

The functions of psychiatric diagnosis

Thesis submitted in accordance with the requirements of the
University of Liverpool for the degree of
Doctor in Philosophy

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July 2017

Acknowledgements

This research would not have been possible without all the people who kindly gave up their time to be interviewed. Listening to their experiences was a privilege for which I am extremely grateful. To those who were given psychiatric diagnoses, thank you for sharing your stories and your battles. To the psychiatrists, clinical psychologists, and GPs, thank you for giving me an insight into your practices, and for being open in your discussion of their strengths and limitations, and the challenges of your work.

Thank you also to my supervisors Professor Peter Kinderman and Professor Rhiannon Corcoran. To Peter for giving me the opportunity to work in this field and for his infectious enthusiasm, and Rhiannon for her support and attention to detail. Thank you to Professor John Read for his guidance while at Liverpool and his thoughtful comments on my thesis draft. I am indebted to Dr Ciara Kierans and Dr Jessie Cooper, who were unfailingly generous with their time, ideas and feedback.

I cannot thank enough Chris Hall and Abigail Batty at Pearson Clinical Assessment for part funding this project and opening the doors for me to begin this adventure, and the University of Liverpool for matching their generosity. Thank you to my brilliant family, who were always at the end of the phone, or in James' case, the other side of a pint glass. To all my phenomenal friends, in particular HRH, Ems, Smo, Ric, and the boys in London for reminding me to retain a sense of humour and a well-stocked drinks cupboard, and to Sophie, Jessie, Rosie and Fi in Liverpool for being my family away from home. To Anna, who was always an invaluable font of information, and who frequently gave me her support, wisdom and lunch. To Dr Rachel McKail, who read every last word and was my sounding board and personal cheerleader throughout - I couldn't have done it without you. Finally, thank you to Erika, for being the light at the end of the tunnel that has made finishing this all the sweeter.

Abstract

The functions of psychiatric diagnosis - Kate Allsopp

Psychiatric diagnoses are ubiquitous, but historically have been seen as problematic, even contested, categories. Calls for new models of mental distress have originated from psychiatry, clinical psychology, and the service user movement. However these proposals are limited in their scope. Taking a social constructionist critical realist epistemological approach, the thesis framed psychiatric diagnoses as active categories; constructed to meet particular needs and functions. The central research question of the thesis was to explore, from multiple perspectives, the functions of psychiatric diagnosis. Theoretical questions addressed the conceptual underpinnings of diagnostic categories, how they are used in practice, and their implications.

Three methodologies were used. A textual examination of chapters of the DSM-5 analysed the heterogeneity across diagnostic criteria and explored diagnostic classification as a protocol for practice. Semi-structured interviews with clinicians (GPs, psychiatrists, clinical psychologists) and individuals who had received psychiatric diagnoses were used to examine the practices of diagnosis within and beyond the clinic. Finally, Freedom of Information Act requests made to NHS mental health trusts in the north of England were used to explore the uses of diagnosis in service entry and eligibility criteria.

The findings revealed that psychiatric diagnoses performed multiple clinical, social, and administrative functions in multiple contexts, and acted as a proxy for various factors, with tensions arising across these functions. These functions invoked different underpinning conceptualisations, which were inconsistent across contexts. Diagnostic practices were found to be often at odds with the use prescribed by diagnostic manuals. Although clinicians used diagnosis as a flexible tool, categories were reified beyond the clinic with important implications for those diagnosed. The thesis structure reflects the tensions that arose as a result of these multiple functions, through a process of diagnostic categories travelling from the text of the classification itself, to clinicians, services, and beyond the clinic to the individuals who received them. These multiple uses and changing conceptualisations meant that the utility of one function could result in harmful costs elsewhere. At the intersection of these functions were the people diagnosed, for whom diagnostic categories had potentially damaging consequences. Diagnosis-focused clinicians and administrative structures such as benefits payments placed limitations on the extent to which individuals could publicly reject their diagnosis should they choose to.

In contrast with previous proposals focused on replacing specific aspects of psychiatric diagnosis (such as taxonomy or individual assessment), a broader programme of system reform is advocated. Recommendations include the use of psychosocial and descriptive codes of the International Classification of Diseases and competency-based services.

Diagnostic categories defined by their syndromes should be regarded as valid only if they have been shown to be discrete entities with natural boundaries that separate them from other disorders. Although most diagnostic concepts have not been shown to be valid in this sense, many possess high utility by virtue of the information about outcome, treatment response, and etiology that they convey. They are therefore invaluable working concepts for clinicians. (Kendell & Jablensky, 2003, p. 4)

As far as I am concerned, I am not sick. What my abusers did to me was sick. I have had a perfectly natural, human response to devastating experiences. Living with the knowledge of what was done to me, and the way in which psychiatry has added insult to injury by blaming me, is enough to drive anyone mad. (Dillon, 2011, p. 145)

Table of Contents

1	CHAPTER 1: LITERATURE REVIEW	1
1.1	Preface	1
1.2	What is psychiatric diagnosis?	2
1.2.1	Definition	2
1.2.2	Aetiological agnosticism.....	3
1.2.3	Functions of psychiatric diagnosis	4
1.3	Critiquing diagnosis	6
1.3.1	Psychiatric limitations and the technological.....	6
1.3.2	Psychological perspectives: Incorporating individual social context.....	21
1.3.3	The personal and political implications of diagnosis: Service user / survivor and social sciences literature	34
1.4	The social functions of diagnosis: Historical development of the DSM	46
1.4.1	Early influences on classification	48
1.4.2	The removal of homosexuality	49
1.4.3	The making of a diagnosis	49
1.5	The actions and practices of classification	51
1.5.1	Diagnostic categories as active constructs.....	51
1.5.2	Stabilising categories	52
1.5.3	Diagnostic classification as infrastructure	54
1.5.4	Diagnoses in practice.....	55
2	CHAPTER 2: METHODOLOGICAL BACKGROUND	58
2.1	Overview	58
2.2	Personal and political positioning	58
2.3	Epistemology	59
2.3.1	A note on language.....	61
2.4	Overall research design	63
2.4.1	Refining the central research purpose	63
2.4.2	Theory questions	65
2.4.3	From theory to data collection: Using multiple sources of data	66

3	CHAPTER 3: HETEROGENEITY IN PSYCHIATRIC DIAGNOSTIC CLASSIFICATION: A TEXTUAL ANALYSIS	70
3.1	Abstract	70
3.2	Introduction.....	70
3.2.1	Rationale: Analysis of the DSM-5.....	71
3.3	Aims.....	72
3.4	Methodology	72
3.4.1	Included chapters	72
3.4.2	Excluded chapters	73
3.4.3	Method of analysis.....	73
3.5	Findings.....	74
3.5.1	Heterogeneity across specific diagnostic criteria.....	75
3.5.2	Wider heterogeneity across diagnostic categories	81
3.6	Discussion	83
3.6.1	Construction of disorder	83
3.6.2	Threats to the model of discrete disorders	86
3.6.3	Implications for understanding cause	87
3.7	Conclusions	89
4	CHAPTER 4: THE FUNCTIONS OF DIAGNOSIS FOR CLINICIANS WITHIN THE CONTEXT OF INDIVIDUAL CLINICAL ASSESSMENT	90
4.1	Abstract.....	90
4.2	Introduction.....	90
4.2.1	Rationale: Clinical diagnostic practices	92
4.3	Aims.....	92
4.4	Methodology	92
4.4.1	Design: Using qualitative interviews as a source of data	93
4.4.2	Ethics.....	94
4.4.3	Participants.....	95
4.4.4	Procedure	99
4.4.5	Methods of analysis.....	101

4.5 Findings	112
4.5.1 Pattern recognition.....	113
4.5.2 Intervention and treatment planning.....	117
4.5.3 Communication between professionals.....	128
4.6 Discussion	130
4.6.1 Differences between diagnostic classification as protocol and its use in clinical practice.....	130
4.6.2 Conceptual underpinnings of diagnostic categories.....	131
4.6.3 Clinical implications.....	133
4.6.4 Implications for data capture.....	135
4.7 Conclusions	135
5 CHAPTER 5: ASSESSING HOW DIAGNOSIS IS USED IN MENTAL HEALTH SERVICE ENTRY CRITERIA	137
5.1 Abstract	137
5.2 Introduction	137
5.2.1 Rationale: Analysis of NHS adult mental health services eligibility and entry criteria 138	
5.3 Aims	139
5.4 Methodology	139
5.4.1 Freedom of Information requests.....	139
5.4.2 Trust responses.....	139
5.4.3 Method of analysis.....	140
5.5 Findings	142
5.5.1 Broadly diagnostic specialist services.....	143
5.5.2 Problem-specific but non-diagnostic services.....	145
5.5.3 Services supporting specific life circumstances.....	146
5.5.4 Needs led services providing specialist/particular services.....	147
5.5.5 Central access and referrals.....	149
5.5.6 Exclusion criteria.....	150
5.6 Discussion	152
5.6.1 How diagnostic are diagnostic services?.....	152
5.6.2 Use of broad, quasi-diagnostic, categories.....	153
5.6.3 Use of diagnoses in exclusion criteria.....	153

5.6.4	Wider uses of diagnosis	154
5.6.5	Clinical implications	155
5.6.6	Future research	156
5.7	Conclusions	157
6	CHAPTER 6: WAYS IN WHICH PSYCHIATRIC DIAGNOSIS TRAVELS BEYOND THE CLINIC: THE PRACTICES OF RECORDING DIAGNOSES.....	158
6.1	Abstract.....	158
6.2	Introduction.....	158
6.2.1	Moving from flexible local uses of diagnosis beyond the immediate clinical relationship	158
6.2.2	Use of diagnoses in organisations outside of the NHS	159
6.2.3	Rationale: Analysis of the travel of diagnostic records	159
6.3	Aims.....	159
6.4	Methodology	160
6.4.1	Presentation of findings	160
6.5	Findings.....	162
6.5.1	NHS uses of diagnosis: Bridging between clinical and business spheres.....	163
6.5.2	Bridging between clinical and legal worlds	167
6.5.3	Bridging between clinical and social spheres to facilitate practical support	170
6.6	Discussion	172
6.6.1	Pragmatically applied diagnoses	173
6.6.2	Records of diagnosis as 'boundary objects'	173
6.6.3	Reification of diagnostic categories	174
6.6.4	Implications for research and data capture	175
6.6.5	Clinical implications: Practical utility vs. therapeutic utility.....	176
6.7	Conclusions	177
7	CHAPTER 7: THE MEANINGS AND PRACTICES ASSOCIATED WITH A PSYCHIATRIC DIAGNOSIS: RECIPIENTS' PERSPECTIVES.....	179
7.1	Abstract.....	179

