing research. Mellsop et al. (2007) suggested it was important to "carry out research on the way [diagnostic] systems actually shape and inform clinical care" with all types of practitioner (p. 25). Developing a theory of how diagnosis is used in practice could contribute to an understanding of the processes behind its survival as a dominant paradigm. The aim of the current study thus was to develop a grounded theory to explain how diagnosis is used in adult mental health practice in the NHS.

Method

Design

A grounded theory (GT) methodology was used (Strauss & Corbin, 1998), drawing on techniques from Charmaz (2006), adopting a social constructivist epistemology, where it is acknowledged that all those involved in research (including the researcher) co-construct the realities under study (Pidgeon & Henwood, 1997). GT was considered appropriate to answer the research question because developing a theoretical model of practice, grounded in data, was the primary interest and because it was anticipated that there would be little homogeneity in responses of participants. Traditional GT is defined by its creators as "the discovery of theory from data systematically obtained from social research" (Glaser &

Strauss, 1967, p. 2), originally developed in a positivist paradigm to bridge the gap between

quantitative and qualitative research. The development of GT has been considered a

"methodological spiral" (Mills, Bonner, & Francis, 2006, p. 2), with many approaches

proposed.

Charmaz's (2006) methods were used in this study for a number of reasons. As

elaborated on in the critical appraisal of this thesis, the time and resource constraints of the

thesis required some modifications to the GT method, therefore Charmaz's provision of

"flexible guidelines" (2006, p. 16) was vital. GT lends itself to developing an understanding

of how diagnosis is used because it seeks to explain (in this case how diagnosis is used in

practice) rather than describe and explore (Birks & Mills, 2011).

This study did not differentiate between diagnoses, for example as Stalker et al.

(2003) did when exploring attitudes towards 'personality disorder'. It was felt that this

maintained focus on the use of diagnosis as a general construct and avoided the use of

heavily contested diagnostic categories; as Church (2013) suggests, "our studies remain

encased in the diagnostic categories" we criticise (p. 29).

Research Approvals

The research was approved by Lancaster University Research Ethics Committee (see

ethics section for approval letter [p. 4-29] and other documents) and the trust's Research and

Development (R&D) Department (see ethics section for approval letter [p. 4-30]).

Participants

Participants were recruited from the nine adult mental health complex care and

treatment teams (CCTTs) in one NHS trust. The aim of the sampling method was to recruit

participants who would have experience using psychiatric diagnosis in their work. In

accordance with a purposive sampling method, participants were recruited according to their

job role, which was care coordinator (CC), to ensure that they would be able to provide data

relevant to the research question; they would have experience using psychiatric diagnosis in practice. All participants were qualified social workers or mental health nurses, practising in the CC role, responsible for the care of a caseload of adults who had been labeled as having 'severe and enduring mental health problems' and varying psychiatric diagnoses.

Theoretical sampling is considered by some to be a distinctive feature of GT (Glaser & Strauss, 1967). According to Charmaz, theoretical sampling is seeking "people, events, or information to illuminate and define the boundaries and relevance of the categories" but it is not an essential component of GT research (2006, p. 189). Here, theoretical sampling of participants was not possible due to the small number of participants and demographic data not being collected (in an attempt to preserve anonymity).

Following ethical approval, 10 participants in total volunteered to participate and all were subsequently interviewed. The recruitment strategy, as laid out in Figure 1, was followed. The intention was to interview a representative sample of participants from all nine teams. However, due to only 10 participants expressing an interest, all were interviewed, representing only 7 teams. The methodological implications of recruitment and sampling are elaborated on in the discussion section and in the critical appraisal.

FIGURE 1 HERE

Data Collection

Interviews were conducted at participants' places of work. The participant and interviewer both signed the consent form (see ethics section, p. 4-26) before each interview. Each interview was transcribed and analysed before the next was conducted and interviews were done in blocks (three in the initial block, four in the subsequent block and three in the final block) to allow time in between blocks for theory development (see Figure 2 for data collection and analysis diagram). Interviews were completed between September 2014 and January 2015. An interview schedule that would capture information relevant to the research

question was developed with supervisors and was subsequently altered to test out the

emerging categories (Charmaz, 2006).

FIGURE 2 HERE

Data Analysis

Data was analysed using GT methods (see Figure 2), drawing on techniques from

Charmaz (2006). Consulting the literature on the research topic before conducting a GT study

is a controversial topic, with Glaser and Strauss originally advocating not consulting the

literature to avoid imposing its ideas onto data (Glaser & Strauss, 1967). However, some

grounded theorists suggest that it is unrealistic to expect researchers will not be familiar with

research and theory in their area (Pidgeon & Henwood, 1997).

This issue was approached by conducting a brief, preliminary literature review, to

offer a theoretical rationale for the research, as was a requirement of the ethics protocol (see

ethics section, p. 4-2). However, consulting the literature about practitioner perspectives on

diagnosis in depth was suspended until data analysis was complete (Dey, 1999). It was hoped

that this approach, as well as using memos to make clear any links to extant theoretical ideas,

literature or research, avoided as much as is practicable, imposing those ideas onto the data.

As Charmaz (2006) advises, these extant ideas were also considered critically and treated as

problematic, not as given truths which data should be constructed around.

Grounded theory as an approach has been criticised for failing to acknowledge

implicit theories that guide theory development (Silverman, 2005). Therefore, links made to

existing theory, impressions, interpretations and connections between interviews were

monitored using memos (see example in Appendix 2-B). Memos took the form of diagrams

or written prose, which supported the analytic grasp of the data, noting comparisons between

codes and initial theoretical ideas. These memos were kept in chronological order initially but

were then sorted according to which focused code they explicated or theoretical link they

elaborated on and these were constantly compared to and fed back into the resulting grounded GT. A reflective diary was also used when necessary to record the researcher's reactions to the research process, the interviews and the data gathered, which helped when considering the researcher's role in the construction of the data, in line with a social constructivist approach.

Two levels of coding, advocated by Charmaz (2006), were completed during data analysis, which was done following the transcription of each interview. An example of both levels of coding is given in Appendix 2-C. Initial coding was the first coding stage, which involved line by line coding, focusing tightly on the actual data rather than the preconceived ideas of the researcher (Charmaz, 2006). These codes were specific and active (using gerunds), to enable identification of processes in the data (Charmaz, 2006).

Following this, focused coding was completed, which subsumed initial codes to explain segments of the data and to "advance the theoretical direction" (Charmaz, 2006, p. 138) of the coding. Focused coding allowed comparison between initial codes to determine their power to explain certain phenomena within the data and also to determine the codes or groups of codes that were initial categories (had explanatory power for phenomena noticed in the data). Focused codes were raised to categories where analytic links were made and the properties of the category were defined, as well as the conditions it operated within and its relationship to other categories. This was done by representing focused codes, with their initial codes and an example data extract on Post-Its and grouping them, using flip chart paper, into categories. Examples of coding and category development are given in Appendix 2-D. The theory was built throughout this process, creating links between categories to form the GT (shown in Figure 3).

FIGURE 3 HERE

A constant comparison method was used, where data collection, coding and memo writing were alternated and new findings accommodated into the existing theory (Glaser & Strauss, 1967). This method allows for comparisons at all levels, comparing codes within and between interviews, going on to compare categories with codes, comparing categories and codes with and using memos (which compare links with existing theory to data), going back over transcripts to recode where necessary, when new focused codes had emerged in later transcripts. Again this supported a social constructivist approach, treating analysis at all levels as one understanding of the data, constantly comparing it with new and existing data, codes and categories, altering it to reflect the evident actions and processes. For example, as discussed in the series of memos in Appendix 2-B, attachment theory emerged early on as a potential way to understand some aspects of the use of diagnosis. This was recognised as a link to existing theory, so was considered using memos, in an attempt to set it aside and allow a fresh perspective on the data. However, making that link explicit through memo writing allowed further questioning about the idea of having a foundation from which to practise and the issue of challenging that foundation.

Findings

This section presents the findings of the study and should be read alongside the GT diagram (Figure 3). Participant quotations are provided, identifying participants by number (e.g. participant one is represented by the identifier P1). A summary of the GT is given, followed by explanation of the categories.

Summary of the Grounded Theory: How Practitioners Use Diagnosis in Practice

Participants felt the pressure of their jobs, mostly due to excessive workloads and working with risk (P1 explained their work as "really really risky"). That pressure caused anxiety and uncertainty, setting in motion the core category (*needing a certain foundation for practice*). A core category is a category that relates to other categories and has strong

explanatory power (Strauss & Corbin, 1998), here explaining overall why and how practitioners used diagnosis; *needing a certain foundation for practice* drove participants to choose a foundation for their work to reduce uncertainty. There were three strands, which divided participants according to what they used as their *certain foundation*. In the first strand (S1), participants used diagnosis, in the second (S2) participants were wary of diagnosis and relied on their team and their own experience and in the third (S3) participants rejected diagnosis and relied on a psychological model they had been trained in.

These strands operated within the other categories (*holding and coping with inconsistent and differing views* and *impact on practice; depersonalisation and not challenging diagnosis*) in different ways, explaining how diagnosis affected practice. All participants, regardless of their preferred strand, held *inconsistent views* about diagnosis, particularly its validity. Participants in the different strands had different ways of *coping with* those views. In S1, those views were ignored and diagnosis revered. In S2 there was some engagement with inconsistent views but they were mostly ignored. Those in S3 purported to fully recognise their inconsistent views and used the poor validity of diagnosis to bolster confidence in their own model. Differing views about diagnosis in teams seemed to be ignored by all, with no space to reflect on those issues. Also, those in S1 did not discuss issues around diagnosis because they ignored them, those in S2 did not discuss them because they did not want to challenge the team they relied on for their *certain foundation* and those in S3 did not debate diagnosis in their teams because they avoided engaging with others with differing opinions.

Further consequences for practice, resulting from participants' choice of secure foundation, were *depersonalisation and not challenging diagnosis*. Those in S1 used diagnosis to depersonalise PRPD, allowing emotional distancing when difficult decisions were made under pressure. They did not challenge diagnosis because they believed it to be a

useful and valid framework. Those in S2 also depersonalised PRPD but would advocate on

diagnostic issues, for example challenging a diagnosis, when this was initiated by the

individual. Otherwise they were apathetic about challenging diagnosis, not wanting to

challenge the team they relied on for certainty and feeling powerless to affect change. Those

in S3 were indifferent to diagnosis because they did not see it as important in practice, so

they tended to ignore diagnostic issues. Therefore, all strands, regardless of their views about

diagnosis or how they used it in practice, did not challenge diagnosis.

Participants broadly fell into one of the three strands but could switch strands. For

example when risk was high, participants in S2 reported at times relying on diagnosis to

justify decision making. For some this seemed like a necessary relinquishing of responsibility

to a medical model, which they believed offered some certainty. Participants in S1 talked

about using their teams for support but only when that team was supportive. However, using

psychological models was exclusive to participants in the third strand who had been trained

in those models; those in strands one and two could not access that practice foundation.

Those in S3 reported sticking to their model for decision making. Even in high risk situations

they did not revert to using diagnosis; a paradigm they felt was lacking validity. Below,

categories are further explained and illuminated with quotations.

Core Category: Needing a Certain Foundation for Practice

This category explains how, because of the pressure of their jobs creating uncertainty,

all participants were driven to find a foundation for practice they felt reduced uncertainty.

This foundation consisted of an evidence base and, for some, a clear treatment pathway that

provided some certainty in the rationale for their decisions. This foundation was either

accessed through diagnosis (for participants in strands one and sometimes those in S2), their

team (for those in S2 and sometimes those in S1) or psychological models (for those in S3).

Working with risk seemed to drive this need for a secure foundation because it was "anxiety-provoking" (P7).

Participants in all strands spoke about needing to make "defendable" (P9) decisions, what P10 called "that cover your arse need". The need for a certain foundation was linked to making decisions that could be defended if something went wrong; "I need to make sure that I've covered all bases as well for the benefit of the service user, not just, erm, you know for myself (laughs) and my career and stuff" (P2).

For those in S1 diagnosis offered certainty in a treatment pathway to follow; "there's a pathway in terms of care that is led by the diagnostic part of that" (P5), and so deciding on this pathway from diagnosis was "relatively straightforward" (P8). The certainty that diagnosis offered for some was reflected in the certain language they used to describe it; for example P5 used the term "rubber stamped" a number of times.

Participants in S2 talked about using their team to clearly define the rationale for decisions (e.g. P7 discussed "using knowledge within the team, especially around care planning"). They also used diagnosis to access an evidence base, which provided a rationale for decisions;

> We do work from an evidence base, so, you know, if someone does have a diagnosis of personality disorder, you work from an evidence based practice. Such as, erm, 72 hour beds […] because otherwise, if you just had a caseload of people with severe and enduring mental health and that wasn't categorised, how would you, kind of, intervene for someone with bipolar. Because, they may need- they wouldn't respond to 72 hours in hospital. Whereas the evidence base for people with personality disorder, there's lots of evidence to suggest that short, sharp periods of inpatient treatment is more beneficial. So the diagnoses do lead to evidence based practice. (P1)

There was a tension that was not explicated or perhaps realised by any participant in S1 and S2; they rely on an evidence base, which is differentiated in terms of diagnosis, however (as discussed below) some do not feel that diagnoses truly represent the difficulties of the PRPD they work with and express inconsistent views about its validity. P1, despite relying on diagnosis to access evidence base, previously expressed strong views that diagnosis should be seen as "just how you describe it" and that description is not robust or reliable;

> Diagnosis can be based on that very simplistic, you know, how many boxes have we ticked? You've ticked 3 boxes in bipolar, you've ticked 2 boxes in schizophrenia and a box in depression and anxiety so… we'll go with the bipolar.