7.2 Introduction	179
7.2.1 The impact of psychiatric diagnoses	179
7.2.2 Avoiding diagnosis and the 'mentally ill' identity	180
7.2.3 Rationale: The use of psychiatric diagnoses by those who receive them	181
7.3 Aims	181
7.4 Methodology	182
7.4.1 Participants	182
7.4.2 Procedure	186
7.4.3 Methods of analysis	188
7.4.4 Presentation of findings	188
7.5 Findings	190
7.5.1 Positive functions of diagnosis	191
7.5.2 Damaging effects of diagnosis	196
7.5.3 "I'm smelling a bit of a rat..." Questioning the value of diagnosis	199
7.5.4 Reframing distress outside of the diagnostic model	201
7.6 Discussion	207
7.6.1 Summary of findings	207
7.6.2 A process of responding to psychiatric diagnosis	208
7.6.3 Removing the social relations of diagnosis	208
7.6.4 The infrastructure of diagnosis becoming visible	210
7.6.5 Reframing distress	211
7.6.6 Clinical implications	213
7.7 Conclusions	213
8 CHAPTER 8: DISCUSSION	215
8.1 Thesis overview	215
8.2 Summary of findings	216
8.3 Implications and recommendations for mental health services	221
8.3.1 Neutralising the model underpinning assessment	222
8.3.2 Changing the use of tools that stabilise diagnostic categories	225
8.3.3 Broad groups of difficulties and competency-based service organisation	226
8.3.4 Representing heterogeneity by making flexibility explicit	228
8.4 Research methodology and limitations	229
8.4.1 Personal reflections on interviewing	229

8.4.2	Limitations	231
8.5	Future research	236
8.5.1	Alternative qualitative methodologies	236
8.5.2	Exploring patterns of distress that incorporate psychosocial factors	237
8.5.3	Operationalising levels of need	238
8.5.4	Using non-diagnostic outcome measures that better represent improvement	238
8.5.5	Evaluating alternative approaches	239
8.6	Possibilities and potential for change	239
8.6.1	Changing practices within existing mental health care structures	240
8.6.2	Are things changing already?	242
8.7	Personal reflections on research findings	246
8.7.1	Choice and the availability of alternative discourses	246
8.7.2	Driving forward the social	247
8.8	Conclusions	248
9	REFERENCES	250
10	APPENDICES	287
	Appendix 1: University of Liverpool confirmation of sponsorship approval.....	287
	Appendix 2: NRES Committee North West – Greater Manchester East confirmation of favourable ethical opinion	290
	Appendix 3: Confidentiality agreement between researcher and interview transcriber	295
	Appendix 4: Interview questions / topic guides.....	296
	Appendix 4.1: Clinicians who make psychiatric diagnoses as part of their clinical practice	296
	Appendix 4.2: Clinicians who do not make psychiatric diagnoses as part of their clinical practice	298
	Appendix 4.3: Demographic questions – Clinicians	299
	Appendix 4.4: Service users who have been given a psychiatric diagnosis	300
	Appendix 4.5: Demographic questions – Service Users	301
	Appendix 5: Participant information sheet - Clinicians	302
	Appendix 6: Participant information sheet – Service Users	304

Appendix 7: Participant consent form – Clinicians	306
Appendix 8: Participant consent form – Service Users	308
Appendix 9: Debrief pack – Service Users	310
Appendix 10: A section of the list of codes generated from initial open coding (alphabetically organised by nVivo)	316
Appendix 11: Example of the organisation of codes generated from open coding into subthemes	318
Appendix 12: Organisation of subthemes into themes and main themes using an example of the main descriptive theme ‘Uses of diagnosis and other assessments’	322
Appendix 13: Example of the reorganisation of themes and subthemes to represent clinicians’ uses and conceptualisations of psychiatric diagnosis	325
Appendix 14: Example of the reorganisation of themes and subthemes to represent the travel of psychiatric diagnosis beyond the clinic, through an examination of the practices of recording diagnosis	330
Appendix 15: Example of the reorganisation of themes and subthemes to represent service users’ uses and conceptualisations of psychiatric diagnosis	332

Index of Figures

Figure 2-1: Flowchart representing organisation of the following empirical chapters	68
Figure 2-2: Thematic map of themes and subthemes for each of the following five empirical chapters	69
Figure 4-1: Flowchart detailing consolidation of data codes to create coding framework...	105
Figure 4-2: Thematic map showing themes and subthemes from the three domains of findings of the interview data analysis	111
Figure 6-1: Thematic map showing themes and subthemes from the three domains of findings of the interview data analysis	161
Figure 7-1: Thematic map showing themes and subthemes from the three domains of findings of the interview data analysis	189

Index of Tables

Table 3-1: Outline of themes and subthemes	74
Table 4-1: GP demographic information	97
Table 4-2: Psychiatrist demographic information	97

Table 4-3: Clinical psychologist demographic information	98
Table 4-4: Area of speciality within with psychiatrists and psychologists worked, ordered by descending frequency	99
Table 4-5: Outline of themes and subthemes	113
Table 5-1: Outline of responses received from north of England NHS mental health trusts	140
Table 5-2: Outline of themes and subthemes	143
Table 5-3: Number of Trusts reporting service entry criteria for broadly diagnostic services	143
Table 5-4: Number of Trusts reporting service entry criteria for problem-specific but non- diagnostic services	145
Table 5-5: Number of Trusts reporting service entry criteria for services that support specific life circumstances	146
Table 5-6: Number of Trusts reporting service entry criteria for needs-led services	147
Table 6-1: Outline of themes and subthemes	162
Table 7-1: Service user demographic information	184
Table 7-2: Psychiatric diagnoses received by participants, ordered by descending frequency	185
Table 7-3: Outline of themes and subthemes	190
Table 8-1: Recommendations for mental health services & implementation examples.....	222

1 Chapter 1: Literature Review

1.1 Preface

The chapter begins with an overview of psychiatric diagnosis, including definitions and some of its multiple functions. These vary from clinical uses, to the ways it is taken up by the people who are diagnosed, to categories for research. Diagnoses are valued by many people, professionals, and organisations in multiple ways, and facilitate multiple clinical activities, care and support, and research progress on a day-to-day basis. Yet, as the quotes on page iii illustrate, alongside these valued uses are longstanding concerns about a range of aspects of psychiatric diagnosis.

To reflect these multiple functions, and the perspectives of those who use them, the following literature review outlines four key bodies of literature associated with psychiatric diagnosis: psychiatric, psychological, service user/survivor, and social sciences. The stances and arguments of each are summarised. There is, inevitably, overlap between these literatures, and the review informs the thesis as an overview rather than as an exhaustive account. These four bodies of literature are used as a way of broadening out from the technical to contextual, social, and political aspects of mental distress and its classification. The perspective and focus of study of each of the literatures is central to positioning the methodological and theoretical background of the thesis, which is further elaborated in Chapter 2.

Section 1.3 explores the critiques of diagnosis from the perspectives of psychiatry, clinical psychology, and service user/survivor accounts. Psychiatric diagnosis is seen as a problematic domain by each of these literatures, and the review summarises the key arguments, problems and implications of diagnosis, and different ways of thinking about mental distress, where these are proposed. Section 1.3.1 explores the point of view of the psychiatric literature around diagnosis. The predominant focus of this literature is the technological aspect of psychiatric classification, such as its reliability and validity. Section 1.3.2 concerns the clinical psychological literature. The perspectives of this literature are widened from the classification itself to a focus on the clinical relationship between clinician and service user. A slightly wider stance in this literature begins to incorporate a contextualised understanding of the lives of the people experiencing mental distress, and some of the negative implications of the use of psychiatric diagnosis for them. Section 1.3.3 gives an overview of the service user/survivor literature, the perspective of which is wider still, with a theme of not only the impact of psychiatric diagnosis on the individual, but also the political and societal positioning that results from being labelled with a psychiatric diagnosis.

Sections 1.4 and 1.5 take up a somewhat different perspective. These sections outline the sociological and social sciences literature that, rather than focusing on the limitations of diagnosis, seek to open up diagnostic categories and classification in terms of their historical development and practices. This literature positions diagnostic classification as a form of constructed infrastructure of productive categories that seek to fulfil particular needs and functions. The literature in these sections aims to make visible the social relations involved in the development and practices of psychiatric diagnosis.

1.2 What is psychiatric diagnosis?

1.2.1 Definition

The Oxford English Dictionary defines medical diagnosis as the “Determination of the nature of a diseased condition; identification of a disease by careful investigation of its symptoms and history; also, the opinion (formally stated) resulting from such investigation” (Oxford English Dictionary, 2017). Diagnosis is the medical assessment of symptoms, which are interpreted and organised within the frameworks of that profession (Goldstein Jutel, 2011). Psychiatric diagnoses are organised into classification systems; two currently predominant versions are the US Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5, American Psychiatric Association, APA, 2013) and the International Classification of Diseases, 10th Edition (ICD-10, World Health Organization, WHO, 1992). There are also regional adaptations of psychiatric classification, including the Chinese Classification of Mental Disorders (CCMD-3, Chinese Psychiatric Association, 2001), the Third Cuban Glossary of Psychiatry (Otero-Ojeda, 2000) and the Latin American Guide for Psychiatric Diagnosis (Berganza et al., 2004). A survey of psychiatrists across 66 countries showed that the DSM and the ICD are the most frequently used (Mezzich, 2002), with ICD most frequently used for training and clinical diagnosis, and DSM more valued for research purposes. The ICD is the psychiatric classification that the National Health Service (NHS) formally uses (NHS Choices, 2013). The two classification systems are not identical, but the DSM-5 provides the equivalent ICD codes alongside its diagnostic categories. As the most recent version of the ICD-10 is now over 20 years old (WHO, 1992), much of the literature included in this chapter pertains to the DSM-5 (APA, 2013). The decision to include literature that applied to both the DSM-5 and ICD-10 was made because the DSM-5 provides a considerably more recent representation of the classification of and thought around mental distress.

1.2.2 Aetiological agnosticism

Unlike many physical diagnoses, which typically include information about the causes of diseases, psychiatric diagnostic criteria are descriptive, and with only some exceptions, do not include information about cause. The DSM-III (APA, 1980), for example, explicitly states:

“[b]ecause DSM-III is generally atheoretical with regard to etiology, it attempts to describe comprehensively what the manifestations of the mental disorders are, and only rarely attempts to account for *how* the disturbances come about, unless the mechanism is included in the definition of the disorder” (APA, 1980, p.7, italics in original).

The introductions of the DSM-IV-TR (APA, 2000) and DSM-5 (APA, 2013a) state that, “since a complete description of the underlying pathological processes is not possible for most mental disorders, it is important to emphasize that the current diagnostic criteria are the best available description of how mental disorders are expressed...” (p. xli, APA, 2013a). Both introductions give a caution that “a diagnosis does not carry any necessary implications regarding the etiology or causes of the individual’s mental disorder...” (p.25, APA, 2013a).

This descriptive approach is a consequence of not having complete information about the causes of mental distress. Pioneered by Jaspers, the concept of ‘descriptive psychopathology’ focuses on defining and differentiating disorders, and avoids making assumptions about the cause of these experiences (Burton, 2011). Since the publication of the DSM-III (APA, 1980), psychiatric diagnostic categories have consisted of a series of criteria which must be met in full for the diagnosis to be assigned. Psychiatric classification represents diagnoses within a positivist framework whereby revised editions of the DSM are seen as improving accuracy in identifying disorders (Kupfer, First, & Regier, 2002). Using a traditional medical model, diagnostic categories are presented as discrete representations of diseases, underlying, or ‘latent’, disorders, and through this means the clinician seeks to identify from which disease a patient is suffering (Borsboom et al., 2016). It could be said that there is a tension between this conceptualisation of mental distress as a series of diagnoses representing disorder and the concept of aetiological agnosticism put forward by the DSM (and by default the similarly descriptive mental disorders section of the ICD-10). That is, psychiatric classification is presented as the organisation of distress into categories of a diseased state or disorder, in keeping with the Oxford English Dictionary’s definition, yet the categories are simultaneously described as purely descriptive representations of particular states of distress.

1.2.3 Functions of psychiatric diagnosis

There are multiple functions of psychiatric diagnosis, which are broadly described below, organised according to:

- Clinical practice
- Functions for the people who are given psychiatric diagnoses
- Research

1.2.3.1 *Clinical practice*

1.2.3.1.1 Communication

The DSM-5, as it is introduced in its preface, was “designed first and foremost to be a useful guide to clinical practice” (APA, 2013, p. xli). Likewise, an editor for the DSM-IV-TR (APA, 2000) describes the primary role of diagnosis as being the facilitation of communication between clinical practitioners (First, 2015). Psychiatric diagnosis allows clinicians to identify and communicate what experiences have been observed or recorded, as well as features that are not present, for example, a diagnosis of depression demonstrates to others that the low mood is not caused by drugs or a general medical condition. However, this notion of differentiating cause sits uncomfortably with causal agnosticism, and may relate to the issues of the “essentialist fallacy” raised by Scadding (1996, p. 596), whereby the diagnosis is seen as the cause of the distress itself. This is discussed further in Section 1.3.2.1.1, Epistemological confusion.

1.2.3.1.2 Management and treatment

Diagnosis is seen as important for the management and treatment of distress, including predicting individuals’ response to treatment. NHS guidelines from the National Institute for Health and Care Excellence (NICE), for example, are organised by diagnosis, such as Clinical Guideline CG90, Depression in adults: recognition and management (NICE, 2009). Pharmaceutical drugs, for example ‘antidepressants’ and ‘antipsychotics’, are marketed towards particular diagnostic categories, although the concept of psychiatric drugs having specific action for specific diagnoses has been contested (Healy, 1997; Moncrieff, 2011). The use of diagnoses in predicting clinical outcomes offers clinicians a heuristic, although, a review by McMahon (2014) demonstrates the additional predictive information that is needed alongside the diagnostic label. For example, people with diagnoses of depression appear to respond better to medications when their distress is severe, whereas those with diagnoses of schizophrenia and severe difficulties appear to have a lesser response to psychiatric drugs (McMahon, 2014). Furthermore, diagnostic categories are but a very broad indicator in

comparison with the complex modelling techniques now being used to more accurately predict treatment outcome (Hahn, Nierenberg, & Whitfield-Gabrieli, 2017).

1.2.3.2 *Positive functions for the people given psychiatric diagnoses*

1.2.3.2.1 Meaning and understanding for those diagnosed and their families

The final use of diagnostic classification that First discusses is in giving psycho-education to patients and families, and enabling patients to know that their experiences have been seen and studied in others (First, 2015). Pies (2012), however, believes that the ultimate purpose of diagnosing in psychiatry is to reduce the suffering and misery of those seeking help from mental health services. Pies argues that if diagnostic categories can 'usefully identify' (p. 112), and go on to treat, distress, then they have 'instrumental validity' (p. 111).

For the people who are given psychiatric diagnoses, many find it can have positive functions. Often, people seek the explanatory power of a diagnosis, to find an explanation for 'what is wrong with me?', and the doctor is authorised to provide it (Goldstein Jutel, 2011). Positive responses to diagnosis include feelings of relief and validation from having a name for one's difficulties (Pitt, Kilbride, Welford, Nothard, & Morrison, 2009; Probst, 2015a).

1.2.3.2.2 Communication and understanding from others

Some research suggests that having a diagnosis helps people receive more care and understanding from both family and friends and mental health professionals (Pitt et al., 2009). As well as reassuring service users that their difficulties are recognised, diagnosis has been argued to reduce feelings of shame, loneliness, and stigma by individuals recognising, and being able to inform others, that their difficulties represent the presence of an illness (Craddock & Mynors-Wallis, 2014). It has been argued that by using the sick role psychiatric diagnosis can reduce stigma (Davis, 2009), and many anti-stigma campaigns take up this idea.

1.2.3.2.3 Access to care and support

Having a diagnosis means that individuals have a means of finding out more about the label, and access information and support from others with the same diagnosis. Diagnoses are also used to facilitate access to treatment and support (Pitt et al., 2009), by clinicians making referrals to other services, and by service users directly.

1.2.3.3 *Research*

The DSM-5 presents the manual as a tool for collecting data for epidemiological studies and other research. Research studies are typically organised by diagnosis in order to convey comparability with other research samples. Randomised control trials, for example, may use diagnostic categories to both include and exclude particular diagnoses to minimise the impact of other variables (e.g. March et al., 2004). Diagnostic categories are typically more rigorously applied in research than in clinical settings, for example through the use of structured clinical interviews to carefully match participants to diagnostic criteria in randomised control trials (Ehlers et al., 2003).

1.3 **Critiquing diagnosis**

These varying functions across individuals and organisations reflect Blaxter's (1978) observation of diagnosis as both a category within a classification system and a process, for example, a negotiation between doctor and service user (Goldstein Jutel, 2011). It is often the juxtaposition of these different functions that results in the critiques of diagnosis outlined below. The following section considers to what extent psychiatric diagnosis can actually meet the multiple functions claimed for it. Many of the above functions are contested in the literature that follows. Some of the literature regarding psychiatric diagnoses offers proposals for meeting these functions in different, non-diagnostic ways.

1.3.1 **Psychiatric limitations and the technological**

Psychiatric diagnosis currently attempts to occupy multiple roles within mental health, its conceptualisations, and care. These roles range from a way of explaining difficulties, to a framework for treatment and intervention planning, to data gathering on which to base health service planning. Despite its efforts to meet these functions and the demands of health services, clinicians, and service users and their families, psychiatric diagnosis has met with longstanding critique from differing perspectives (e.g. Boyle, 2002; Division of Clinical Psychology, 2013; Kutchins & Kirk, 1997; Szasz, 1974). The following section outlines the limitations of diagnosis as outlined in psychiatric literature. Psychiatric literature regarding diagnosis focuses largely on its function as a system of taxonomy. The limitations highlighted by the psychiatric literature primarily concern technological problems of classification, such as reliability and validity.

1.3.1.1 *Reliability*

Diagnostic classification in psychiatry has long suffered with a problem of reliability. Reliability concerns identifying the same diagnosis across clinicians (inter-rater reliability)

and across time points for the same individual (test-retest reliability). These problems became particularly apparent following the publication of the DSM-II (APA, 1968). Blashfield and colleagues (2014) outline the research between each version of the DSM that led to these changes, including two significant studies that undermined perceptions of the reliability of the DSM-II. One study found that psychiatrists' conceptualisations of different clusters of 'psychopathology' were very different to actual patients' distress and how this presented within the clinic (Overall & Woodward, 1975). The second found that American and British psychiatrists varied strikingly in the diagnoses they assigned to the same set of patient videotapes. The Americans tended to diagnose schizophrenia for each of the videos, whereas the British psychiatrists diagnosed a wider range of difficulties, including manic depressive and personality disorders (Kendell et al., 1971). In response, the DSM-III (APA, 1980) was the first edition to introduce itemised diagnostic criteria in a bid to improve reliability, which although necessarily continued to describe diagnoses on a 'symptom' basis, the criteria replaced the less technical paragraphs of the previous, more psychodynamically-oriented, editions. The historical development of the DSM is discussed further in Section 1.4.1.1.