The difficulties with using an evidence base determined by diagnosis are recognised and articulated more fully by those in S3, who use formulation to find certainty about and a rationale for their decision making; " [I use] formulation because it helps to provide a rationale for what we're doing and it helps people feel more competent and comfortable" (P6). For these participants, pathways being based on diagnosis caused confusion; "We have clear pathways about what we're doing with borderline personality clients, what we're doing with our psychosis clients, quite often they have a mixture of both presentations (laughs), so it's like which one are we following?!" (P4). P6 succinctly suggested that they preferred "having a strong rationale for the person as opposed to having a strong rationale for the diagnosis" and discussed the same issue of the 72 hour admission, as discussed by P1 above; "So, this person might present in this way and we've learnt from history […] that a maximum of 72 hours is important because X, Y and Z as opposed to 'we know that all people with BPD should have'." Therefore participants in S3 rely on their models to access an evidence base predicated on diagnosis in a more individualised way, taking into account the needs and histories of individual PRPD.

Holding and Coping with Inconsistent and Differing Views

This category captures the inconsistent views about the validity of the diagnostic paradigm and causation of distress expressed by all participants. How participants coped with this inconsistency and differing opinions was influenced by *needing a certain foundation for practice*.

Inconsistent views. Those in S1 who relied on diagnosis recognised the issues with validity ("they might have had several different diagnoses" [P2]), but seemingly ignored them or pushed them aside; believing in "right" and "wrong" (P2) or "true diagnoses" (P5), showing a quest for certainty in "a definitive diagnosis" (P3). Working with a PRPD with the "wrong" diagnosis was difficult because they would be on the "wrong" treatment pathway (P2). There was a sense of responsibility here; "it's about making sure that you get it right. Because they have to go on and live their lives appropriately, you know, with the right treatment" (P3) and perhaps having a sense of certainty about getting it right alleviated some of the anxiety about responsibility.

Therefore, participants in S1 were aware of debates around the validity of diagnostic categories but did not allow themselves to challenge their paradigm, perhaps because it is the thing that offers certainty. P5 believed that research and education had improved accuracy in diagnosis; "Historically people have been misdiagnosed and as more education and research has developed about diagnoses then, you know, perhaps 10-15 years ago they wouldn't have been diagnosed as they would now and may have been given a different one". Here, P5 is suggesting that the same presentation being labelled differently as time goes on is due to the accuracy of labelling improving. Participants in S1 were aware of potential issues of validity but had developed a way to cope with these inconsistent views, being selective in the evidence they chose to accept, their interpretations of such evidence and the degree to which they engaged in the debates.

Many participants in the second and third strands expressed and justified views that could be broadly identified as social constructionist, that diagnosis is a product of time and culture ("It's so subjective" [P4]):

> The Virgin Mary would have been detained on a treatment order if she'd have lived now. With those sorts of beliefs she would have been diagnosed with schizophrenia […] If we had someone walk in here today and say they were gonna give birth to a baby but they'd never actually… had … sex… (laughs)… we'd be going "delusional! Needs treatment!". (P1)

However those in S2 did not dismiss the validity of diagnosis outright and still held onto some beliefs about biological causation, for example P10 discussed psychological and genetic causation for some presentations of distress; "we can't even find a biological basis for *most* things" (emphasis added). Participants in S2 seemed unaware of their inconsistent views but most insisted on the importance of being "reflective" (P9), which ensured "you don't just accept unquestioningly everything that's done"; P10 understood this reflectiveness as having "a questioning nature". However, P9 also reflected that time pressures meant reflection was not part of routine practice, perhaps explaining why this reflection only went so far.

Participants in S3 expressed that they never felt "confident" (P4) that diagnosis was a valid description of an individual's presentation. However there was still a sense of inconsistency, for example P6 discussed their view that the only thing diagnosis indicates is "other people's perceptions" but later concedes it is "*a* tool not *the* tool", which is useful for research and prescribing, and used a job title that included a diagnostic term. This suggests that there is a belief in the lack of validity of diagnosis, with P6 presenting themselves as rejecting diagnosis, but that it still has some utility for them in practice. P6 blamed this on the "gap between psychological formulation and the medical model", which made it impossible to fully reject diagnosis and meant that it was still useful in some areas, as discussed.

Differing views. Despite differing views being expressed by those in the different strands and P9 describing an "ideological battle" between diagnostic and other frameworks, most insisted that this was not an issue in practice. However, this seemed to be because there was "no real forum to have a debate" (P8) due to the time pressures of the job, which had resulted in a process of "streamlining" where treatment based within a diagnostic evidence base was advocated with little discussion (P10). Debate seemed pointless anyway because a psychiatrist always "calls the diagnosis" (P2). Despite a lack of more formal debate, disagreement around diagnosis happened informally and there was an awareness of others' views on diagnosis; "I know that some people would disagree with me, some of my colleagues are really against, erm, diagnosis (laughs), some of the banter we have!" (P2).

For those in S2, having diagnostic debates was not well received, with P1 having been branded "awkward" by psychiatry colleagues and seemingly developing a thick skin to tolerate that; "I have been called the second most awkward AMHP [approved mental health professional] one doctor has ever known (laughing). I went 'that's a shame why can't I get top spot' (laughing)" (P1). However, for some working every day in a system that was not in line with their views was clearly difficult and frustrating. P9 spoke about their frustration with diagnostic streamlining of the service;

> [It's] almost like dehumanising people. It's 'well it's a bipolar person and this is what they get, that's what happens, they'll get 18 months and should be on their way'. You know we're not dealing with tins of peas we're dealing with people and I think the service is in massive danger of losing sight of that, if it hasn't already. Which I suspect it has.

There was a sense, particularly for those in S2 but also in S1 that they did not want to upset the team with too much disagreement. For those in S1, this seemed to be about not wanting to disregard hierarchies ("there's still a hierarchy at the end of the day so I'm happy

to be overruled", P2). For those in S2 it seemed to be more about not damaging the relationships relied on to offer their secure foundation (P9 expressed views that suggested criticism of the validity of the diagnoses made by the team's psychiatrist but then insisted "I wouldn't go as far as to say that I'm questioning validity" [P9]).

Those in the third strand were more explicit about how they coped with those views, describing "holding" those views in mind (P6) and using supervision to flesh them out and gain support in trying to use psychological ideas in a medically dominated system. They were clear about how their views differed from their colleagues', for example P6 was aware that their views about diagnosis and the way they used it in practice were "different to how kind of, how the medical model works" and this sometimes caused conflict with others. However, there was a more subtle sense of burrowing down, ignoring those with other views. For example, when discussing the utility of diagnosis, P6 said, "that is [psychiatry's] role and from my perspective we hear that, we hold that in mind and we get on with our jobs at the same time". This also came through, although not as strongly, for participants in S2; there was a sense that they gravitated towards colleagues who had similar views to them ("I mean I guess you have your own individual sphere of influence" [P9]).

The Impact on Practice: Depersonalisation and Not Challenging Diagnosis

This category explains the differing ways in which participants' use of diagnosis impacted on their practice, in particular considering how *needing a certain foundation for practice* in some instances resulted in depersonalising PRPD and not challenging the diagnostic paradigm.

Depersonalising PRPD. The depersonalisation of PRPD came across in the way some participants in S1 and S2 spoke about them; for example grouping PRPD with similar diagnoses together, describing people as 'disorders'; "I have a few emotionally unstable personality disorders on my caseload" [P7]). For those in strands one and two, this

depersonalisation enabled difficult decisions to be made, for example about discharging someone who had not recovered, with emotional distance. In that instance, diagnosis and treatment pathways can be used as evidence that the person has not improved despite evidence based treatment being offered ("it makes it less personal to that person that it is a process we need to follow" [P2]). As P4, who was predominantly in S3, articulates when criticising this approach; diagnosis almost gives an excuse for difficult, unethical decisions, "and if they don't engage in that then they're discharged, let's not worry about them and just say we've offered what we were meant to offer […] job done."

Taking diagnosis seriously and advocating. Across the strands, participants spoke about the value of diagnosis for PRPD, many of whom wanted a diagnosis for validation ("people need it in black and white, why they are like they are" [P1]) and proof of their difficulties ("if you're supporting people with their economic wellbeing, to claim benefits. The first question you get is 'what is your diagnosis?'" [P1]). It can also lead to access to services ("it can open up avenues" [P6]), which makes throwing "a name in a hat" powerful (P3).

Due to the power carried with diagnosis, those in S2 saw themselves as advocates for PRPD who felt they needed a diagnosis or a change in diagnosis. They would support individuals in accessing a second opinion, however there was a sense that this was a pointless process because "once a diagnosis is given, it's hard to change" (P2). Participants in S2 reported only doing this if the PRPD asked directly for a second opinion, perhaps because this activated their own views about the diagnostic system and its poor validity. However, P7 recognised how power may play a part in PRPD questioning or discussing their diagnosis "the power imbalance, you know, doctors are up here (points up) and service users feel much lower down. So to disagree with a doctor? I don't think you get that a lot." It seemed participants too were sometimes subject to that power imbalance: P8 said;

I've certainly known consultants to be quite defensive about any challenges, you

know questioning of diagnosis because they see it as their domain to make that and

it's kind of, 'what qualification do you have to', you know, whereas I don't think you

need any qualifications to be able to ask a question.

For those in the first strand, a lack of agreement with diagnosis on the part of a PRPD

was seen as lack of insight into their difficulties. P5 said that, in response to PRPD

questioning diagnosis they would "remain professional and explain why that decision's been

made". One consequence of not challenging diagnosis was that participants in S1 and S2

supported PRPD to look at diagnostic criteria and try to understand how they applied to them;

"it's about people discovering what bipolar or whatever means for them" (P2), exploring the

potential personal relevance of diagnosis.

However, participants in S3 discussed not challenging because they "ignore"

diagnosis (P4) in practice. P6 said "I wonder if I'm sometimes not too driven to challenge a

diagnosis just because I don't put so much emphasis on diagnosis anyway that it kind of

doesn't matter so much (laughs)". Challenge again felt pointless in the current system; "I

think the difficulty is that it's just so subjective that people can have half a dozen different

diagnoses on the system and each psychiatrist will say they're right (laughs). (P4)"

Discussion

These findings suggest that, regardless of views about diagnosis, all strands lead to

not questioning diagnosis, either due to relying on it for security and certainty in practice, not

wanting to threaten the team which provides certainty, or not respecting the framework and

therefore not engaging with issues around its validity. This GT explains why diagnosis

remains a dominant framework in this adult community mental health setting; theoretical

links are made here to explicate this further. Implications for clinical practice in psychology

and mental health are explored.

Links to Existing Theory

      Cognitive theories. It seems that all participants experienced cognitive dissonance, which is discomfort that occurs in situations where attitudes, beliefs or behaviours conflict, driving efforts to alleviate discomfort by altering those attitudes, beliefs or behaviours (Festinger, 1957). Participants were trying to work in a system dominated by diagnosis, some relying on it as the foundation of their work, in the face of information which cast doubt on its validity and utility, causing dissonance. Those in different strands dealt with this differently, in ways consistent with those conceptualised by Festinger (1957). In S1, participants ignored information that caused dissonance and tried to acquire new information to outweigh dissonant beliefs (e.g. P5's discussion of research that supports diagnostic validity). In S2 participants attempted to integrate conflicting information but then ignored it because of dissonance (reducing the importance of cognitions that create dissonance). In S3, participants were more aware of this dissonance and rejected diagnosis in favour of psychological approaches (changing their attitudes, beliefs and behaviours). Therefore, the ways they used diagnosis reduced dissonance as well as uncertainty in practice.

      Further, cognitive theory about tolerating uncertainty is relevant here. Tolerance of uncertainty is a concept used in psychological understandings of anxiety and suggests that a core feature of worry is inability to tolerate uncertainty (Davey & Wells, 2006). Perhaps here, the pressure of the job caused worry and a quest for certainty and so the perception of these secure foundations (diagnosis, the team, psychological models) as certain and dependable is a protection against uncertainty. Uncertainty and dissonance are ignored, foundations become reified as empirical, rather than based on subjective opinion (Timimi, 2011b) and these foundations in turn go unchallenged, which in part explains why diagnosis remains influential.

Attachment. Practitioners' need for a certain foundation fits in with the concept of a secure base in attachment theory. A consistent attachment figure, according to attachment theory, offers a secure base so that a child can develop independence, being able to explore its environment with a secure base to rely on in response to threat, allowing regulation of distress (Bowlby, 1980; 1988).

It seems that these participants quested for a secure base from which to practise; attachments to those bases can be conceptualised in terms of secure, preoccupied and ambivalent attachments (Main & Solomon, 1986). Those in S1 could be considered to have a preoccupied attachment to diagnosis; they accommodated inconsistent views about diagnosis and treated it as a secure base, driven by the need for a certain foundation. Those in S2 were perhaps ambivalently attached to diagnosis; these participants did not fully reject diagnosis and were inconsistent in their use of it as a secure base, sometimes using their team. Those in S3 seemed to believe they had found a secure base in their psychological models, but the rejection of diagnosis could make working in a diagnostically driven environment challenging.

Clinical Implications

Protective depersonalisation. As seen in the findings, using diagnosis as a foundation for practice can result in the depersonalisation of PRPD, which is protective for participants, allowing them to disengage with distress and the ethical complexity of their work, something suggested by CPs discussing diagnosis in Christofides et al.'s (2011) study and by Dillon (2013), who claims clinical terminology "enables a distancing" (p. 16). It can be argued that this is an understandable reaction to working in such a pressured system.

Therefore, any approach that moves away from diagnosis requires understanding that diagnosis can be protective and, as Dillon (2013) suggests, developing systems that "adequately support mental health professionals to bear witness to the pain of people who

have endured terrible things" (p.17). CPs are perhaps well placed to offer supervision to cope with this potentially additional distress. Tolerating uncertainty may be key here, allowing a position of "safe uncertainty" for clinicians and PRPD, where alternative meanings and explanations can sit alongside, not subsume, each other (Mason, 1993). It may also be important to encourage practitioners to reflect on the frameworks they are using and the consequences of using them.