Since the mid-20th Century, kappa statistics have been used to estimate reliability, giving a measure of agreement between assessments whilst accounting for chance agreement (Gwet, 2010). Fleiss' generalized kappa statistic (Fleiss, 1971) has been a mainstay for estimating the reliability of psychiatric diagnosis, however the subject is much discussed and debated (e.g. Kraemer, 1992; Wongpakaran, Wongpakaran, Wedding, & Gwet, 2013). Kappa estimates range from minus one to plus one, with 0.7 and above typically being considered good agreement (Spitzer & Forman, 1979), and 0.4 or below considered poor (Fleiss, 1971; Spitzer, Williams, & Endicott, 2012). DSM-III showed improved overall reliability compared with poor reliability ratings for DSM I and II, with an overall test-retest kappa coefficient of 0.66 for Axis 1 diagnoses (Spitzer, Forman & Nee, 1979). The published DSM-III figures, however, only ever gave overall reliability estimates for diagnostic classes (such as schizophrenia disorders and anxiety disorders), without giving a complete published breakdown of ratings for individual diagnoses (Kirk & Kutchins, 1992).

DSM-IV reliability estimates ranged at their lowest from 0.55 (oppositional defiant disorder) and 0.57 (conduct disorder), to their highest from 0.76 (schizophrenia) and 0.85 (autistic spectrum disorder) (Carney, 2013). These are compared with the DSM-5 field trial findings, which ranged from the lowest at -0.03 (non-suicidal self-injury) and -0.004 (mixed anxiety and depressive disorder, adults) to 0.69 (autistic spectrum disorder) and 0.78 (major neurocognitive disorder) (Freedman et al., 2013). The poorest performing DSM-5 categories, scoring at worse than chance agreement, were not included in the main section of the published manual but nevertheless remain as conditions for further study. The lowest ratings of diagnoses eventually included in the main manual were 0.20 and 0.25 (generalised

anxiety disorder and disruptive mood dysregulation disorder, respectively) (Freedman et al., 2013). Compared with previous DSM estimates and kappa standards, DSM-5's were low, with only one diagnosis exceeding the threshold of 0.7 for good agreement, and the majority being under 0.6, which represents less than good agreement according to previous DSM field trial standards (Spitzer & Forman, 1979). The recent DSM-5 field trials have as such been argued to demonstrate a continued failure to establish reliability (Kirk, Cohen, & Gomory, 2015).

Despite Cohen's kappa being criticised as too lenient for health research because within it 0.41 may be considered acceptable (McHugh, 2012), the DSM-5 development team issued a statement regarding expectations of reliability levels, arguing that lowering the limits of acceptable reliability estimates from DSM-IV-TR to DSM-5 was justifiable when compared with reliability estimates for medical diagnosis (Kraemer, Kupfer, Clarke, Narrow, & Regier, 2012). The new levels of acceptability were adjusted to a kappa coefficient of 0.2-0.4 for acceptable, 0.4-0.6 as a realistic goal, and 0.6-0.8 being seen as 'cause for celebration' (Kraemer et al., 2012, p. 14). Psychiatrists involved in the development of the DSM-IV have highlighted their concern over these shifting goal posts for DSM-5 reliability (Spitzer, Williams, & Endicott, 2012). However, other writers have highlighted the importance of methodology, arguing that the measurement of inter-rater reliability used in the DSM-IV trials produces higher estimates than the test-retest reliability used for the DSM-5 (Chmielewski, Clark, Bagby, & Watson, 2015).

Alongside the use of criterion matching over prototype matching, the use of diagnostic categories in everyday clinical practice is likely to vary considerably within primary care in particular. The participating clinicians in the DSM-5 field trials had a minimum of 2 years' psychiatric training (Clarke et al., 2013) and each of the clinic sites were psychiatric settings. In practice, many diagnoses, usually those identified as 'common mental disorders', are made by GPs or Improving Access to Psychological Therapies (IAPT) workers rather than psychiatrists. In comparison with the minimal mental health training general practitioners in the UK receive, the now reduced reliability estimates for DSM-5 categories are likely to bear little resemblance to the reality of diagnosis in primary care, which might encompass diagnoses from depression and anxiety to obsessive compulsive disorder (OCD) and post-traumatic stress disorder (PTSD) as well as potentially bipolar disorder or psychosis.

Nevertheless, reliability, although necessary, is not a sufficient condition for an effective classification system. Reliably identifying a collection of observations does not necessarily make a syndrome or mental illness. Reliability alone cannot mean that a disorder is a valid concept (Kinderman, 2014).

1.3.1.2 Validity

Robins and Guze (1970) were among the first to apply concepts of validity to psychiatric diagnoses. Their ideas focused on developing specific clinical descriptions of homogeneous categories of problems. Delineation of disorders is seen as central to the pursuit of validity, with follow up and family studies used to support or disconfirm categories. Within their criteria, the development of homogeneous categories is pursued in association with prognosis; for example, poor prognosis was seen as inherent in the diagnostic category of schizophrenia, such that a good prognosis for someone with a schizophrenia diagnosis was seen as suggesting that that person simply had a different illness (Robins & Guze, 1970). The DSM takes as its basis for validity Robins and Guze's terms, and privileges reliability as the initial test of validity for diagnoses (Freedman et al., 2013), which as seen in the previous section has considerable limitations in the context of psychiatric diagnosis.

The DSM strategy is one of honing diagnostic categories with ever more refined descriptive clinical criteria (Kupfer et al., 2002). However in addition to problematic reliability, there remain some key areas of concern regarding validity, which will be discussed below:

- 'Disjunctive' diagnostic categories
- Lack of separate, delineated disorder categories
 - Comorbidity
 - Discrete entities?
- An arbitrarily defined divide between 'normality' and 'disorder'
- Causal information
- Prediction of treatment outcome: Non-specific drug action
- Utility vs. validity

1.3.1.2.1 'Disjunctive' diagnostic categories

Within specific diagnostic categories, Bannister highlighted, as early as 1968, the "disjunctive" (p.181) nature of the category of schizophrenia, whereby a person given this diagnosis might have some but not all of the characteristics within the diagnostic criteria, such that two people with the same diagnosis might not share any common experiences. In fact Bannister referred to the category as "so diffuse as to be unusable in a scientific context" (Bannister, 1968, p. 181). Many diagnostic categories have polythetic criteria, in which a minimum number of criteria must be present to reach the threshold for diagnosis, but no single criterion is essential (Skodol, 2012; Young, Lareau, & Pierre, 2014). This is in comparison with nomothetic criteria, in which all the criteria in a category must be met in order to warrant the diagnosis. As a result of the multiple symptom clusters within a diagnostic category, it has been demonstrated that the number of possible symptom

combinations to reach a diagnosis of PTSD using DSM-5 numbers over 600,000 (Galatzer-Levy & Bryant, 2013).

1.3.1.2.2 Lack of separate, delineated disorder categories

The aim of increasing validity through delimitation of disorders takes as its assumption that diagnosis should, as Plato described of natural science, 'carve nature at its joints' (Kinderman, 2014). Hacking (2013), amongst others, critiques this assumption, complaining that each revision of the manual perpetuates the idea that different categories of mental illness can be tidied into separate compartments much as the Linnean system of taxonomy of plants and animals. Indeed, psychiatric literature increasingly argues against the concept of 'zones of rarity' or natural boundaries between diagnostic categories (e.g. Cloninger, 1999; Kendler & Gardner, 1998). That is, individual diagnostic categories have not been demonstrated to be sufficiently separate from each other to warrant the categorical approach that is taken in classification systems. For example, continuous, as opposed to discontinuous, boundaries have been demonstrated between psychotic and neurotic depressions (Kendell & Gourlay, 1970a) and affective psychoses and schizophrenia (Kendell & Gourlay, 1970b).

1.3.1.2.2.1 Comorbidity

Comorbidity is described as when a person is diagnosed with more than one psychiatric disorder, although it is taken from medical literature in the context of disease indices, where comorbidity is defined as the presence of "any distinct additional entity" (Feinstein, 1970, p. 467). Over half of individuals who meet the criteria for a psychiatric diagnosis in a 12-month period will meet criteria for multiple diagnoses (Kessler, Chiu, Demler, & Walters, 2005). High rates of comorbidity have been seen by many as indicative not only of a high prevalence of societal mental health problems but as a symptom of a problematic classification system (Hyman, 2010; Maj, 2005) that cannot adequately capture the co-occurrence of difficulties (Sullivan & Kendler, 1998). The comorbidity problem is seen as a challenge to the validity of psychiatric classification. It has been argued that the scientifically unwarranted splitting of experiences into diagnostic categories that are presented as discrete, both from each other and discontinuous from 'normal', is the cause of the high degree of comorbidity reported across clinical groups (Hyman, 2010). The heterogeneity of diagnoses with amorphous or diffuse criteria is emphasised when combined with other diagnoses in comorbidity. Furthering the idea of heterogeneity within the polythetic criteria of the DSM-5 PTSD diagnosis described by Galatzer-Levy and Bryant (2013), described above in Section 1.3.1.2.1, Young, Lareau, and Pierre (2014) have calculated the number of possible symptom combinations to reach a diagnosis of PTSD in combination with other common diagnoses. Their findings range from 270 million possible combinations of

symptoms that would result in meeting the criteria for both PTSD and major depressive disorder diagnoses, to over a quintillion symptom combinations that would meet the criteria for PTSD and five other diagnoses.

1.3.1.2.2.2 Discrete entities?

These and other findings undermine the DSM model that diagnoses represent 'natural kinds', or discrete entities that represent specific dysfunction within an individual and exist independently of a clinician or other means of assessment (Cramer, Waldorp, van der Maas, & Borsboom, 2010; Hyman, 2010; Kendell & Jablensky, 2003; Thakker, Ward, & Strongman, 1999; Zachar, 2000). Clinicians are generally seen as aware of the processes of diagnostic creation and their purposes of clinical utility over identification of reality (Callard, Bracken, David, & Sartorius, 2013), however, "once a diagnostic concept such as schizophrenia or Gulf War syndrome has come into general use, it tends to become reified" (Kendell & Jablensky, 2003, p. 5). Reification in psychiatric literature relates to 'natural kinds', whereby diagnoses are seen as 'real things' or diseases rather than their intended purpose as clinical tools; this process was recognised as problematic by the DSM-5 research team (Kupfer et al., 2002). It has been argued that the use of terms such as 'comorbidity' further contributes to the problematic reification of diagnostic categories as natural or real entities (Lilienfeld, Waldman, & Israel, 1994).

1.3.1.2.3 An arbitrarily defined divide between 'normality' and 'disorder'

Further to problematic diagnostic categories, Kendell and Jablensky (2003) highlight the fuzzy nature of the boundary between 'normality' and 'disorder'. This changing recognition in the conceptualisation of mental health is acknowledged in the DSM-5 research agenda, and consequently the decision of where to make this boundary is "somewhat arbitrarily defined" (Rounsaville et al., 2002, p. 2). The changing concept of the definition of disorder has recently been empirically driven by personality research, which increasingly supports a continuum rather than a categorical model towards 'personality disorder' diagnoses (e.g. Clark, 2007). Philosophical debates regarding the definition of disorder are longstanding and lack consensus (Fulford, 2001; Lilienfeld & Marino, 1995; Wakefield, 1992; Wakefield, 2007). Researchers have argued that this important distinction struggles to hold up cross-culturally (Thakker et al., 1999). Bingham and Banner (2014) used a test of whether current conceptualisations succeed in excluding homosexuality from their definition of disorder to ascertain whether definitions can protect against future value-laden abuses of psychiatric diagnoses. The authors found that fact-based definitions failed to use scientific theory to exclude homosexuality, and value-based definitions did not acknowledge the consequences of oppressive societies or where particular behaviours happen to be negatively valued in some social contexts.

It has been suggested by some that the DSM-5 has increased psychiatry's pathologization of 'normal' by expanding the net of disorder with loosened criteria for some categories (Wakefield, 2013). An example of this increasing pathologization is the removal of the grief exclusion from the category of major depressive disorder, such that mourning might now be considered disordered (Pilgrim, 2014). Frances, psychiatrist and the chair of the APA task force for the previous edition of the DSM (DSM-IV-TR, APA, 2000), has been an outspoken critic of the DSM-5 for these reasons. The argument in his book 'Saving Normal' (Frances, 2013) is not that the diagnostic premise of psychiatric classification is incorrect, but that the changes in the DSM-5 represent a blurring of the distinction between 'normality' and 'sickness'. In it he quotes Wykes and Callard, who state, "the pool of normality is shrinking to a mere puddle" (Wykes & Callard, 2010, p. 302). Frances argues that psychiatrists, by allowing diagnosis to encroach upon those who are 'normal', will mislabel people as sick, in turn devaluing the 'genuinely' unwell. Although Frances is strongly against the DSM-5 in this respect, it is of note that he believes that the distinction between well and unwell is nevertheless real, valid, and important.

1.3.1.2.4 Causal information

In physical medicine having a diagnosis generally offers information about what is causing the problems experienced (Maung, 2016). This idea is also present in mental health, but psychiatric diagnostic categories are explicitly atheoretical and do not give information about the cause other than in special cases such as PTSD. The idea of particular groups of diagnoses having particular causes has been discussed in the scientific literature for many years, such as 'schizophrenia' being biologically caused (e.g. Rietkerk et al., 2008; Ross, Margolis, Reading, Pletnikov, & Coyle, 2006; Tsoi, Hunter, & Woodruff, 2008; Tsuang, 2000) and 'personality disorders' being 'associated with' trauma and other negative life experiences (e.g. Bandelow et al., 2005; Herman & van der Kolk, 1987; Lewis & Grenyer, 2009; Liotti, Pasquini, & Cirrincione, 2000). However, this has been described as 'misplaced epistemological certainty' (Lakeman & Cutcliffe, 2009) in that, for example, the concept of psychosis being a solely biological problem has been challenged very often, particularly in recent years, with increasing recognition of the role of childhood trauma in causing such experiences (e.g. Bentall et al., 2014; Read et al., 2005; Sitko, Bentall, Shevlin, O'Sullivan, & Sellwood, 2014; Varese, Barkus, & Bentall, 2012). These ideas are addressed further in Section 1.3.2.1.1, Epistemological confusion.

1.3.1.2.5 Prediction of treatment outcome: Non-specific drug action

Further problematic evidence associated with causal information and the differentiation between diagnostic categories relates to their predictive validity, which pertains to the

relationship between the category and prediction of treatment outcome. Distinct, homogeneous categories should be effectively treated with interventions specific to those groups (Kupfer et al., 2002). Drug treatment generally utilises a 'disease centred' theory that follows this model, in which drugs such as antidepressants and antipsychotics are seen as having a specific action that corrects biochemical abnormalities (Moncrieff, 2011). However, there is little evidence supporting the specificity of psychiatric drugs (Moncrieff, 2011; Moncrieff & Cohen, 2006). It has been argued, for example, that prescribing in psychiatry is different to that of physical medicine, as the range of psychiatric drugs' action is such that it makes diagnosis "almost irrelevant" (Taylor, 2016, p. 224). Taylor says of psychiatric classification, "it has little or no relevance to psychotropic drug action and as a consequence an accurate diagnosis is not required for optimal prescribing" (p. 224).

Some argue that a 'drug centred' model (Moncrieff & Cohen, 2006) better explains the action of antidepressants, in which rather than correcting a biological abnormality, the drugs are thought of as creating abnormal chemical states in the brain that temporarily relieves unpleasant mood states or other 'symptoms'. Drugs are not, however, seen as correcting an imbalance or abnormality in the brain (Moncrieff, 2011), and this action is unrelated to diagnostic categories.

1.3.1.2.6 Utility vs. validity

Other researchers have viewed validity from different perspectives, such as Kendell and Jablensky (2003) who value a distinction between validity and utility, arguing that use of 'validity' in the DSM research is conflated with utility. They conclude that current psychiatric diagnostic categories have little scientific validity for many of the reasons discussed here. Validity is defined as an invariant characteristic of a diagnostic category; that validity does not depend on the context of use, and that partial validity is not possible. However, despite poor validity, it is suggested that the categories are invaluable in their utility. The authors make an interesting point about utility (unlike validity) not being a stable property, and that this varies according to function and context, and that statements about the utility of diagnostic categories must be embedded within the context in which those categories are used, and for which purposes.

1.3.1.3 *Psychiatric calls for alternatives*

The problematic nature of diagnosis is evidenced by its frequent revision, and an expectation of a continual need for updates and amendments. Since its initial publication in 1952, the fifth edition of the DSM was released in 2013, with future revisions expected, for example via a formal process for proposing changes (APA, 2017) and the 'Conditions for further study' section within the text. Extensive revisions are anticipated to the 'mental and behavioural

disorders' chapter of the ICD-11, due for implementation in 2018 (WHO, 2017a)

Furthermore, diagnosis is recognised as problematic to the extent that psychiatric communities have discussed the need for adaptations to the diagnostic model, and in some research programmes, a complete overhaul has been proposed and embarked upon.

Different ways of conceptualising mental health difficulties in the psychiatric literature are outlined at the levels of taxonomic classification and clinical utility.

1.3.1.3.1 Dimensional components within diagnostic categories

Driven by a need for greater clinical utility, and in recognition of the research, discussed above, undermining the categorical approach to diagnosis, proposals have been made to begin introducing dimensional components to some diagnostic categories. Dimensional models were first proposed as a way of formally adapting DSM diagnoses in 2002 in the DSM-5's research agenda (Rounsaville et al., 2002), first with reference to personality and later adaptation of the psychotic and mood disorder categories was anticipated in the DSM-5 development. The DSM-5 work group aimed to form a hybrid 'personality disorder' model in which dimensional components were introduced into existing diagnostic categories (Krueger, 2013). In spite of strong support from the DSM-5 Personality and Personality Disorders Work Group, a dimensional model was not included in the main section of the final publication of the DSM-5, and instead was noted under the later section of emerging models as an alternative provision. The alternative model represents aspects of problems associated with both 'normal' personality functioning, relating to the self and others, and five domains of pathological personality traits, which are described as 'maladaptive variants' (p. 773) of the domains of the Five Factor Model of personality (FFM) (APA, 2013). Additional dimensional elements have also been proposed for ADHD (Swanson, Wigal, & Lakes, 2009), social anxiety disorder (Skocic, Jackson, & Hulbert, 2015), substance dependence (Helzer, Bucholz, & Gossop, 2007), depressive episodes (Andrews et al., 2007), and psychosis (Allardyce, Suppes, & Os, 2007). Taxometric research supports this notion, and suggests that experiences categorised within diagnoses spanning mood and anxiety disorders, eating disorders, aggressive and antisocial behaviour, personality, and other individual differences including psychosis, are dimensional in nature rather than categorical (Haslam, Arcelus, Farrow, & Meyer, 2012). Some of these recommendations are uni-dimensional for particular diagnoses; others are multi-faceted, representing the heterogeneity of traditional diagnostic categories. The dimensions typically represent the nature and severity of specific experiences entailing diagnostic criteria. A quantitative measure is used to avoid the problems that stem from using strict categorical cut offs for diagnoses, such as sub-threshold presentations (Helzer et al., 2007). Whilst supporting in part the current categorical diagnostic approach, these dimensional components represent a loosening of the DSM/ICD model of separation between categories. Further research suggests that cross-cutting dimensions may better represent empirical findings, more flexibly representing

transdiagnostic difficulties that bridge between categories, for example across psychosis and affective disorder diagnoses (Allardyce et al., 2007).