       Considerations for Clinical Psychologists. The CP role has moved beyond individual work towards supervision, training and consultation (BPS, 2007). This will be vitally important if psychological approaches are to be integrated within mental health services as approaches that stand up alongside diagnosis as accessible to those not trained in such approaches (those in S1 and S2), through consultation and training. As discussed in the introduction, team formulation is one way for CPs to promote alternative approaches, however, current findings support the claim that practitioners are largely unaware of psychological or other alternative explanations for distress (BPS, 2014), unless they have been directly trained in them.

       Research about CPs' work in teams could provide clues about its lack of influence. Christofides et al. (2011), in their study of clinical psychologists' use of formulation in teams, found that CPs work by informally 'chipping in' ideas based on formulation and psychological theory, to avoid taking an expert position. However, participants in the Summers (2006) study felt some of the hypotheses in team formulation were too speculative; perhaps then they did not offer enough of a certain foundation for practice. This is difficult to negotiate, given that participants in the Hollingworth and Johnstone (2014) study liked that no one took the expert position in the team formulation process. Perhaps then, CPs need to promote psychological models as practice frameworks that are as useful as diagnosis and

show confidence using these approaches to manage risk, whilst acknowledging the expertise of other clinicians.

Offering alternative frameworks does not have to become a battle against diagnosis; using them with diagnosis (with cautions about its perceived certainty) would move towards an approach that does not seek to "replace one paradigm with another" (Bracken et al., 2012, p. 432). However, as Berger (2011) suggests, diagnosis is widespread in thinking about distress so people will continue to think in terms of those categories. Therefore, given the dominance and power of diagnosis, CPs perhaps need clearer guidance about navigating service systems when offering alternative frameworks. Existing guidance claims that a useful formulation can make diagnosis redundant but only aims to "establish some broad principles for best practice psychological formulations in order to inform the debate [about formulation and diagnosis]" (DCP, 2011, p. 3). The BPS could provide firmer guidance on using diagnosis *and* formulation in practice.

Strengths and Limitations

The strengths and limitations of this study are discussed in detail in the critical appraisal. In brief, the study has a small sample size (limited by the number of practitioners who volunteered to participate) and the sample was recruited from one NHS trust, which raises issues about theoretical saturation. Because this is a qualitative study with a relatively small sample, the findings cannot be widely generalised, however it has generated a number of further research ideas.

Further Research

The current study did not explore how practitioner views about diagnosis developed. Although demographic data were not collected, participants always talked about their practice discipline but this did not split participants into strands, as might have been hypothesised. Future research could explore the development of views about diagnosis and

why practitioners might occupy different strands. Further research ideas are discussed in the critical appraisal.

Conclusion

The findings of this study suggest that diagnosis has remained as a dominant paradigm for understanding distress partly because some practitioners rely on it to manage uncertainty and stress in practice and so ignore issues with its validity. This reliance subsides and diagnosis is abandoned only when practitioners have another model to use and feel secure practising within that model. These practitioners then ignore diagnosis and the complex impact it can have on PRPD.

The understanding of practitioners' work developed here suggests a need for viable alternatives to be used alongside diagnosis. Clinical psychologists perhaps need to have stronger influence in offering such alternatives, allowing practitioners to gain certainty from psychological models and the rationales they offer for decisions in practice. This is not an easy task in a system predicated on diagnosis, as P6 suggests, "things are completely skewed anyway in mental health, you know the spotlight's on, what I would suggest, are maybe not the most helpful things." Changes at practice, policy and a societal level would shift that spotlight towards more helpful ways of understanding distress.

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Figure 1

Recruitment and sampling strategy
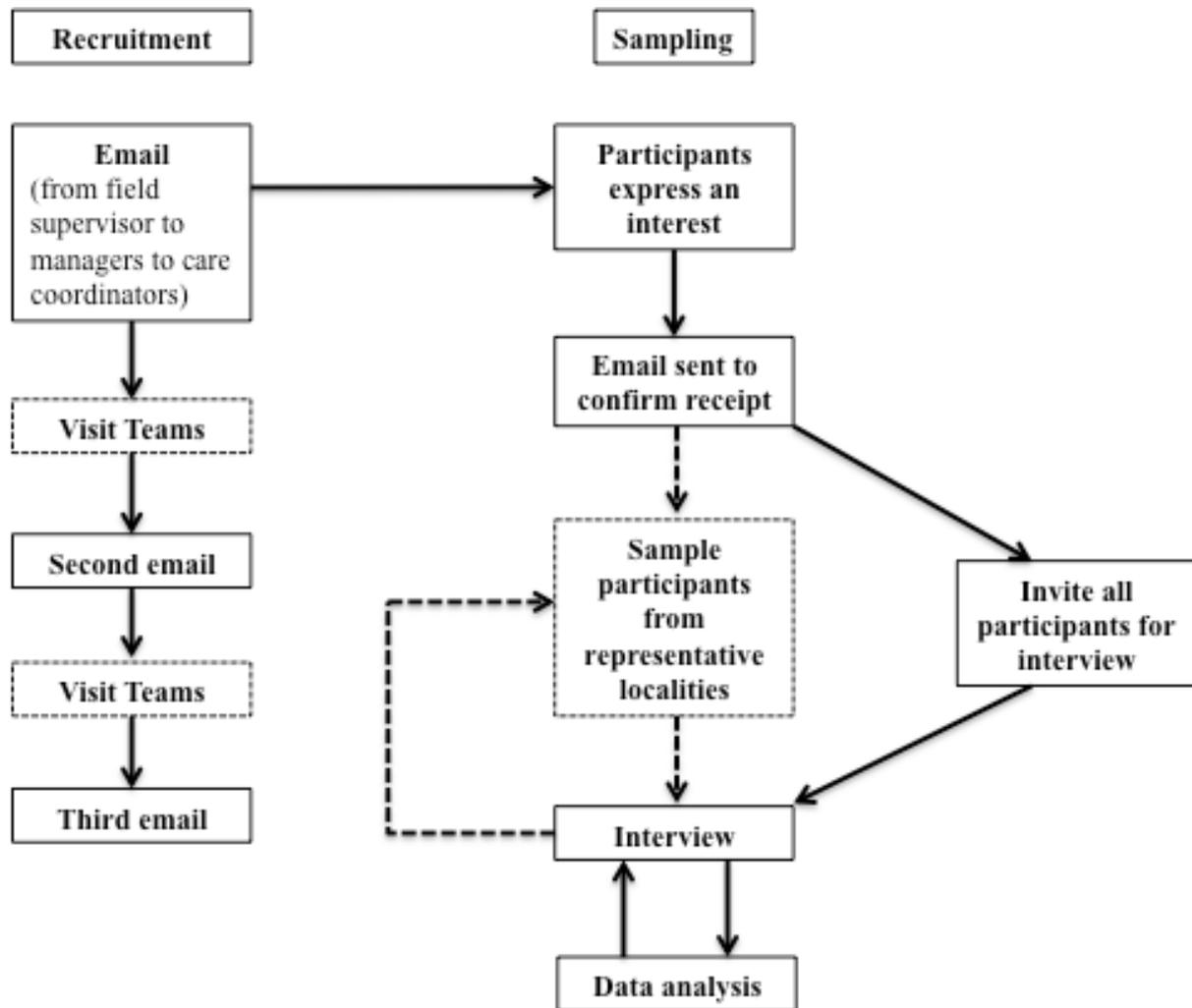
Note. Broken line depicts the planned sampling method and the unbroken line depicts the actual sampling method.

Figure 2

Data analysis diagram

Figure 3

Grounded theory representing how practitioners use psychiatric diagnosis in practice

Appendix 2-A

Author's notes for the *Journal of Mental Health*

Journal of Mental Heath
Instructions for Authors

Aims and Scope

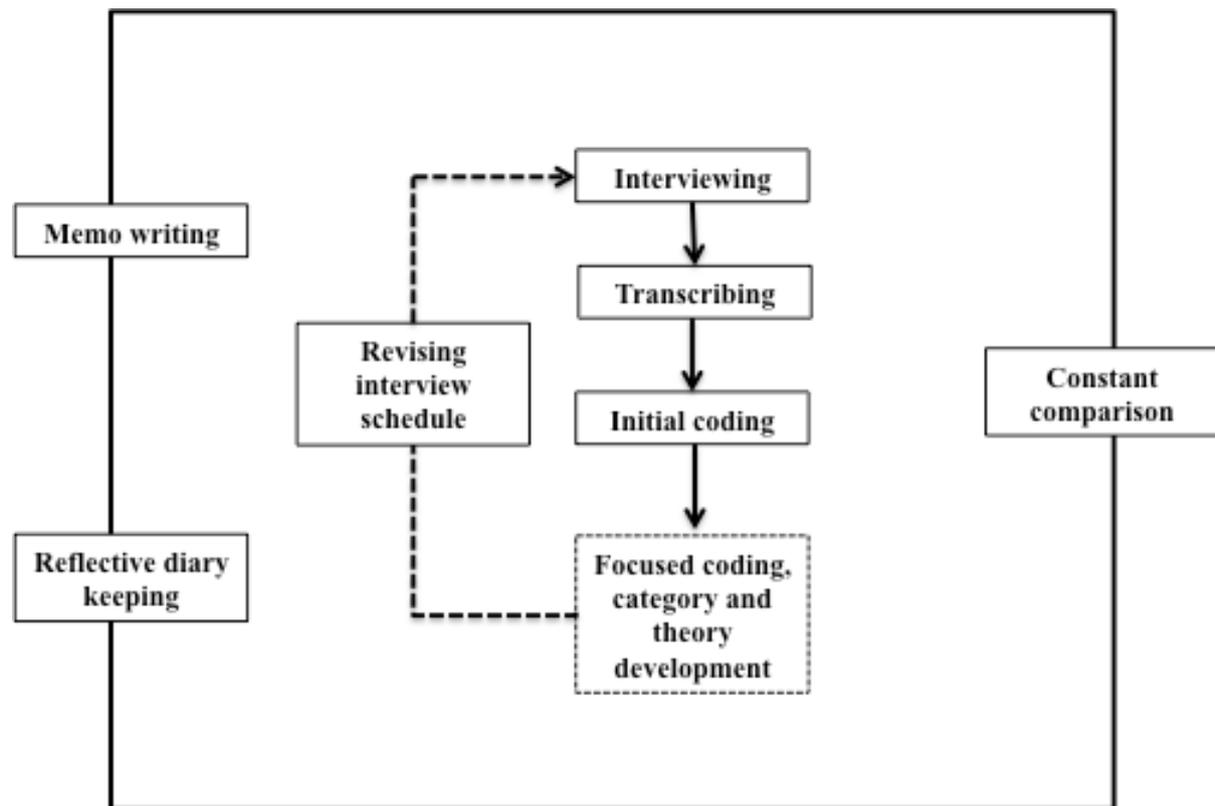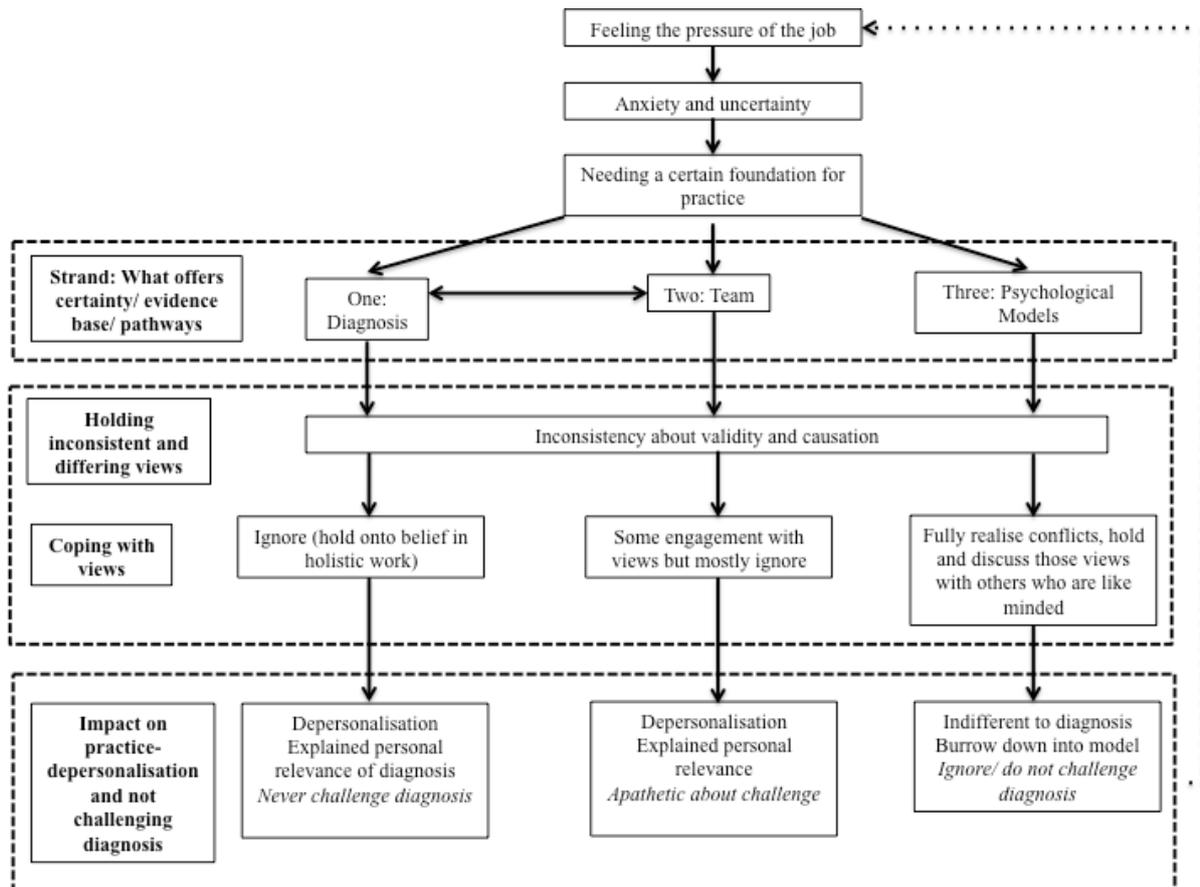The Journal of Mental Health is an international forum for the latest research in the mental health field. Reaching over 65 countries, the journal reports on the best in evidence-based practice around the world and provides a channel of communication between the many disciplines involved in mental health research and practice.