Clinical staging is an assessment approach that aligns with a dimensional model of diagnostic categories. Borrowed from physical medicine, clinical staging identifies an individual's place on a continuum of disorder progression from 'at risk' to 'end stage'. Proponents of the adaptation of clinical staging to mental health problems argue that existing diagnostic classification consists of 'late stage' representations of diagnosis that are difficult to apply in primary care. This is based on the argument that relative specificity is a marker of later, more severe difficulties, which are associated with poorer outcomes, in contrast with earlier, less specific stages of distress (McGorry & van Os, 2013). The approach complements 'early intervention' strategies, and encourages more specific and detailed identification of difficulties at more non-specific stages of problem development (McGorry, Hickie, Yung, Pantelis, & Jackson, 2006; McGorry & van Os, 2013). The approach aims to combine categories of classification across stages of progression with specific individualised information (Wigman et al., 2013). Despite using diagnostic language, authors use a developmental model, contextualising difficulties within environmental events, and with the potential for expanding assessment across broad categories of common or severe mental disorders (van Os, Delespaul, Wigman, Myin-Germeys, & Wichers, 2013; Wigman et al., 2013).

A critical review (Baumann, Marion-Veyron, Bardy, Solida, & Conus, 2015) of clinical staging expresses concern regarding its emulation of the medical model of physical health, and its focus on problems over strengths, to the potential exclusion of the meaning individuals apply to their difficulties. As individuals progress across stages, the authors question whether progression must be unidirectional towards severe and persistent difficulties (a "prognosis of doom", p. 27), or whether recovery towards levels of better functioning has been conceptualised. McGorry and van Os (2013, p.343) acknowledge difficulties of distinguishing between 'normality' and 'disorder', and ask, "how crucial or feasible is the creation of such a precise definition? Would a grey area with soft and flexible entry (and exit) and personal choice as key features of a new primary care culture be acceptable?" The authors highlight the desire to assess broader bands of problems in order that people can access more timely care, yet without a change in ethos (i.e. here psychotic experiences continue to be problematised as illnesses, whether 'prodromal' or 'late stage') this shift represents the widening of the net of disorder, and the negative implications that come with it; not least potentially damaging drug treatment and stigmatising labels. Nieman and McGorry (2015) acknowledge these concerns in relation to an 'at risk mental state' (ARMS) category. Although they note that stigma may be related more to general association with mental health problems rather than the ARMS category specifically, the need for further research into the impact of such categories is recognised.

1.3.1.3.2 Internalizing-externalizing dimensions

By contrast to diagnostic manuals, latent variable modelling has been used to identify two broad but separate spectra of ‘internalizing’ problems, encompassing mood- and anxiety-related difficulties, and ‘externalizing’ problems, such as antisocial behaviour, hyperactivity, and substance abuse (Kessler, Ormel, et al., 2011). Associations tend to be strongest between experiences within the same spectrum compared with between-spectrum comparisons, for example meeting the criteria for diagnoses in the internalizing spectrum have been shown to predict later development of problems meeting criteria for another diagnosis in this spectrum (Kessler, Cox, et al., 2011). As such, the internalizing and externalizing factors are used to explain within-domain comorbidity. There is also some evidence for associations between these dimensions and experiences of adversity, such as sexual abuse being more strongly associated with the internalizing than externalizing spectrum for both genders (Keyes et al., 2012). Variations on this dimensional model have been suggested, such as sub-domains with the internalizing spectrum of distress, or anxious-misery, and fear (Eaton et al., 2013; Krueger, 1999). Some heterogeneous diagnostic categories appear to fall across both internalizing and externalizing spectra, for example, bipolar and borderline personality disorder diagnoses (Krueger & Markon, 2011). The most notable exception to the two-factor internalizing-externalizing model suggests that diagnoses related to psychosis should be considered as dimensional across diagnostic categories (Kingston et al., 2013). Research supports a continuum between ‘normal’ and traditionally considered ‘disordered’ psychotic experiences, supporting a dimensional approach (Shevlin, Boyda, Houston, & Murphy, 2015; Subramaniam, Abidin, Vaingankar, Verma, & Chong, 2014). Research in this area is not unified, with some suggesting a third psychosis dimension (Fleming, Shevlin, Murphy, & Joseph, 2013; Kotov et al., 2011; Krueger, 1999; Vaidyanathan, Patrick, & Iacono, 2012). Alternatively, psychosis has also been conceptualised as three-factor (e.g. Liddle, 1987) and five-factor (e.g. Demjaha et al., 2009; van Os & Kapur, 2009; Wigman et al., 2012) models. A higher order ‘psychopathology’, or ‘P’ factor, has also been suggested that cuts across both psychosis and mood-related diagnoses (Caspi et al., 2013; Reininghaus, Priebe, & Bentall, 2013). What this research has in common, however, is strong empirical support for conceptualisations of mental health that bridge across traditional diagnostic categories, undermining the goal of identifying increasingly delineated ‘disorders’.

1.3.1.3.3 Research Domain Criteria

The problem of diagnostic comorbidity, discussed above, has been described by one of the former directors of the US National Institute of Mental Health (NIMH) as, “so extensive among DSM-IV diagnoses as to forcefully raise questions about the underlying structure and

assumptions of the classification” (Hyman, 2010, p. 167). In response to these significant concerns about psychiatric diagnosis, the NIMH established the Research Domain Criteria (RDoC) project in 2009, which proposes an overhaul of the way that psychiatry views mental health and its causes. RDoC came to the fore in 2013 when the NIMH’s then director wrote an NIMH blog entry criticising the DSM, and declaring that the NIMH would no longer be guided by DSM categories (Insel, 2013, 29th April). RDoC is a dimensional framework for research organisation (Insel, 2014) that aims in the future to develop a more precise diagnostic system based on mechanisms rather than symptoms. Whereas current diagnostic categories seek to describe patterns of symptoms on which research into causal factors is based, RDoC aims to explore emotional, behavioural and neurobiological functioning and subsequently define disorder on the basis of disruption to these functioning patterns (Cuthbert, 2014). The focus of RDoC research centres on core processes and their association with brain systems, with the aim of using units of analysis better suited to neurophysiological research than traditional diagnostic categories (Patrick et al., 2013). Five domains incorporate positive and negative valence, cognitive systems, social processes, and arousal/modulatory systems. Constructs within these are identified, for example, fear, loss, responsiveness to reward, and biological systems (Cuthbert & Insel, 2013).

Reflecting the potential tension between the functions of taxonomy and clinical assessment, RDoC’s current state as a framework for research remains vague about how the different units of analysis would be incorporated to form a comprehensive clinical assessment that directly informs intervention planning. Many commentators have expressed concern about the application of RDoC’s research focus to clinical practice, including the identification of specific clinical problems, and the extent to which clinical work would be impacted (MacDonald & Krueger, 2013; Shankman & Gorka, 2014; Zoellner & Foa, 2016). Patrick and Hajcak (2016) cite research on the FFM and other dimensional models to warn of the potential for descriptive-based models of mental health to be equally as susceptible to reification and transformation into immovable constructs that are resistant to novel research findings.

1.3.1.4 *‘Psychiatry in dissent’*

It should be noted that the views of psychiatrists are not necessarily homogeneous. Anthony Clare wrote the book *Psychiatry in Dissent* (Clare, 1976) over 40 years ago, highlighting the different voices within psychiatry, representing not a single cohesive viewpoint but differing groups and theoretical perspectives within the discipline. These varying perspectives and values are still relevant today. They also reflect, but are certainly not limited to, differing views on psychiatric diagnosis.

Historically, there have been several changing conceptualisations of ‘madness’, from which psychiatry’s various perspectives stem. Modern concepts have origins in the “great confinement” described by Foucault (1967), in which asylums were used as a means of restoring social order by locking up the impoverished, unemployed, and vagrants, as well as those with mental distress and physical ailments. Influenced by the Enlightenment and ideas from biological and physical medicine, doctors later began to see ‘madness’ as a disease that could be treated (Stylianidis, 2016). Kraepelin’s classification of madness had a significant influence on the taxonomy of psychiatry (Stylianidis, 2016), however these ideas prioritised “intellectualistic” symptoms concerning thought processes (hallucinations and delusions, for example), over mood and affect (Berrios, 1996). Stack Sullivan, an American psychiatrist, argued that the Kraepelinian approach of diagnosis according to patient outcomes (used by Robins & Guze, 1970, discussed above in Validity) had, “...been a great handicap, leading to much retrospective distortion of data, instead of careful observation and induction” (Stack Sullivan, 1927, p. 760, cited in Read, 2013, p. 22).

Meyer’s focus on community mental health care and the rise of psychodynamic treatments in response to World War I contributed to a focus on psychodynamic and psychotherapeutic approaches, expanding psychiatry from madness alone to its incorporation of ‘nervous disorders’ (Stylianidis, 2016). Different groups within psychiatry place different emphasis on each of the social, biological, and psychological concepts that developed from these historical changes within the discipline.

1.3.1.4.1 Anti-psychiatry

The anti-psychiatry movement developed in the 1960s in the UK. The term ‘anti-psychiatry’ was coined by Cooper (1967) to describe critical thinking within the discipline. Other figureheads commonly associated with the movement were Szasz and Laing. The ‘movement’ was loosely defined, and itself consisted of many disagreements between proponents, with Laing eventually rejecting the term (Crossley, 1998). Commonalities, however, included a conceptualisation of psychiatry as “an agent of repression and of power” (Clare, 1976, p. 2). Szasz argued that the notion of mental illness was a myth, and that psychiatry’s ‘treatments’ were a means of social control (Szasz, 1974). The movement represented a critique of a central concept of psychiatry of demarcating a division between sanity and insanity (Crossley, 1998). Laing’s therapeutic community, Kingsley Hall (1964-72), represented the concept of supporting individuals through their distress, rather than necessarily attempting to ‘cure’ them of it (Crossley, 1998). The movement could be argued to be humanistic and psychodynamic in nature, rather than biologically focused.