The journal encourages multi-disciplinary research and welcomes contributions that have involved the users of mental health services.

The international editorial team are committed to seeking out excellent work from a range of sources and theoretical perspectives. The journal not only reflects current good practice but also aims to influence policy by reporting on innovations that challenge traditional ways of working. We are committed to publishing high-quality, thought-provoking work that will have a direct impact on service provision and clinical practice.

The Journal of Mental Health features original research papers on important developments in the treatment and care in the field of mental health. Theoretical papers, reviews and commentaries are also accepted if they contribute substantially to current knowledge.

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All submissions, including book reviews, should be made online at Journal of Mental Health's Manuscript Central site at http://mc.manuscriptcentral.com/cjmh

New users should first create an account. Once a user is logged onto the site submissions should be made via the Author Centre. Please note that submissions missing reviewer suggestions are likely to be un-submitted and authors asked to add this information before resubmitting. Authors will be asked to add this information in section 4 of the on-line submission process.

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The names of authors should not be displayed on figures, tables or footnotes to facilitate blind reviewing.

Word Count

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All books for reviewing should be sent directly to Martin Guha, Book Reviews Editor, Information Services & Systems, Institute of Psychiatry, KCL, De Crespigny Park, PO Box 18, London, SE5 8AF.

Manuscript Style

Manuscripts should be typed double-spaced (including references), with margins of at least 2.5cm (1 inch). The cover page (uploaded separately from the main manuscript) should show the full title of the paper, a short title not exceeding 45 characters (to be used as a running title at the head of each page), the full names, the exact word length of the paper and affiliations of authors and the address where the work was carried out. The corresponding author should be identified, giving full postal address, telephone, fax number and email address if available. To expedite blind reviewing, no other pages in the manuscript should identify the authors. All pages should be numbered.

Abstracts: The first page of the main manuscript should also show the title, together with a structured abstract of no more than 200 words, using the following headings: Background, Aims,

Method, Results, Conclusions, Declaration of interest. The declaration of interest should acknowledge all financial support and any financial relationship that may pose a conflict of interest. Acknowledgement of individuals should be confined to those who contributed to the article's intellectual or technical content.

Keywords: Authors will be asked to submit key words with their article, one taken from the pick-list provided to specify subject of study, and at least one other of their own choice.

Text: Follow this order when typing manuscripts: Title, Authors, Affiliations, Abstract, Keywords, Main text, Appendix, References, Figures, Tables. Footnotes should be avoided where possible. The total word count for review articles should be no more than 6000 words. Original articles should be no more than a total of 4000 words. We do not include the abstract, tables and references in this word count. Language should be in the style of the APA (see Publication Manual of the American Psychological Association, Fifth Edition, 2001).

Style and References: Manuscripts should be carefully prepared using the aforementioned Publication Manual of the American Psychological Association, and all references listed must be mentioned in the text. Within the text references should be indicated by the author's name and year of publication in parentheses, e.g. (Hodgson, 1992) or (Grey & Mathews 2000), or if there are more than two authors (Wykes et al. ., 1997). Where several references are quoted consecutively, or within a single year, the order should be alphabetical within the text, e.g. (Craig, 1999; Mawson, 1992; Parry & Watts, 1989; Rachman, 1998). If more than one paper from the same author(s) a year are listed, the date should be followed by (a), (b), etc., e.g. (Marks, 1991a).

The reference list should begin on a separate page, in alphabetical order by author (showing the names of all authors), in the following standard forms, capitalisation and punctuation:

a) For journal articles (titles of journals should not be abbreviated):

Grey, S.J., Price, G. & Mathews, A. (2000). Reduction of anxiety during MR imaging: A controlled trial. *Magnetic Resonance Imaging, 18*, 351–355.

b) For books:

Powell, T.J. & Enright, S.J. (1990) *Anxiety and Stress management.* London: Routledge

c) For chapters within multi-authored books:

Hodgson, R.J. & Rollnick, S. (1989) More fun less stress: How to survive in research. In G.Parry & F. Watts (Eds.), *A Handbook of Skills and Methods in Mental Health Research* (pp. 75–89). London:Lawrence Erlbaum.

Illustrations: should not be inserted in the text. All photographs, graphs and diagrams should be referred to as 'Figures' and should be numbered consecutively in the text in Arabic numerals (e.g. Figure 3). The appropriate position of each illustration should be indicated in the text. A list of captions for the figures should be submitted on a separate page, or caption should be entered where prompted on submission, and should make interpretation possible without reference to the text. Captions should include keys to symbols. It would help ensure greater accuracy in the reproduction of figures if the values used to generate them were supplied.

Tables: should be typed on separate pages and their approximate position in the text should be indicated. Units should appear in parentheses in the column heading but not in the body of the table. Words and numerals should be repeated on successive lines; 'ditto' or 'do' should not be used.

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Appendix 2-B

Series of memos about the 'abandoning evidence for a secure attachment' focused code (part

of the 'holding and coping with inconsistent views' category)

<u>Memo (following P3)</u>

All three participants seem to have a need for a secure base (an evidence base but it

seems to go beyond this) in their practice and for some, diagnosis offers that. Diagnosis

permeates their practice, the way they understand distress, which is clear from the way they

talk, using medicalised language.

There seem to be two views expressed here about diagnosis, one accepting and one

mixed. However both express ideas about the flawed evidence base for diagnosis and

problems with its validity (for example mentioning that people with the same diagnosis can

present very differently). All three seem to be ignoring that evidence for some reason? They

provide the evidence for questioning validity but don't question that validity themselves.

There are some potential links to attachment theory, for example needing a secure base.

It seems that for some diagnosis offers this and maybe that's why diagnosis can't be criticised

too much or dismissed outright. So information that would threaten its security doesn't

penetrate or affect practice. I have also noticed that there have been a lot of pauses before

criticising diagnosis, psychiatry or any other professionals', systems. Again perhaps this is

the fear of upsetting the system that, for some, is disdained but relied on for certainty.

It will be interesting to ask subsequent participants about any examples where they

have challenged dominant practice and what made that OK (to challenge their secure base),

as well as further exploring what they do with the information they are clearly aware of about

concerns about validity. How can they hold two conflicting beliefs at the same time? It might

be fruitful to ask more explicitly about their beliefs about causation in mental health but

perhaps that risks alienating those who value diagnosis. Do they make attribution errors

based on overvalued paradigms that offer a secure base? Albeit a false one (my belief/

judgement).

Memo (following P6)

Ways of coping with issues around diagnosis are becoming clearer as a result of more

focused questioning in that area. Some seem not to bring such disagreement to light or push it

down. However the new group that has emerged are those trained to use psychological

models. These people prefer a psychological understanding of problems and thus are more

rejecting of diagnosis. They seem able to do this because their model then provides the secure

base. They have thought much more about issues of validity in diagnosis and seem to discuss

this much more with like-minded colleagues. This seems also to help them practise in a way

that is quite different to the medically dominated norm.

Appendix 2-C

Transcript extract with coding (P1)

Data	Initial coding	Focused coding	Category
Respondent (R): I quite like diagnosis because it gives me a, erm, more clarity on the treatment pathway. Erm, I also think it's a good explanation for the service users, erm, you know, I find often they feel very alone when they've got mental health problems, whereas if there's a diagnosis, a label to it, it becomes less personal and they can look into that themselves and gain mastery over different treatment options that have helped other people in that situation and the support and that. Especially for things like personality disorder where people have felt so isolated, it kind of gives people a bit of hope I find. Erm, so I quite like diagnosis really. **Interviewer (I):** So in terms of your work it offers clarity about what pathway someone should be on (yeah) and in terms of it's use for patients, it sounds like you're kind of saying that it signposts-	**Liking diagnosis/ Finding clarity on a treatment pathway/ diagnosis gives a good explanation to service users/ label makes it less personal/ diagnosis signposts/ diagnosis giving hope**	*Justifying the use of diagnosis based on benefits for PRPD*	
R: Yeah, so saying whilst it's a diagnosis it's not to say it's all of you, it's an illness that needs to be gained control of, as you would- you wouldn't say 'my name is such and such and I'm diabetic', so gaining mastery and also seeing it for what it is, it's not a reflection of the person's character and personality but it is unfortunately luck of the draw; they've got this and they need to gain control over it. **I:** Yes because you also said- it's almost like externalising it, so it makes them feel less alone perhaps because they've got a name for it and they know they can perhaps access support in that way.	**Explaining diagnosis as an illness that needs to be controlled/ Drawing physical health parallels/ Separating out the person and the illness**	*Belief in genetic causation* *Using physical health metaphors*	Inconsistent views
R: Less personal I think, there's not a judgment that someone acts in a particular way or chooses a lifestyle choice to behave in a certain way, but they've got, unfortunately, a set of symptoms that fall under the umbrella of a particular diagnosis and this is what's helped people in the past. Because I think as well in mental health it can feel so hit and miss for people; some medications will work for some people and not for others,	**Diagnosis makes it less personal/ Diagnosis is not a judgment or a choice/ Describing PRPD as lacking agency/ Diagnosis leads to treatment/ Treatment as hit**	*Diagnosis = seeing the person as having less agency* *Seeing the illness not*	Impact on practice: depersonalisation

with no clear way of saying 'this is definitely going to work for you'. So again it just makes it less personal, people can be more objective and see their illness as something they need to manage, control and learn to live with, rather than, erm, you know sitting themselves at home and saying 'I'm a terrible person, everyone hates me, sort of thing'.

I: And what do you think about, well what's your experience of the diagnostic process as it is at the moment, in the NHS or in your team?

R: Erm, our doctor's very good I think at reaching an appropriate diagnosis, he doesn't leap into a diagnosis. Because most people want a name for it as soon as they come in and he will do, erm, a … get people to keep some diaries and for the care coordinators to spend a period of time assessing that person, but he's also not shy of giving a diagnosis if it's obvious, you know, erm. I've found that the hardest diagnoses to get are ones of personality disorder. I think historically, as well, it was seen as a diagnosis of exclusion, a lot of very kind doctors don't want someone to be left without a service, so they might suggest that it's some kind of mood disorder. I find that unhelpful because the treatment pathways are quite different. I also think that, erm, erm, for people that have say a personality disorder, if they've already presented with several different ways they might have had several different diagnoses before we even get to that point and that can be quite invalidating for somebody and quite hard to establish a therapeutic relationship with, when they've already got preconceived ideas about what illness they might be suffering from. Yeah.

I: So psychiatrists are reluctant to give some kinds of diagnoses and it comes from a place of kindness?

R: I think with some, not with all. You know we're still trying to change a culture really and seeing that as something that can be controlled and treated.

I: And I suppose thinking about that, erm, the culture that is perhaps around personality disorder, or was, that it cannot be treated and thinking about wider stigma about mental illness in society and what people have to put up with when they've been given that diagnosis. Does that come up

and miss/ Seeking a treatment that works/ Diagnosis makes it less personal/ Seeing the illness as separate to the person gives control over it/ Seeing the illness as separate to the person	*the person*	
Believing an appropriate diagnosis can be reached/ Patients want a name/ Diagnosis can be obvious/ Some diagnoses harder to get/ Believing kindness of doctor affects diagnosis given/ Considering stigma/ Relying on clarity of diagnosis for treatment pathways/ ignoring questions of validity linked to changing diagnoses/ PRPD have preconceived ideas about their illness/ believing the PRPD is wrong about diagnosis	*Seeking certainty in diagnosis and treatment pathways* *Ignoring evidence about validity* *Ignoring the knowledge held by PRPD*	Needing a certain foundation for practice Impact on practice: (not challenging diagnosis, not respective views of PRPD).

with your clients at all? Do they experience stigma because of the diagnosis that they've got?

R: Yeah I think so and especially with personality disorder when people tend to judge themselves and stigmatise themselves. As soon as they start to go on the internet and googling things, that can make people panic a lot really but I find that if you've explained it properly, if anything it's a source of support from people; that they can sort of separate themselves from the overwhelming feelings that they have and get the appropriate treatment for it. So... yeah.

I: So it sounds like you're saying there's a self stigma as well? (Yeah, yeah). The ideas that people get from whoever about what people with personality disorder are like, they kind of internalise it

R: Oh yeah, yeah definitely and then perpetuating that self invalidation and the invalidation from people around them as well. Usually it's had such an impact on people's lives, it's so chaotic that it's not terribly validating. I think diagnosis can be good in that way that it, if it's explained properly, it gives people a bit of hope really I think.

Recognising self stigma/ Believing that explaining diagnosis properly is supportive/ Diagnosis can cause panic if not explained/ Diagnosis separates person from distress/ Diagnosis leads to appropriate treatment	*Recognising the importance of explaining diagnosis to the person*	Impact on practice (explaining the personal relevance of diagnosis)
Diagnosis can be validating if explained properly/ Not realising invalidation can come from diagnosis/ Diagnosis gives hope	*Recognising the importance of explaining diagnosis to the person*	
	Not realising negative consequences of diagnosis	

Appendix 2-D

Example codes

Initial (line by line) coding	*Focused Coding*	Category
Diagnosis giving certainty	*Experiencing uncertainty*	Needing a certain foundation for practice
Finding certainty in model	*Questing for certainty*	
Seeking certainty		
Seeking treatment that works		
Using physical health metaphor	*Expressing inconsistent views*	Holding and coping with inconsistent and differing
Ignoring evidence that questions validity	*Coping with inconsistent views*	views
Contradicting previously expressed views		
Holding views in mind		
Believing in the need to explain diagnosis	*Depersonalising their client*	Impact on practice: depersonalisation and not
Ignoring diagnosis in practice	*Making difficult decisions*	challenging diagnosis
Not realising negative consequences of diagnosis	*Ignoring diagnosis*	
Making difficult decisions based on diagnosis		

Section Three: Critical Appraisal

A critical appraisal of the research process

Rebecca Hough

Doctorate in Clinical Psychology

Division of Health Research, Lancaster University

Correspondence should be addressed to:

Rebecca Hough

Department of Clinical Psychology,

Faculty of Health and Medicine,

Furness Building,

Lancaster University,

Lancaster,

Lancashire, UK.

LA14YW

Email: r.hough@lancaster.ac.uk

Tel: +44 1524 593378

Fax: +44 1524 592981

In this critical appraisal I will present a review of the research process. I will offer an initial recap of the results of the research paper to orientate the reader. Second, further findings about the role of psychology and power will be considered. Third, I will discuss the challenges of developing an epistemological position. Then I will review the limitations of this project, more specifically the challenges of using a grounded theory (GT) methodology within the context of the National Health Service (NHS) and the requirements of a Doctorate in Clinical Psychology thesis. Reflections are offered about how conducting this research has shaped and been shaped by my continuing clinical practice and finally, using diagnosis in research is explored.

Summary of findings

The aim of this thesis was to develop a GT to explain how diagnosis is used in adult mental health practice. The findings suggest that the pressure of the job felt by participants (due mostly to workload and risk) led to anxiety and uncertainty, which drove them to seek a certain foundation for their work to decrease this uncertainty. Participants split into three strands according to what they used to gain this certainty. Those in strand one (S1) used diagnosis, those in strand two (S2) used their team and those in strand three (S3) used psychological models they had been trained in. Participants in all strands expressed inconsistent views about the validity, reliability and utility of diagnosis, which were dealt with in different ways. Those in S1 ignored those views, those in S2 mostly ignored them and those in S3 realised their inconsistency but held those views in mind in order to explore them.

The GT illuminates how diagnosis affected practice. For those in S1 and S2, diagnosis allowed depersonalisation of 'people in receipt of a psychiatric diagnosis' (PRPD) in order to create emotional distance from them when making difficult decisions. The GT also explains why diagnosis remained dominant despite inconsistent views about it; no

participant, regardless of strand, was really challenging diagnosis in practice.

Further findings

Where was psychology? The role of psychology was only discussed by half of participants (all were asked about it but some did not know enough to discuss it), so there was not enough data to justify a separate category, so those data is discussed here. Participants in S2 discussed a desire to depart from the medical model. There was recognition of the value of psychology and formulation; "It always opens up doors for me as well and it really helps me understand somebody a bit better and once you've got that formulation and thinking of different ways of approaching, you know, dealing with certain challenges" (P8). However, access to psychology was difficult due to long waiting lists and there was difficulty managing risk whilst waiting ("it's about sort of managing risk in between" [P7]), which meant other treatment options were used instead.

One participant noted there was a power in diagnosis that psychologists did not have (P4 states "she's [the psychologist] not the one that's putting the diagnosis down, even though she can disagree quite strongly with the psychiatrist"), creating a sense that the frameworks they advocate for cannot be as influential as diagnosis. This power imbalance between CPs and psychiatrists has been noted by Smail (1996), who suggests that lack of power to diagnose and coerce may put CPs in weaker professional standing but in a strong position to form positive relationships with PRPD. It would seem diagnosis is revered over formulation, giving more power to those who can do the former and so psychology's ability to influence is constrained in the ways mentioned above.

Power. Professional, systemic and individual power was an important concern running through this research. Conducting this research, I hoped to redress the professional power imbalance created by diagnosis somewhat, giving professionals a voice when considering these dominant paradigms, which does not happen currently; professions other

than psychiatry do not have significant input into revisions of the Diagnostic and Statistical

Manual of Mental Disorders (DSM) (Aitchison & Mellsop, 2010) and clinical psychologists

(CPs) are the only professional group represented in the British Psychological Society's

(BPS) Division of Clinical Psychology's (DCP) working party (BPS, 2013). I also believe

that, given the importance of therapeutic relationships in outcomes for PRPD (Castonguay

& Beutler, 2006), the way staff approach their work and the frameworks they bring to it are

important to consider in research.

The power of working within a framework dominated by the DSM, now in its fifth

edition (American Psychiatric Association [APA], 2013), has been articulated by Simblett

(2013);

> People who are caught by DSM discourse (including myself) are always in a relation
>
> to power and that discourse acts on people by creating a limited field of possible
>
> actions and responses. People are themselves capable of a much greater field of
>
> possible actions and responses than that imposed by any particular discourse.
>
> Perhaps not an infinite one, but one that nevertheless is much, much greater than
>
> those posed by any single discourse. Not only that, but the ability to do resistance is
>
> always present for people (p. 116).

Considering power in this research has allowed me to see that participants were acting in

understandable ways, according to the situations they were in. It feels like the power of

diagnosis was so strong, those who did resist diagnosis were somewhat powerless anyway.

S2 participants discussed how challenging diagnosis seemed pointless because often that

diagnosis did not change (the power is with the diagnosing clinician) and those in S3 who

rejected diagnosis avoided discussing their views about it, because again they felt that

discussion was pointless because of the power of the paradigm. Simblett (2013) suggested

increasing uncertainty about DSM ideas and discourses might take away some of its power.

However, the findings of the research paper show that uncertainty about diagnosis is ignored by some in practice because it is relied on as a certain foundation for practice.

Those in S3 understood the uncertainty about diagnosis and chose then to ignore it in their practice. Chambers, MacDonald and Mikes-Liu (2013) suggest that coming across issues relating to diagnosis can be "emotionally charged" for some clinicians (p. 131) touching on personal and professional values as well as power inequalities (they give the example of differential pay scales and weight given to the opinions of different professionals). Chambers et al. argue that clinicians feel particularly negative when they are forced to work within a diagnostic framework that goes against their professional training or values and they describe cutting off from others with differing views or frameworks as a way of coping with emotional reactivity to disagreement, which was the response of participants in this study who did not debate diagnosis. Chambers et al. apply this to PRPD also, concerned that hearing contrasting opinions from PRPD and their families might make it difficult to work with them or really hear their perspectives. Power imbalances and the emotion attached to these issues for participants were clear but not explored explicitly in this research and may be useful to explore in future research, as well as interpersonal processes in interactions with others with differing views.

Developing an epistemological position

I have found inherent challenges in using qualitative paradigms, working in a system (the NHS) and a society that views knowledge in a predominantly positivistic way; truth is found by means of logic, science and thus quantitative paradigms. I recognised this when discussing this research with colleagues (nurses, social workers and CPs) and was asked 'can you really claim to have a model based on 10 participants?' This taught me the importance of having faith in my methodology and being clear on my own epistemological position.

I first started to develop my own epistemological position as an undergraduate. I read Hacking's (1986) essay *Making Up People*, which presents a form of dynamic nominalism that started to solidify my ideas about how important language is in how we understand other people and, most importantly, how they understand themselves. Hacking suggests mental health problems have essentially been made up, or invented, by labeling existing behaviours and when we create such a label "the category and the people in it emerge hand in hand" (p. 165). He argues that there are no 'real' entities awaiting scientific discovery but new realities are made possible by our descriptions. As Hacking discusses, these were ideas that had existed for some time but his writing was my first exposure to them.

Another important concept for me, which I was introduced to during my social work training, was the social model of disability (e.g. Oliver & Sapey, 2006). Much has been written and theorised about that model but, in short, it presents the idea that impairment (for example, experiencing unusual beliefs or 'psychosis') does not disable someone. Instead, it is society's reaction to that person and their impairment that disables them (for example, fear in response to someone expressing unusual beliefs). I have held onto this somewhat simple but seminal idea throughout my career in mental health social work and more recently during CP training.

These ideas are inherently social constructionist and that epistemological stance has underpinned this research and influenced the choice of a social contructivist GT method (Charmaz, 2006), which acknowledges the GT that develops through interviews was co-constructed, through narratives or conversation, by me and my participants. Charmaz (2006) criticises traditional social constructionist GT for not acknowledging the role of the researcher in this construction of data. However, the idea about having no ultimate truth to uncover in research and reality being constructed through interactions, made it difficult to

convince my colleagues, in the example above, about the value of this research.

In my clinical work, over the course of training, I have understood the similarities between PRPD. Despite how their distress has been labeled, PRPD I have seen clinically have experienced some type of trauma, with the link between trauma and distress now well researched (e.g. Hammersley et al., 2013; Luntz & Widom, 1994). Their distress (or 'symptoms') is also real, regardless of the narratives they use to describe it. So how could this fit with Hacking's (1986) idea that the way we describe others creates ways for them to be, or social model ideas that it is society's reaction to impairment that creates disability? Surely if it were this simple, offering a different narrative (formulation) or a less disabling response would alleviate distress. However this is not always the case and sometimes distress remains after offering formulation, for example. This is when I started to look beyond social constructionism to critical realism.

A realist would argue that there are definite things existing in the world that we have "come to recognize and classify correctly" (Hacking, 1986, p. 164). Throughout training I have increasingly noticed that PRPD can also, some more easily than others, be seen to fit certain categories. There are similarities in how distress is communicated, which are not necessarily well explained or described by diagnosis. For example, the content of 'delusional ideas' is often similar between PRPD and I believe this is how services learn to help people, by noticing that some communications of distress are similar to others and finding what works for groups of people. It could be argued that this is how evidence bases and classification systems develop and that if diagnosis is abandoned, it will be replaced by another classification system, which could have negative consequences similar to diagnosis. Perhaps this is due to our inherent need for social categorisation; categorising people into certain groups based on simplified characteristics (Tajfel and Turner, 1979).

Critical realism suggests that reality can only be imperfectly known and so findings

about that reality can only be probably true (Guba & Lincoln, 2005). There are similarities

between critical realism and Hacking's (1986) "two vectors" of labeling (p. 168). Hacking

contends that "labeling from above" comes from those in an expert position who create

potential realities that "some people make their own". The second vector, labeling "from

below" is "the autonomous behavior of the person so labeled", which creates a reality that

experts must take into account. Critical realism, similarly, sees reality as outside our current

understanding, therefore we cannot explain everything and must accept the reality of, for

example, distress, but also understands that we cannot fully know; reality includes powers

and processes that operate in potential, not just those that are represented in actual events

(Pilgrim, 2015). Therefore, not all distress will fit into the constructs we have available

(thanks to the person operating in the second vector), thus creating the uncertainty in

practice, which was an issue for the participants in this study.

However there is a tension in this thesis, with the research paper defending a

constructivist position and epistemological concerns and the focus in this paper on the utility

of critical realism, which has an ontological emphasis. As Guba and Lincoln suggest,

"interweaving" or "borrowing" different aspects of ontological and epistemological stances

is possible (2005, p. 197) and I continue to do this throughout my work. It seems that, whilst

conducting research, epistemological concerns were greater but when reflecting on this

research and its wider context, ontological concerns predominated and furthered my journey

in considering my own ontological and epistemological views. The tension between the

social constructivist stance of the research paper and, for example, using attachment theory

to contextualise some findings, is an example of this. The use of attachment theory is also

perhaps an example of the need for pragmatism within the constraints of the Doctorate in

Clinical Psychology Thesis and its requirement to apply existing theory to findings.

Critical realist ideas have helped me in discussing research in a positivistic

environment. I cannot claim that my GT is representative of the whole population sampled but neither could a quantitative study, because there are always realities and processes hidden from our methods. My aim was to present a useful snapshot but not claim representativeness. In clinical practice, critical realism has aided my understanding that distress is constructed in the narratives we use to communicate it, but this is not the whole story, because distress is part of people's realities and not all of reality can be known. In practical terms, this has taught me that formulation cannot explain everything and that perhaps the key to making all systems of understanding (diagnosis or formulation, for example) more humane, is to treat them all as provisional; Pilgrim (2015) suggests that a critical realist formulation would be "tentative, as inclusive as possible and revisable" (p.298).

The challenges of becoming a grounded theorist

       Theoretical saturation and sampling. The issue of data saturation is contested in GT. Some scholars argue that data collection should continue until theoretical saturation is reached, where there are no new properties of categories emerging (Glaser, 1978). Dey (1999) has offered an alternative to saturation, 'theoretical sufficiency', arguing saturation implies that all categories have been exhausted but this idea is not in line with a constructivist epistemology; saturation is not possible because the aim is not to provide an objective truth and the findings represent the researcher's understanding, not the only possible understanding, of the data. This is supported by Charmaz (2006) who suggests that interviewing should cease when the data has provided sufficient theoretical insights. However, others argue that theoretical integration should be the goal for GT, where the theory provides a comprehensive explanation of the processes apparent in relation to the phenomenon under study (Birks & Mills, 2011).

       As discussed in the method section of the research paper, the number of participants

interviewed was the number of participants who volunteered for the study, which limited the ability to reach theoretical sufficiency. Due to the time limits of the thesis, recruitment only took place within one trust (although the participant pool was approximately 150 people). I felt that the categories were sufficient and integrated after 10 participants, however I would have liked to have recruited more participants to test the categories further and perhaps offer more richness and depth to them. Theoretical sufficiency could have been improved by conducting second interviews with staff, however there were concerns from R&D and service managers about how much staff time the research was going to take up and therefore second interviews were not agreed as part of recruitment.

Despite this, I feel able to conclude that the categories are sufficient and integrated (although not 'saturated') and therefore the sample size and sampling strategy were sufficient to achieve this. This conclusion can be drawn because the study has met its primary aim, which was to develop a GT to explain how diagnosis is used in practice. The resulting GT meets this aim, and although the study does not perhaps meet the more positivist aim of saturation, it has provided a GT, which gives an abstract understanding of the area of study, theorising patterns and connections between categories, to offer an understanding of meanings, actions and how they are constructed by participants (Charmaz, 2006).

Recruitment efforts were time consuming and challenging. I sent the follow up recruitment emails and chased up those who expressed an interest but did not follow up in arranging an interview (two potential participants). I also made phone calls and wrote emails to team managers asking if I could go to team meetings to present the research proposal and recruit, however only one manager allowed me to do this, most citing team pressures and the preciousness of teams' time together.