1.3.1.4.2 Critical psychiatry and social psychiatry

Today, the concepts of anti-psychiatry have been transformed into critical and social psychiatry. The critical and social psychiatry literature is somewhat diversified, with overlap across the two concepts. Some psychiatrists have called for the abolishment of psychiatric diagnosis (Timimi, 2014). Other authors, however, focus on the medicalisation of mental distress, arguing that psychiatry's focus on the technological leads to increasing prioritisation of drug treatment over other forms of intervention such as psychological therapies (Bracken et al., 2012; Sedler, 2015). Others are not averse to labelling in psychiatry but advocate a separation of labelling from a disease model, instead supporting a social framework for understanding distress, which takes into account issues of power (e.g. Moncrieff & Middleton, 2015), discussed further in Section 1.3.3.1.1. Thus, the critical and social psychiatry movements relate predominantly to psychological and social aspects of mental health.

1.3.1.4.3 Humanistic approaches

Whilst the alternatives proposed within psychiatric literature represent medical approaches to mental distress, other approaches could be said to represent more of a humanistic approach to mental distress. Humanistic approaches hold centrally the meanings and perspectives of participants. Unlike some approaches, the humanist model does not seek to reduce difficulties and their causes to variables or mechanisms (Wong, 2017). Two such approaches were predominantly developed by psychiatrists; Soteria and the Open Dialogue approach. These methods are described within this section as they represent non-traditional approaches to psychiatry. Both relate primarily to the treatment of psychosis.

1.3.1.4.3.1 Soteria

The Soteria project (San Francisco, 1971-1983) was developed loosely on the model of Laing's Kingsley Hall therapeutic community in London. The approach rejected the disease model of 'schizophrenia' and, as described above, prioritised individuals' meanings of their experiences and developing shared understandings (Mosher & Bola, 2013). Rather than traditional in-patient treatment that takes place within institutions according to professional practices, Soteria, and a replication facility, 'Emanon', were homes within the community, and employed non-professional staff to avoid imposing psychiatric pre-conceptions or labels on residents (Mosher & Bola, 2013). Two central tenets of the approach were of hope and expectation of recovery, and minimal reliance on antipsychotic drugs. Participants newly diagnosed with schizophrenia or schizophreniform disorder were assigned to either standard treatment as usual (TAU) or the alternative approach using a quasi-experimental design.

Two-year outcomes from the project were positive (Bola & Mosher, 2002, 2003). For example, those diagnosed with schizophrenia had a 44% higher probability of being in the lowest scoring categories on the Global Psychopathology Scale, a 49% higher probability of being in the best psychopathology improvement categories (good to excellent), and a 40% higher chance of working at two-year follow-up than those in the TAU group (Bola & Mosher, 2003). Of those treated at Soteria, 43% were referred to as 'drug-free responders' as they did not take antipsychotic drugs during follow-up (compared with 94% continuous drug use in the TAU group). At the two-year follow-up evaluation, the effect size for this group was the equivalent of 38% better than the overall group mean on the composite outcome scale. Although the improvement was only statistically significant in one iteration of the analysis, the medium effect size nevertheless appeared an important finding (Bola & Mosher, 2002).

1.3.1.4.3.2 Open Dialogue

Rather than an existing application of applied science as such, Open Dialogue represents a novel ethos for intervention for mental distress. Open Dialogue is a way of thinking and relating to mental health that uses a family and social network-centred intervention. It was primarily developed in response to high prevalence of individuals with a schizophrenia diagnosis in Western Lapland (over twice the rates of new schizophrenia diagnoses in the 1980s compared with the rest of Finland, Seikkula, Alakare, Aaltonen, Holma, & Rasinkangas, 2003) but is now used as the mainstream approach to mental health care within the Western Lapland area. The Open Dialogue approach has less of a focus on categorisation and classification of problems, and does not seek to identify deficits within the individual (Seikkula, Alakare, Aaltonen, Holma, & Rasinkangas, 2003). Problems are not identified by the professional but as they emerge from the social network, either defined by the individual or by someone near to them. The intervention was developed with a focus on crisis-resolution and a quick response following referral. The intervention consists of a series of open meetings between the service user or individual referred, their family and others in their social network or support system, and two to three staff members trained in psychotherapy, who might include psychiatrists, psychologists, and nurses. Open Dialogue has seven guiding principles: (1) immediate help within 24 hours of referral or contact with the team; (2) a social networks perspective including for example colleagues or friends; (3) flexibility and mobility which includes needs-based adaption of the therapeutic response and/or location of meetings; (4) responsibility of the staff team who works with the family across the course of the intervention; (5) psychological continuity, whereby meetings continue to be held for as long as is necessary and across outpatient and inpatient care if necessary; (6) tolerance of uncertainty, whereby a safe space is created for the team, the individual and their network, and premature decisions or conclusions are avoided; and finally, (7) the promotion of dialogism as a primary concern, empowering families with a

sense of agency (Seikkula & Arnkil, 2014). The value placed on dialogue takes a constructionist epistemology that emphasises the ways that individuals construct themselves in response to others; meetings adapt to the client's changing needs (Ulland, Andersen, Larsen, & Seikkula, 2013). By responding to what is brought to meetings by the client, greater equality of power is established (Seikkula & Arnkil, 2014).

The open dialogue founders have published three naturalistic outcome studies for the approach. The initial descriptive study suggested that across a two-year follow up period, in comparison with a treatment as usual (TAU) group who had diagnoses of schizophrenia, the Open Dialogue groups were found to have shorter hospitalisations and less neuroleptic medication was prescribed (Seikkula et al., 2003). During early stages of the approach, groups from the initial two phases of development (1992–3 and 1994–7) were compared over a five-year follow up period. Findings showed that the second group had fewer days in hospital and fewer family meetings as the programme was developed. The outcomes were broadly similar across the two groups, and showed better outcomes in comparison with a Swedish five-year follow up TAU study (Svedberg, Mesterton, & Cullberg, 2001). 29% of the second open dialogue group used neuroleptic medication in the course of treatment, compared with 93% in the TAU study, and 86% had returned to studies or full-time work with 14% on disability allowance, compared with 62% of the TAU study patients who were on disability allowance at the end of follow up (Seikkula et al., 2006). A further study (Seikkula, Alakare, & Aaltonen, 2011) compared the earlier two phases of open dialogue intervention with a later period from 2003-5 to assess the consistency of findings across a ten year period. The findings were broadly consistent across groups, with similar percentages of people back in full time employment or study at follow-up (84%). The proportion of brief psychotic episodes was slightly higher in the third phase and their scores were higher on a symptom measure at follow up, however there were significantly fewer remaining psychotic symptoms experienced at the end of follow up for this group. Across the three groups the mean duration of untreated psychosis (time between first emergence of psychotic symptoms and start of psychosocial intervention) reduced from 4.2 months in the first group to half a month in the third group. The authors attribute the lower rates of development of severe difficulties to early contact and intervention following initial crisis. Transferability of the approach from Western Lapland to the UK has yet to be established, but pilot studies have begun (NELFT NHS Foundation Trust, 2017).

1.3.2 Psychological perspectives: Incorporating individual social context

The psychological literature also takes an understanding of mental distress beyond simply the person presenting at the clinic. It should be noted that there is some overlap between this literature and that of critical psychiatry, introduced above. Formal guidance from the British Psychological Society (BPS) (2013a) acknowledges that clinical psychologists may

use ICD or DSM categories for various functions, including facilitating communication, accessing support, or otherwise helping clients, carers and colleagues. However, the guidance is also explicit about psychologists being aware of the problems with diagnosis, both in terms of its technological limitations, outlined above, and the potential damaging impact of the use of pathologising diagnostic labels. This literature focuses less on classification, and more strongly values the individual relationship between psychologist and service user, and the representation of individual meaning and understanding associated with experiences of mental health. Three key topics are discussed in the review of this body of literature, a) limitations of the deficit model of diagnosis, b) impact of diagnosis, and c) psychological ways of conceptualising and working with mental distress.

1.3.2.1 a) *Limitations of the biomedical deficit model of diagnosis*

Critics have expressed concern that psychiatric classification represents distress not as a human response to upsetting experiences such as war or bereavement, but, within the biomedical model, as caused by an underlying defect or deficit within the individual (Kinderman, Read, Moncrieff, & Bentall, 2013). The DSM is framed as descriptive and atheoretical, however this literature argues that the language it uses is predominantly biomedical, and therefore representative of a particular perspective of conceptualising mental health, encouraging a biomedical view of causation. Indeed, in spite of this framing of diagnostic categories, psychiatrists nevertheless state, "Psychiatry has abandoned the reductionist "organic" vs "functional" distinction and now regards all mental disorders as disorders of brain function" (Spitzer & First, 2005). Along with the critiques raised within psychiatry, the psychological literature discusses the diagnostic model as being a reductionist account that limits explanations to the biomedical model. By minimising the role of context and life experience, evidenced contributory factors such as trauma and other adversities, the perspective that is encouraged by diagnostic categories is one of establishing what is wrong with a person, rather than understanding what has happened to them (Division of Clinical Psychology, 2013; Kinderman, Read, et al., 2013).