As mentioned in the discussion of the research paper, theoretical sampling was not possible, due to the time constraints of the project and collecting demographic data compromising anonymity. As discussed above, further recruitment would have been ideal to test out the categories further and theoretical sampling could have extended the results. For example, focusing recruitment on those who had been trained in psychology models to further test out that strand.

Another issue was that the plan to sample an equal number of participants from all nine CCTTs in the trust did not come to fruition because all those who volunteered to take part were interviewed, representing seven teams. This sampling strategy was planned to account for differences in team cultures but this did not seem to be an issue, with heterogeneous experiences coming from participants from the same teams. Thus despite the challenges I faced around recruitment I believe that the study has produced a robust GT and a valuable contribution to knowledge.

Further methodological limitations. It would have been interesting and useful to consider the impact of the professional affiliation of study participants on the way diagnosis was used. As discussed in the research paper, it would have been particularly useful to consider what factors affect which strand practitioners align with. However, professional discipline did not seem to help explain the findings, as discussed in the research paper it was not the case that nurses occupied one strand and social workers another. If the study had been larger and spread over another trust, more detailed demographics could have been considered to look at their possible impact on use of diagnosis. However, collecting and reporting demographic data in this study would have surely compromised the anonymity of the professionals who participated.

The GT constructed here is based on 10 participants' perspectives and the researcher's analysis of these perspectives. Therefore it is important to acknowledge that the

findings represent one construction of the data forged within the context and conditions of the study. It is hoped that this GT can be further tested and expanded on in future research. For example, it might be useful to consider further, how use of psychiatric diagnosis in practice impacts on referral rates to psychology, for practitioners in different strands.

The impact of research on practice and of practice on research

Throughout training I have noticed a tension between my academic knowledge and what is possible or what works in practice. For example, how do I use the understanding about diagnosis gained in my literature review whilst practising in a system where diagnosis is necessary? The issue of power in this research has led me to consider how feasible the idea of challenging the use of diagnosis at a systemic level is, given that the whole system is structured around diagnosis. If I believe that diagnosis has a damaging impact on PRPD, how do I find a common language to clinically discuss distress with colleagues in an environment where medical language dominates?

The truth is this is very difficult and I consider recent DCP guidance (DCP, 2015) idealistic and too far removed from the conversations happening at ground level. However, what I have realised and reflected on in this research process, is that I can use labels to describe what someone's experience might be like but I can do that in a compassionate way. For example, if someone experiencing distress has been labeled as having 'antisocial personality disorder', according to the DSM-5 (APA, 2013) they would have a 'pathological personality trait' of 'manipulativeness'. If I understand this as a label, or a social construction, in practice I can offer another conceptualisation. For example I can encourage the view that 'manipulative' behaviour represents a resourceful pattern someone has developed to get their need met, which can leave others feeling manipulated; their response, not necessarily the person's intention. I often challenge the 'manipulative' label without

single handedly trying to eradicate it; I find it more useful to use and unpack diagnostic terms.

Diagnosis and research

The issue of using diagnostic categories to organise qualitative and quantitative research is, as mentioned in the discussion of the literature review, one that needs to be addressed more fully by CP as a profession. In the planning of this thesis, discussions were had about the issues of considering diagnosis as a whole phenomenon in both the literature review and the research paper, rather than studying a single diagnostic category, for example. In response to such discussion, I looked to the literature for guidance and found some discussion in *Clinical Psychology Forum*, the DCP's monthly publication. Gill, Mullin and Simpson (2013), in a brief opinion piece, discuss this issue in relation to quantitative research, with the suggestion that "methodologies which place a greater emphasis upon psychological conceptualisations of problems rather than diagnostic clustering can and should be implemented" (p. 30).

Although the focus was on diagnosis in this study, focusing on it as a whole and problematic concept was an attempt to better understand it and therefore use it in more helpful ways. In the literature review, I attempted to look at diagnosis as a whole to bring together research that had been assigned to diagnostic categories in order to break down those artificial barriers and make those findings more useful. In the research study, I wanted to move away from arguments about categories and their utility to try to understand why diagnosis, as an organising principle, has prevailed. Focusing on one or two diagnostic categories would not have allowed those aims to be met.

Final Reflections

I undertook this project because of an interest in why diagnosis has remained so powerful despite being so heavily criticised, believing that the answer would lie in the work

of practitioners at ground level. I have learned about the importance of having a certain

foundation from which to practice, similar to the 'safe base' (Bowlby, 1988) in attachment

theory and how this is created in sometimes unhelpful ways in the chaos of mental health

practice. The intricacies of this need for practitioners and the entanglement of diagnosis in

mental health practice mean that, in my opinion, any drive to replace diagnosis with another

paradigm, eradicating it completely, is wasted energy. As Chambers et al. (2013) point out,

it is difficult to practise in a system where "different paradigms compete for validation,

power and finance" (p. 140). Perhaps clinical psychology as a profession should move away

from seeking that validation, power and finance, towards developing ways of working that

are more useful for practitioners and PRPD.

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Section Four: Ethics Section

Rebecca Hough

Doctorate in Clinical Psychology

Division of Health Research, Lancaster University

Correspondence should be addressed to:

Rebecca Hough

Department of Clinical Psychology,

Faculty of Health and Medicine,

Furness Building,

Lancaster University,

Lancaster,

Lancashire, UK.

LA14YW

Email: r.hough@lancaster.ac.uk

Tel: +44 1524 593378

Fax: +44 1524 592981

University Ethics Application

**Faculty of Health and Medicine Research Ethics Committee (FHMREC)
Lancaster University**

Application for Ethical Approval for Research

A qualitative study of practitioner perspectives on psychiatric diagnosis.

Rebecca Hough

Trainee Clinical Psychologist

Department of Clinical Psychology

1. Title of Project: A qualitative study of practitioner perspectives on psychiatric diagnosis.
2. If this is a student project, please indicate what type of project by ticking the relevant box: □ PG Diploma   □**Masters** dissertation   □**MRes**   □**MSc**   □ DClinPsy SRP □ PhD Thesis   □**PhD Pall.** Care/Pub. Hlth/Org. Hlth & Well Being   □**MD**   **X** DClinPsy Thesis □ Special Study Module (3rd year medical student)
3. Type of study x Involves direct involvement by human subjects □ Involves existing documents/data only. Contact the Chair of FHMREC before continuing.

Applicant information
4. Name of applicant/researcher: Rebecca Hough (principal investigator)
5. Appointment/position held by applicant and Division within FHM: Trainee Clinical Psychologist

6. Contact information for applicant:
 	
  E-mail:
  Address
 	
  Phone:

7. Project supervisor(s), if different from applicant:
 	
  Name(s):
  E-mail(s):
  Name(s):
  E-mail(s):
  Name(s):
  E-mail(s):

8. Appointment held by supervisor(s) and institution(s) where based (if applicable):

9. Names and appointments of all members of the research team (including degree where applicable)

Rebecca Hough, Trainee Clinical Psychologist, Lancaster University

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The Project
NOTE: In addition to completing this form you must submit a detailed research protocol and all supporting materials.

10. Summary of research protocol in lay terms (maximum length 150 words).

This is a qualitative research project which will develop a grounded theory of how non-psychology NHS staff make sense of and use psychiatric diagnosis (PD) in their work. Interviews will be conducted with staff who are care coordinators (CCs) in NHS adult secondary mental health services. Grounded theory will help in developing a theoretical understanding of the processes associated with the use of PD in practice. This will also support clinical psychologists (CPs) to engage with CCs at a consultative level, having a better understanding of their views on PD, enabling CPs to pitch their discussions with CCs from a shared understanding, to perhaps influence and change that understanding.

11. Anticipated project dates

Start date: August 2014   End date: May 2015

12. Please describe the sample of participants to be studied (including number, age, gender):

At least 8 and a maximum of 24 participants from different backgrounds (nursing, social work, occupational therapy), who are currently working as CCs in adult secondary mental health services, will be studied. In the first instance participants will be recruited from the nine complex care and treatment teams (CCTTs) in L_____, widening out recruitment to another trust if needed. No demographic data (for example age, gender) will be collected in order to preserve anonymity of participants.

13. How will participants be recruited and from where? Be as specific as possible.

Participants will be recruited from the 9 CCTTS in ███████████████████████████. An email will be sent from the principal investigator (PI, Rebecca Hough), via the field supervisor (███████████), to all CCTT team managers, who will be asked to disseminate it to all care coordinators, asking people to express an interest in taking part in the study, attaching the participant information sheet for more information and asking them to email back the principal investigator with their name and contact details.
There will be an initial block of data collection, followed by a pause in data collection to allow for data analysis and the initial development of the draft grounded theory. A second block of data collection will allow exploration of gaps in this model.
In both blocks of data collection, an attempt will be made to get an even spread of staff from each team. However it is acknowledged that this may not be possible and it may, for example, be a possibility that the majority of participants come from the team the field supervisor has most contact with. Following any expressions of interest, the PI will email back participants thanking them for their interest, explaining the recruitment process based on the data collection strategy, and informing them that an interview date will be arranged if necessary. The principal investigator will try to sample a similar number of participants from each team. Therefore, based on the number of potential participants who express an interest in taking part, interviews will be arranged with a similar number of participants from each team. If more than one participant from a given team expresses an interest, the first participant to have emailed the PI will be selected over the others.
Then in the second block of data collection, participants from other teams will be chosen in order to get a spread of participants from each team.

If there is a disappointing response from initial emailing, a second email will be sent and a third, if needed, after the initial data collection block. If it is clear that it is not possible to get a spread from each team; for example there is an overwhelming response from some localities and no respondents from others, participants from the same localities will be interviewed and a representative spread will not be achieved. This will be explored in the write up.

There is a potential pool of approximately 150 participants, therefore if there are more declarations of interest than participants needed, an email will be sent informing those who have not been selected to take part of the same. This will happen when all interviews have been conducted.

If insufficient numbers are recruited, recruitment will be widened out to another trust.

14. What procedure is proposed for obtaining consent?

Before interview, the researcher will go through the participant information sheet with participants and then ask them to sign the consent form. Only when that form has been signed will the interview commence. The participant information sheet and consent form informs the participant that they are able to withdraw data up until the point of submission of the thesis (May 2015). Following this, every effort will be made to withdraw individual data up until the point of publication.

15. What discomfort (including psychological), inconvenience or danger could be caused by participation in the project? Please indicate plans to address these potential risks.

Due to the nature of interviews exploring experiences it is possible that some participants may become upset. It is also possible that the material, although work related, will hold some personal significance for them. The interviewer will take every step to support participants if this occurs and to fully debrief before returning to the workplace. Attempts will be made to minimise inconvenience by conducting interviews at a convenient place for participants. If there is indication from interview that the participant is putting themselves or service users at risk the interviewer will report these concerns to the Field Supervisor and agree an action plan. This is explained in the participant information sheet.

Participants will be reminded before interview not to identify any service users, in order to avoid any breach of confidentiality.

16. What potential risks may exist for the researcher(s)? Please indicate plans to address such risks (for example, details of a lone worker plan).

Interviews will be conducted by the PI on Trust sites and lone worker procedures for each site will be followed. As part of the lone working policy the PI has completed Breakaway training and procedures for specific buildings will be followed, for example signing in and out of the building, being aware of fire safety procedures, panic buttons and being aware of any specific risks to lone workers on site. These are thought to be minimal given that interviews are taking place in trust community settings.

17. Whilst we do not generally expect direct benefits to participants as a result of this research, please state here any that result from completion of the study.

There will be no direct benefits to participants from taking part. Findings may be useful to staff once the research is complete.

18. Details of any incentives/payments (including out-of-pocket expenses) made to participants:

Up to £10 reimbursement for travel expenses should any be incurred.

19. Briefly describe your data collection and analysis methods, and the rationale for their use

Grounded theory will be used to analyse the data gathered through semi-structured interviews. The wide focus here on psychiatric diagnosis could give a diverse set of data as practitioners will have a range of experiences and influences. Therefore using grounded theory should allow focus on specific emerging issues as data are collected and analysed.

20. Describe the involvement of users/service users in the design and conduct of your research. If you have not involved users/service users in developing your research protocol, please indicate this and provide a brief rationale/explanation.

Service users from the ██ were involved in the design of this study, as part of the peer review process.

21. What plan is in place for the storage of data (electronic, digital, paper, etc.)? Please ensure that your plans comply with the Data Protection Act 1998.

Interviews will be digitally recorded by the PI (Rebecca Hough) on a portable digital recording device. Following the interview the data will be uploaded by the PI onto Lancaster University's server. Because the portable device cannot be encrypted, the transfer of the file onto computer will be completed as soon as possible by the PI following the interview and the data file will then be deleted from the portable device. The interviews will then be transcribed verbatim by the PI, with transcripts kept on the university server. All identifying information, including any service user names will be anonymised. Consent forms will be scanned in and saved on the university server, by the PI. After the thesis has been examined, the PI will create and encrypt a file containing transcripts and consent forms and send it to the research coordinator of the course for long term digital storage. Following the examination of the project, the PI will delete the audio files. Supervisors may access transcribed interviews to support data analyses. An anonymised data file of the transcripts and consent forms will be kept on the Lancaster University server for up to ten years following submission of the report, uploaded and then destroyed after 10 years by the research coordinator. This complies with the Data Protection Act 1998.

22. Will audio or video recording take place?   □ no   x audio   □video
If yes, what arrangements have been made for audio/video data storage? At what point in the research will tapes/digital recordings/files be destroyed?

Interviews will be digitally recorded on a portable digital recording device, by the PI. Following the interview the data will be uploaded onto Lancaster University's server. The transfer of the file onto computer will be completed as soon as possible following the interview and the data file will then be deleted from the portable device. Following the examination of the project, the PI will delete the audio files.

23. What are the plans for dissemination of findings from the research?

The findings of this study will be disseminated to all participants who wish to be informed of the outcome. All team managers will be asked if they would like the PI to visit their teams on completion of the study to present the findings. The research report will be submitted for publication in a peer reviewed journal. The research will also be presented at the DClinPsy thesis presentation day at Lancaster University in June 2015.

24. What particular ethical problems, not previously noted on this application, do you think there are in the proposed study? Are there any matters about which you wish to seek advice from the FHMREC?

As the teams are relatively small and specific within the trust anonymity of participants may be compromised and it is possible that they may be recognised from some of the information in the final report. An attempt has been made to maximise anonymity and confidentiality of interviews by pooling recruitment from all 9 teams. All results will be anonymised without the team being mentioned and no demographic data will be collected in order to preserve anonymity.
The content of interviews will be kept confidential. As set out in the participant information, this confidentiality must be broken if the participant divulges any information that may indicate that they are likely to harm a service user, or that brings their fitness to practise into question. The field supervisor (██████████████) will be available when the PI is interviewing and if such a matter arises, the PI will, if possible, inform the participant that the breach of confidentiality must occur and what action will be taken (a discussion with the field supervisor). The PI will then contact the field supervisor and agree a plan of action. There is also a limit to confidentiality if it is felt that the participant presents a risk to themselves and the same process will be followed.
There are no matters about which advice is needed from the FMREC.

Signatures: Applicant: …████████████████████████

Date: ██████████████████████████████

Project Supervisor* (if applicable): ████████████████████

Date: ██████████████████████████████

*I have reviewed this application, and discussed it with the applicant. I confirm that the project methodology is appropriate. I am happy for this application to proceed to ethical review.

Research Protocol

A qualitative study of practitioner perspectives on psychiatric diagnosis

Applicant/ Principal Investigator: Rebecca Hough (Trainee Clinical Psychologist,

Lancaster University/ ███████████████████████████).

Supervisor: ██

                                                                .

Field Supervisor: ███

                                                            .

Supervisor: ████████████████████████████████████

                                            .

Introduction

Current debate

The British Psychological Society's (BPS) Division of Clinical Psychology (DCP) has

released a position statement about the shifting paradigm of psychiatric diagnosis (PD)

in mental health (BPS, 2013). This states that rather than using reductive diagnostic

categories as set out in the Diagnostic and Statistical Manual of Mental Disorders V (APA,

2013), clinical psychologists (CPs) and other mental health professionals need to develop

a framework of understanding for mental distress that is based on

understanding human experience, moving beyond the current disease model.

This statement urges such shifts because the current framework has a detrimental

impact on service users (SUs; BPS, 2013). The DCP has set up a working committee to

develop an alternative to the diagnostic system that takes account of these issues,

however the practitioners who will be implementing and adjusting to any changes in the

diagnostic system (for example mental health social workers, nurses and occupational therapists) do not seem to have a voice in that debate. This debate is not purely academic; the DCP are motivated by "the hope of embedding a more holistic, post-diagnosis paradigm that will be adopted by mental health services and those who use them" (Clarke, Horder & Rosebert, 2014, p. 7). This is in line with the wider, international debate about the lack of validity of psychiatric diagnosis and its inefficacy in guiding mental health treatment; followed by a call for a genuine rethink of mental health care and the paradigms within which it is delivered (Bracken et al., 2012).

Existing research

    Psychiatric diagnosis

There is an existing body of research that explores service user experience of PD, usually focusing on a specific PD (e.g. Pitt, Kilbride, Welford, Nothard & Morrison, 2009). This research largely shows that PD offers a conflict of experience for SUs; it is seen as both offering hope and validation, at the same time as being pejorative and leading to stigma (Leeming, Boyle, & Macdonald, 2009). There is very little research directly exploring staff's views on or use of psychiatric diagnosis. The only existing qualitative study is by Probst (2013), who conducted a US study investigating social workers' use of diagnostic and environmental perspectives in their work in mental health. The findings suggest a 'tightrope' between exaggerating problems associated with diagnosis in order to meet diagnostic criteria and access services and minimising the pathologisation of what social workers saw as problems of living. The findings suggest that diagnosis offers a starting point for intervention but the moulding of presenting problems to fit into pre-defined categories left participants feeling ethically compromised. The findings of this study appeared to be heavily influenced by the US healthcare system due to the need for

a PD to access insurance. Scott and Sembi (2006) make an academic argument that diagnosis should be used as a way of identifying initial hypotheses that should be idiosyncratic and tested but it is as yet unclear how practitioners use diagnosis in practice in the UK NHS.

The service context of therapy

Research into the efficacy of psychological therapies indicates that the therapeutic alliance between practitioner and service user is the most robust indicator of positive therapeutic outcomes across treatment modalities and clinical presentations (Castonguay & Beutler, 2006). Rogers, Pilgrim and Lacey (1993) found that many SUs valued the human aspects of their contacts with professionals (feeling listened to, treated with kindness and respect) rather than technical expertise exhibited. Therefore it is important to understand what frameworks of understanding various professionals bring to their SUs as this could influence the therapeutic alliance and the direction of treatment. This is particularly important for mental health services where the SU may form a number of therapeutic alliances, for example with their care coordinator (CC) and their clinical psychologist, who may be working with those SUs concurrently.

Clinical psychology in the service context

There is an increasing emphasis on CPs being able to work with and influence adult mental health teams in a consultation and training role, to try to maximize the use of psychologists within the NHS (Lavender & Hope, 2007; BPS 2007a; 2007b). This means that CPs need a good understanding of staff teams in order to influence them. As posited by Gill, Mullin and Simpson (2013), PD provides a "joint narrative between systems" and it is the role of the CP to offer a psychological understanding of such narratives. If new frameworks for understanding in mental health are recommended, a

degree of change will be inevitable for practitioners. Cognitive analytic therapy explains

that change has to be encouraged within a person's 'zone of proximal development'

(ZPD), which means that any new learning or change needs to be close enough to what

the person already knows to be palatable (Ryle & Kerr, 2002). As a profession we need

to know what that ZPD is at ground level in order to affect change.

Current study

This study will use qualitative inquiry to consider the views of care coordinators

(CCs) working in adult mental health settings at ground level, those who perhaps would

not get an opportunity to be part of the DCP working party. If a legitimate alternative to

PD is offered by the DCP, these staff will have to adjust to any changes that this might

bring. Therefore it is important to understand their own experiences of and views on

using PD in mental health practice, in order to understand what functions and qualities a

new approach will need to retain in order to be palatable at practice level. This will aid

the current debate about how CPs can deliver an alternative to PD that is more likely to

be taken on board by non-psychology NHS staff. This will also enable CPs to engage with

clients more effectively as they will have an understanding of the frameworks of

understanding that are being perpetuated by their CCs.

This study will produce a grounded theory for clinical practice; answering the call

to examine "values, relationships, politics and the ethical basis of care and caring"

(Bracken et al, 2012, p. 432). This study will deal with a real concern of its participants

and CPs, not only serving an academic interest; a key purpose for any grounded theory

study (Glaser & Strauss, 1967). Grounded theory will help in developing a theoretical

understanding of the processes associated with the use of PD in practice. This will also

support CPs to engage with CCs at a consultative level, having a better understanding of

their views on PD, enabling CPs to pitch their discussions with CCs from a shared

understanding, to perhaps influence and change that understanding.

Research Questions

What is the experience of NHS staff working with PD in NHS secondary adult

mental health services?

Aim

To explore the experience of staff working with PD in the NHS.

Method

Design and participants

This is a qualitative study with a sample of at least eight participants from

different backgrounds who are currently working as CCs in adult secondary mental

health services. Using a grounded theory methodology, it is difficult to predict what

sample size will be needed to achieve theoretical saturation, however eight to 24

participants is the range suggested by Riley (1996) to achieve data saturation. In the

first instance participants will be recruited from the nine complex care and treatment

teams (CCTTs) in ██████████, widening out recruitment to another trust if needed. It is

acknowledged that secondary mental health services in this locality are undergoing

service changes, like much of the NHS. Therefore recruitment will take place from these

teams as they exist at the time, which may be under a different name, but they will still

employ CCs. Purposive sampling of a balanced number of participants from each team

will attempt to allow for the potential influence of certain working cultures within

teams, which may influence views on psychiatric diagnosis.

Procedure

Following ethical and R & D approval, an email (see Appendix 4-A) will be sent from the PI, via the field supervisor, to all CCTT team managers, who will be asked to disseminate it to all CCs, inviting people to express an interest in taking part in the study, attaching the participant information sheet for more information (see Appendix 4-B) and asking them to email back the PI with their name and contact details if they are interested in taking part.

Alongside recruitment, the principal investigator (PI) will endeavour to visit all 9 teams to talk at the team meetings to give a brief overview of the research, to try to maximize recruitment. It is acknowledged this may not be possible for all teams, for a number of reasons. For example, infrequency of team meetings where time is precious may mean that managers do not want to allocate time for the PI to speak. The PI will approach team managers to request a slot for the PI to speak at their team meeting.

There will be an initial block of data collection, followed by a pause in data collection to allow for data analysis and the initial development of the draft grounded theory. A second block of data collection will allow exploration of gaps in this model.

In both blocks of data collection, an attempt will be made to get an even spread of staff from each team. However it is acknowledged that this may not be possible and it may, for example, be a possibility that the majority of participants come from the teams that the field supervisor has most contact with. Following any expressions of interest, the PI will email back participants thanking them for their interest and informing them that an interview date will be arranged if necessary (see Appendix 4-C).

The PI will try to sample a similar number of participants from each team. Interviews will be arranged with those participants. If there is a disappointing response

from initial emailing, a second email will be sent and a third, if needed, after the initial

data collection block. If there are more declarations of interest than participants needed,

an email will be sent informing those who have not been selected to take part of the

same (Appendix 4-D).

At interview participants will be given time to read the participant information

sheet if needed (Appendix 4-B) and asked to sign the consent form (Appendix 4-E). They

will be asked if they would like to receive a summary of the research. They will also be

reminded not to disclose any names of service users; if this happens inadvertently this

information will be removed from the written transcript. If they opt in to this their email

address will be taken for the dissemination list. The research summary will be sent after

the thesis has been examined. The dissemination list will be kept electronically on the

University server, password protected and destroyed following the dissemination of

participant summaries. Only when they have signed the consent form will the interview

begin.

Data will be collected using semi-structured interviews, approximately 1 hour

in duration, asking staff to reflect on their experience of using psychiatric diagnosis in

practice (see Appendix 4-F for interview schedule). As a grounded theory methodology

will be used and data analysis completed after each block of interviews, as interviews go

on the interview schedule may change to allow the PI the chance to direct questioning

towards areas of interest.

Throughout the interview the interviewer may keep notes for their own

understanding and may check this understanding or link themes, checking these

conclusions with the participant.

Interviews will be digitally recorded on a portable digital recording device.

Following the interview the data will be uploaded onto Lancaster University's server.

The transfer of the file onto computer will be completed as soon as possible following the interview and the data file will then be deleted from the portable device. The interviews will then be transcribed verbatim by the principal investigator, with transcripts kept on the university server. Consent forms will be scanned in and saved on the university server. After the thesis has been examined, a file containing transcripts and consent forms will be encrypted and sent to the research coordinator of the course for long term digital storage. Following the examination of the project, the PI will delete the audio files. Supervisors may access transcribed interviews to support data analyses. An anonymised data file of the transcripts and consent forms will be kept on the Lancaster University server for up to ten years following submission of the report.

<center>Data Analysis</center>

Grounded theory will be used to analyse the data gathered. The wide focus here on psychiatric diagnosis could give a diverse set of data as practitioners will have a range of experiences and influences. Therefore using grounded theory should allow focus on specific emerging issues as data are collected and analysed. The aim is to create a grounded theory explaining the utility of psychiatric diagnosis for NHS staff.

This is an inductive approach to data collection, taking a constructivist approach to grounded theory (Charmaz, 2006). An initial attempt will be made to develop categories which illuminate the data, followed by an attempt to saturate those categories with appropriate cases to demonstrate their relevance. These categories will then be developed into more general analytic theoretical frameworks, giving an account of PD that is grounded in the real world of the participants.

Practical Issues

Participants will be interviewed at a location convenient for them, which is likely to be their workplace. The university will cover the cost of the PI's travel to interview. The PI will attempt to ensure that travel time and cost is minimised, for example by interviewing staff based at the same site on one day. The course will also cover the cost of producing any materials such as printing and photocopying.

The results will be fed back to all CCTTs who wish to receive feedback via team meetings and a written summary will be produced for dissemination to anyone in the Trust who expresses an interest. In the initial email to team managers, they are asked to express an interest in hearing the results of the study (see Appendix a-A).

Ethical Concerns

Anonymity

As the teams are relatively small and specific within the trust anonymity of participants may be compromised and it is possible that they may be recognised from some of the information in the final report. An attempt has been made to maximise anonymity and confidentiality of interviews by pooling recruitment from all 9 teams. All results will be anonymised without the team being mentioned and no demographic data will be collected in order to preserve anonymity.

Interviews

As the initial request for taking part in the study will be sent via team managers, it is possible that members of that team will feel obliged to or coerced into taking part. This should be offset by the participant information, which specifies that there is no obligation for those approached to take part.

Due to the nature of interviews exploring experiences it is possible that some participants may become upset. It is also possible that the material, although work related, will hold some personal significance for them. The interviewer will take every step to support participants if this occurs and to fully debrief before returning to the workplace. If there is indication from interview that the participant is putting themselves or service users at risk the interviewer will report these concerns to the Field Supervisor and agree an action plan. This is explained in the participant information sheet (Appendix 4-B).

Withdrawal

The participant information sheet (Appendix 2) indicates that the participant can withdraw from the study and specifies potential limitations to this.

Timescale

May-August 2014- Prepare and submit ethics and R & D applications.

September 2014- March 2015- Collection and analysis of data.

December 2014- Literature Review 1st draft.

February 2015- Literature review 2nd draft.

March 2015- Research paper 1st draft.

April 2014- Research paper 2nd draft.

April 2015- Critical appraisal 1st draft.

May 2015 Critical appraisal 2nd draft.

May 2015- Hand in.

This is a realistic timescale in which the data collection period may be extended if necessary.

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Appendix 4-A

Email to staff

Subject line: Invitation for care coordinators to participate in research- a qualitative study of practitioner perspectives on psychiatric diagnosis

Dear team manager

I would be grateful if you could disseminate the email below to all care coordinators in your team. If you would like the results of this research to be presented to your team, perhaps during a team meeting, then please email me directly. Please note that the planned completion date for this project is May 2015.

Kind regards

Rebecca Hough

Trainee Clinical Psychologist

Dear colleague

I am a Trainee Clinical Psychologist based at Lancaster University. I am writing to invite you to take part in a research project which I am undertaking as part of my training. It is being supervised by █████████████████████████ **████████████ and █████████████████████████████████. I am interested in exploring the experiences of staff who are care coordinators in secondary adult mental health services; in particular their views about and experiences of working with psychiatric diagnosis. If you decide to participate in the research you will be asked to take part in an interview with me, lasting about one hour, at a venue convenient for you. I have attached a participant information sheet which gives**

you more information. If you would like to take part in the research or have any

other queries regarding it please contact me direct at r.hough@lancaster.ac.uk.

Your research and development department and the Lancaster University

Research Ethics Committee have approved this research.

Yours sincerely

Rebecca Hough

Trainee Clinical Psychologist

Lancaster University ████████████████████████

Appendix 4-B

Participant information sheet

Health and Medicine | LANCASTER UNIVERSITY

Participant Information Sheet

A qualitative study of practitioner perspectives on psychiatric

diagnosis

My name is Rebecca Hough and I am conducting this research as a Trainee Clinical Psychologist on the Doctorate in Clinical Psychology Course at Lancaster University, Lancaster, United Kingdom.

What is the study about?
The purpose of this study is to investigate staff experiences of working with psychiatric diagnosis in multi-disciplinary adult community mental health teams. As you may be aware, the efficacy and utility of psychiatric diagnosis is a much debated area. It is important, as part of this wider debate, to consider the opinions and experiences of staff working with diagnosis. Before the interview we will go through this sheet together and I will answer any questions you have.

Why have I been approached?
You have been approached because the study requires information from people who are care coordinators in secondary mental health care teams.

Do I have to take part?
No. It's completely up to you to decide whether or not you take part. I will go through this information sheet with you, explaining the study and you will have to sign a consent form before being interviewed. You are free to withdraw your participation / data from the study before May 2015, which is when the research will be submitted to the University for assessment. Following this, every effort will be made to withdraw individual data up until the point of publication.

What will I be asked to do if I take part?
If you decide you would like to take part, you may be asked to come to an interview conducted by me at your workplace or other convenient venue. The interview will follow a loose structure with questions about your views on psychiatric diagnosis and experience of working with it in practice. The interview will last approximately 1 hour. In the event of over-recruitment (more people expressing an interest to take part than are needed for the study), you might not be asked to take part. Participants are being selected from all CCTTs in Lancashire and, if possible, an even spread of staff from each

team will be achieved. If there are more staff volunteering to take part from a particular team than are needed, those who expressed an interest first will be selected. If you are not required to take part, you will receive an email informing you of this.

Will my data be confidential?

The information you provide is confidential. The interviews will be digitally recorded and then transcribed and analysed by me. The data collected for this study will be stored securely and only the researchers conducting this study will have access to this data. The typed version of your interview will be made anonymous by removing any identifying information including your name. Anonymised direct quotations from your interview may be used in the reports or publications from the study, so your name will not be attached to them. Please do not use the names of any service users. Audio recordings will be kept until the project has been examined. Anonymised written transcripts will be kept by the university for 10 years after completion of the project.

There are some limits to confidentiality: if what is said in the interview makes me think that you, or someone else, is at significant risk of harm or that your fitness to practise, or another professional's fitness to practise, is compromised I will have to breach confidentiality and speak to my field supervisor about this. If possible, I will tell you if I have to do this.

What will happen to the results?

The results will be summarised and reported in a thesis submitted to Lancaster University and may be submitted for publication in an academic or professional journal. An accessible summary will be made available to participants, other staff members and the Trust. It is possible that the results will also be presented to the teams involved in the research, for example at team meetings.

Are there any risks?

There are no risks anticipated with participating in this study. However, if you experience any distress following participation you are encouraged to inform the researcher and contact the resources provided at the end of this sheet.

Are there any benefits to taking part?

Although you may find participating interesting, there are no direct benefits in taking part. It is hoped that the study will give an accurate picture of the experience of practitioners working with psychiatric diagnosis.

Who has reviewed the project?

This study has been reviewed by the Faculty of Health and Medicine Research Ethics Committee, and approved by the University Research Ethics Committee at Lancaster University. It is being conducted with permission from ███████████████████████

Where can I obtain further information about the study if I need it?

If you have any questions about the study, please contact the main researcher:
Rebecca Hough

Trainee Clinical Psychologist
Lancaster University
r.hough@lancaster.ac.uk

[REDACTED]

[REDACTED]

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

[REDACTED]

If you wish to speak to someone outside of the Clinical Psychology Doctorate Programme, you may also contact:

[REDACTED]

Resources in the event of distress

Should you feel distressed either as a result of taking part, or in the future, the following resources may be of assistance.

[REDACTED]

Appendix 4-C

Email to potential participants who have expressed a declaration of interest

Dear [name]

Thank you for expressing an interest in taking part in my research project "A qualitative study of staff perspectives on psychiatric diagnosis". I will be in touch with you over the coming weeks to arrange an interview, or to let you know that you will not be required to participate. If you have any questions in the meantime please do not hesitate to contact me.

Once again thank you for your interest.

Yours sincerely

Rebecca Hough

Trainee Clinical Psychologist

Lancaster University/ ███████████████

Appendix 4-D

Email to those not selected as participants

Dear [name]

Once again thank you for expressing an interest in taking part in my research project "A

qualitative study of staff perspectives on psychiatric diagnosis". I am writing to let you

know that, due to recruiting more people than necessary for the study from each

locality, you will not be needed to participate.

Yours sincerely

Rebecca Hough

Trainee Clinical Psychologist

Lancaster University/ ████████████████████████

Appendix 5-E

Consent Form

Health and Medicine | LANCASTER UNIVERSITY

Consent Form

Study Title: A qualitative study of practitioner perspectives on psychiatric diagnosis

We are asking if you would like to take part in a research project looking at staff experiences of using psychiatric diagnosis in secondary mental health services.
Before you consent to participating in the study we ask that you read the participant information sheet and mark each box below with your initials if you agree. If you have any questions or queries before signing the consent form please speak to the principal investigator, Rebecca Hough.

Please initial box

1. I confirm that I have read the information sheet and fully understand what is expected of me within this study.

2. I confirm that I have had the opportunity to ask any questions and to have them answered.

3. I understand that my interview will be audio recorded and then made into an anonymised written transcript.

4. I understand that audio recordings will be kept until the research project has been examined,

5. I understand that I am free to withdraw my participation / data from the study, before May 2015. After this date, I understand that the researchers will make every effort to withdraw individual data up until the point of publication.

6. I understand that the information from my interview will be pooled with other participants' responses, anonymised and may be published.

7. I consent to information and quotations from my interview being used in reports, conferences and training events.

8. I understand that any information I give will remain strictly confidential and anonymous unless it is thought that there is a risk of harm to myself or others, in which case the principal investigator will need to share this information with her research or field supervisor.

9. I consent to Lancaster University keeping anonymised written transcriptions of the interview for 10 years after the study has finished. This data will be destroyed by DClinPsy admin staff thereafter.

10. I consent to take part in the above study

Name of Participant_____ **Signature**_____ **Date** _____

Name of Researcher_____**Signature**_____**Date**_____

Appendix 4-F

Interview Schedule

Please could you start by giving a brief overview of your job role?

What are your views on PD?

What are your views on the causation of mental health problems?

What do you see as the consequences of using PD in mental health practice? For service

users? For practitioners?

What is your experience of using PD in practice?

Do you believe that PD is a useful framework for your SUs? What does it offer as a

framework?

What are your professional values and how does using PD in practice fit with these

values?

How do you address any conflicts in values and how do these conflicts impact on your

SUs and your practice?

Do you think there are alternatives to PD?

How do you use PD in your work?

Do your views on PD or the use of PD influence your work with other professionals?

How does PD influence your work with/ relationship the SU?

How does PD sit with your professional views/ training?

How do you see the future of mental health care, including the use of PD and other

frameworks?

Appendix 4-G

University Research Ethics Committee Approval Letter

LANCASTER UNIVERSITY

Applicant: Rebecca Hough
Supervisor: ███████████
Department: DHR

07 October 2014

Dear Rebecca and █████

Re: A qualitative study of practitioner perspectives on psychiatric diagnosis

Thank you for submitting your research ethics application for the above project for review by the Faculty of Health and Medicine Research Ethics Committee (FHMREC). The application was recommended for approval by FHMREC, and on behalf of the Chair of the University Research Ethics Committee (UREC), I can confirm that approval has been granted for this research project.

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;

- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);

- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact the ████████████████████████████████████
████████████████ if you have any queries or require further information.

Yours sincerely,

████████████

████████████

Secretary, University Research Ethics Committee

Cc ████████████████████████████████████
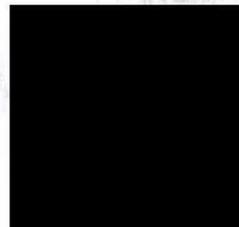
Appendix 4-H

R&D Trust Permission Letter

NHS

21st October 2014

Miss Rebecca Hough
Trainee Clinical Psychologist
Department of Clinical Psychology
Furness
Lancaster University
Lancaster
LA24YT

Dear *Miss Hough,*

Re: NHS Trust Permission to Proceed

Project Reference: 14/19

Project Title: A qualitative study of practitioner perspectives on psychiatric diagnosis

I am pleased to inform you that the above project has received research governance permission.

Please take the time to read through this letter carefully and contact me if you would like any further information. You will need this letter as proof of your permission.

Trust R&D permission covers all locations within the Trust; however you will only be allowed to recruit from the sites/services you have indicated in section 3 of the SSI application form. If you would like to expand recruitment into other services in the Trust that are not on the original SSI then you must contact the R&D department immediately to discuss this before doing so.

You also must ensure you have liaised with and obtained the agreement of individual service/ward managers before commencing recruitment in that service and you must contact the relevant service/ward managers prior to accessing the service to make an appointment to visit before you can commence your study in the trust.

Please make sure that you take your Trust permission letter with you when accessing Trust premises and please include the Trust reference number on any correspondence/emails so that the services are assured permission has been granted.

NHS

Honorary Research contracts (HRC)

All researchers with no contractual relationship with any NHS body, who are to interact with individuals in a way that **directly affects the quality of their care**, should hold Honorary Research NHS contracts. Researchers have a contractual relationship with an NHS body either when they are employees or when they are contracted to provide NHS services, for example as independent practitioners or when they are employed by an independent practitioner (*Research Governance Framework for Health and Social Care,* 2005). If a researcher does not require an HRC, they would require a Letter of Access (LoA). For more information on whether you or any of your research team will require an HRC or LoA please liaise with this office. It is your responsibility to inform us if any of your team do not hold Honorary Research NHS contracts/Letters of Access.

Staff involved in research in NHS organisations may frequently change during the course of a research project. Any changes to the research team or any changes in the circumstances of researchers that may have an impact on their suitability to conduct research <u>MUST</u> be notified to the Trust immediately by the Principal Investigator (or nominated person) so that the necessary arrangements can be put in place

Research Governance

The Research Governance Sponsor for this study is <u>Lancaster University</u>. Whilst conducting this study you must fully comply with the Research Governance Framework. This can be accessed at: http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4108962&chk=Wde1Tv
For further information or guidance concerning your responsibilities, please contact your research governance sponsor or your local R&D office.

Good Clinical Practice (GCP)

GCP is an international ethical and scientific quality standard for designing, conducting, recording and reporting trials that involve the participation of human subjects. It is the responsibility of all researchers who are carrying out a research project involving NHS patients and carers to complete GCP training and to update this every 2 years. All training certificates must be forwarded to the R&D department to comply with Trust permission. <u>Please note that student projects are exempt from this process.</u>

Risk and Incident Reporting

Much effort goes into designing and planning high quality research which reduces risk; however untoward incidents or unexpected events (i.e. not noted in the protocol) may occur in any research project. Where these events take place on trust premises, or involve trust service users, carers or staff, you must report the incident within 48 hours via the Trust incident reporting system. If you are in any doubt whatsoever whether an incident should be reported, please contact us for support and guidance.

Regardless of who your employer is when undertaking the research within ███████████ ████████████ you must adhere to trust policies and procedures at all times.

NHS

Confidentiality and Information Governance
All personnel working on this project are bound by a duty of confidentiality. All material accessed in the trust must be treated in accordance with the Data Protection Act (1998) For good practice guidance on information governance contact us.

Protocol / Substantial Amendments
You must ensure that the approved protocol is followed at all times. Should you need to amend the protocol, please follow the Research Ethics Committee procedures and inform all NHS organisations participating in your research.

Monitoring / Participant Recruitment Details
If your study duration is less than one year, you will be required to complete an end of study feedback report on completion. However if your study duration is more than one year, you will be required to complete a short electronic progress report annually and an end of study report on completion. As part of this requirement, please ensure that you are able to supply an accurate breakdown of research participant numbers for this trust (recruitment target, actual numbers recruited). To reduce bureaucracy, progress reporting is kept to a minimum; however, if you fail to supply the information requested, the trust may withdraw permission.

Recruitment
Please provide the trust details of your recruitment numbers when requested. If you have any concerns with recruitment please contact the R&D team immediately for assistance.

Final Reports
At the end of your research study, we will request a final summary report so that your findings are made available to local NHS staff. The details from this report may be published on the NHS Trust internet site to ensure findings are disseminated as widely as possible to stakeholders. You may also be invited to present your findings to the Trust at an event or meeting.

On behalf of this Trust, may I wish you every success with your research. Please do not hesitate to contact us for further information or guidance.

Yours sincerely,

R&D Director
On Behalf of the Research Governance Sub-Committee

Cc: ethics@lancaster.ac.uk