1.3.2.1.1 Epistemological confusion

Popper's (1945) distinction between essentialism and nominalism has been applied to psychiatric diagnoses (Scadding, 1996). Scadding (1996) cites Popper's distinction between realist notions of essentialism, whereby something's definition is seen as describing its essence, and nominalism, whereby a definition serves to describe the features by which a member of a particular class can be recognised. Scadding's description of a nominalist view of diagnoses reflects the perspective of psychiatric diagnoses as tools with clinical utility (Kendell & Jablensky, 2003), that offer a way of succinctly conveying the product of an assessment of someone's distress:

“The names of diseases are a convenient way of stating briefly the endpoint of a diagnostic process that progresses from assessment of symptoms and signs towards knowledge of causation. They may have gone no farther than recognition of a familiar pattern; they may have progressed to detection of underlying disorders of structure or of function; or they may have identified specific causes... Some diagnoses - e.g. many in psychiatry - can be tested only by clinical observation and failure to find recognized causal abnormalities of structure or function, and convey no specific causal implication.” (Scadding, 1996, p. 594)

However, Scadding argues, descriptions about diagnoses can fall prey to the “essentialist fallacy” (p. 596) of regarding the disease or diagnosis not as a descriptive summary of difficulties but as the cause of the distress itself. Scadding argues that colloquial speech is particularly susceptible to this form of reasoning, however the scientific literature also clearly demonstrates essentialist ideas. For example, recent research papers have reported that “schizophrenia causes a high degree of disability” (Parikh, Robinson & Clayton, 2017, p.299) and that “schizophrenia leads to an increased suicide risk and lowers life expectancy” (Lange, Mueller, Leweke & Bumb, 2017, p.1), showing that the notion of the diagnostic category of schizophrenia is essentialised as the cause of a person’s difficulties rather than simply a description of them. The lack of causal information in psychiatric diagnoses, combined with this essentialist fallacy results in a confusing tautology with regards to the source of individuals’ difficulties. As has been commented frequently in the case of schizophrenia (e.g. Rogers & Pilgrim, 2010), a person may be seen as behaving oddly, and a diagnosis of schizophrenia is described as the explanation for this behaviour. However, at the same time, because diagnostic categories are descriptive of particular behaviours and other representations of distress, the reason a person comes to be given a diagnosis of schizophrenia is because he/she is behaving in a strange way. Therefore, the explanatory power of a diagnosis is lost, because the reasoning used to ascribe the diagnosis and explain the person’s difficulties is circular. This circular reasoning extends to the use of medication, whereby a medical intervention is retrospectively used to explain a person’s difficulties. If medication alleviates distress, for example, then a conclusion is drawn that the distress must be caused by biomedical factors. The diagnosis, therefore, is seen as biomedical in origin (Probst, 2015b). This essentialist view of psychiatric diagnoses, and how it relates to stigma, is discussed further below in Section 1.3.2.2.2.

This essentialist conceptualisation becomes problematic, however, when Moncrieff and Cohen's (2006) ‘drug centred’ model (described in Section 1.3.1.2.2.2, Non-specific drug action) is used instead of the ‘disease-centred’ theory. If psychiatric drugs are not correcting a chemical abnormality, but rather creating an abnormality to produce therapeutic changes

in mood for the individual, then it cannot logically follow that the person's difficulties were biologically caused.

1.3.2.1.2 Contextualising distress

In addition to the literature exploring the problems with labelling and its isolation of difficulties within the individual in a biomedical framework of explanation, the psychological literature discusses extensively the contextual factors that can inform an understanding of a person's difficulties. Within psychological literature, instead of problems being seen as caused by a disorder represented by a diagnostic category, problems are typically 'biographically situated' (Pilgrim, 2013). Individuals' difficulties are understood within the context of a person's life experiences and the ways they make sense of their difficulties. The psychological literature, therefore, acknowledges a slightly broader perspective of the 'social relations' of mental health in the sense of distress being contextualised within a person's life, and often relational between individuals.

There is a long history of literature moving from the individual, moral, mind, to consideration of distress within its social context. Durkheim's (1951) influential text, originally published in 1897, was the first to explore suicide as a 'social fact'. Social facts are described as practices that people tend to do with similarity as a consequence of general socialised ways of acting stemming from a particular social society or community (Durkheim, 1982/1895). Such practices include marriage, language, and currency. Durkheim described suicide as a social fact, conceptualising it not as an act carried out by a single individual, but as a relational consequence of society. Consideration of suicide rates within different communities and societies developed from these concepts. More recently, research has established strong associations between adverse experiences, particularly in childhood, and the later development of mental distress. This research is particularly established in the field of psychosis. Read and colleagues (2005) carried out one of the first literature reviews into childhood trauma and diagnoses of psychosis and schizophrenia, demonstrating a causal and dose-related relationship between the two. Since this paper was published, a growing body of evidence has demonstrated the association between childhood trauma and psychosis (Bentall & Fernyhough, 2008; Dvir, Denietolis, & Frazier, 2013; Varese et al., 2012). A recent analysis of large scale survey data across 17 countries showed a strong association between childhood adversities and onset of psychotic experiences across the life course. A particular association was seen between childhood sexual abuse and onset of psychotic experiences in childhood (McGrath et al., 2017).

Other research shows similar relationships between adversity and other types of mental distress. Recent studies have found significant relationships between intimate partner violence and post-traumatic stress, depression, and anxiety (Começanha, Basto-Pereira, &

Maia, 2017), and between childhood abuse and being diagnosed with bipolar disorder (Palmier-Claus, Berry, Bucci, Mansell, & Varese, 2016). Adversities such as social deprivation and traumatic or abusive life experiences have been found to strongly predict higher levels of anxiety and depression (Kinderman, Schwannauer, Pontin, & Tai, 2013). Studies using mediation analysis have begun to explore the ways in which psychological processes can impact upon these associations. In the study above, for example, Kinderman and colleagues (2013) found that the above relationship was mediated by rumination, self-blame and poor adaptive coping. Social support has been shown to mediate the relationship between childhood maltreatment and later depression and anxiety (Sperry & Widom, 2013) and PTSD (Vranceanu, Hobfoll, & Johnson, 2007). An association between childhood sexual abuse and later life depressive and somatic symptoms and hostility in men is moderated by masculine norms and childhood adversities (Easton & Kong, 2016).

1.3.2.2 *b) Impact of diagnosis*

As well as the limitations resulting from a biomedical deficit model that minimises the strongly evidenced association between adverse and traumatic life experiences and mental distress, the psychological literature outlines some of the ways in which diagnosis can have a negative impact on the individual. The negative implications described by this literature concern the influence diagnosis can have on the clinician's assessment process, and the direct impact on the individual diagnosed. This section outlines literature on different types of impact; diagnostic overshadowing; essentialism and stigma; 'mental illness as an illness like any other'; and diagnosing the problems versus the person.

1.3.2.2.1 Diagnostic overshadowing

The process of 'diagnostic overshadowing' involves an existing diagnosis being used to explain additional problems that might otherwise be investigated or considered in their own right. It was first documented by Reiss, Levitan, and Szyszko (1982), whereby psychologists were found to subsume emotional problems under an existing diagnosis of learning disability, rather than seeing the emotional difficulties as a separate psychiatric problem to be managed and supported in its own right. More commonly documented, clinicians attribute physical health problems to being part of an already diagnosed mental health problem or learning disability, resulting in poorer physical health care for these groups because problems are not investigated or treated (Disability Rights Commission, 2006). The Disability Rights Commission report also found that where service users did not attend appointments or take medications as prescribed clinicians had a tendency to attribute this to the person, such as having a chaotic lifestyle, rather than asking why such problems were occurring, and what might be done about it, such as services taking responsibility for improving access. It has been suggested that diagnostic overshadowing may be the reason for high levels of

medical comorbidity and premature death amongst populations with mental health problems (Jones et al., 2008). Research has suggested that hospital emergency departments are a particular focus for this type of problematic use of diagnosis, particularly where patients have complex presentations, medically unexplained symptoms, and attend frequently (Shefer, Henderson, Howard, Murray, & Thornicroft, 2014). Others have described cases in which additional mental health problems are not recognised in the presence of other diagnoses, for example, missing experiences related to social anxiety disorder where depression has already been diagnosed (Kaufman & Baucom, 2014).

1.3.2.2.2 Essentialism and stigma

Scadding's (1996) argument that descriptions of diagnoses are subject to the essentialist fallacy that diagnoses themselves cause a person's distress was introduced with regard to the epistemological confusion of psychiatric diagnoses (Section 1.3.2.1.1). As Section 1.3.2.1.1 describes, this fallacy applies to both lay and scientific conceptualisations of mental distress. The concept has been applied to stigma (Haslam, 2000). Haslam (2000) argues that the disease model of mental health is itself essentialist, and that it presents diagnoses as natural kinds, that is, that diagnostic categories represent underlying diseases. Haslam's study demonstrates that laypeople in the general public apply this kind of thinking to psychiatric diagnoses, such that "we would expect to observe that the public acceptance of biological claims about mental disorders will be often quite uncritical and total" (p. 1045). Other psychological research shows that, in general, people are more likely to generalise from categories when they are natural kinds rather than arbitrary examples, thus when diagnostic categories are reified as 'things', people's stigmatising generalisations from these diagnoses are likely to be emphasised (Ahn, Taylor, Kato, Marsh, & Bloom, 2013). The following literature concerns primarily public perceptions and stigmatising attitudes towards mental distress, however Section 1.3.2.2.4 (below) explores how these essentialised ideas can also impact upon services provided by mental health professionals.

These findings can have negative consequences with regard to stigma. Public stigma refers to the negative attitudes that the public may hold towards people with mental health problems. A review carried out by Haslam (2011) demonstrates that people who have essentialist thinking about psychiatric diagnoses tend to endorse stereotypical representations of psychiatric patients as violent (Bastian & Haslam, 2006). Essentialist thinking is also associated with endorsing biomedical or genetic explanations of distress (Haslam, 2011), and in turn this may lead people to view those with mental distress as fundamentally different from themselves (Mehta & Farina, 1997; Read, Haslam & Magliano, 2013). This is explored further in the following section ('Mental illness is an illness like any other').

Stigma may impact upon views of oneself as well as public perceptions of mental distress; self-stigma is a process whereby individuals who have been diagnosed with mental health problems endorse public stigma around these difficulties and internalise these beliefs towards themselves, leading to reduced self-esteem (Muñoz, Sanz, Pérez-Santos, & Quiroga, 2011). Studying the impact of self-stigma, Karidi and colleagues (2015) compared people with diagnoses of schizophrenia and bipolar disorder, finding that both groups experienced self-stigma, but the severity and impact that this had on social exclusion and other functioning was significantly worse for those given a diagnosis of schizophrenia. A recent study suggests that the effect of public stigma upon psychosocial outcomes, such as self-esteem and low mood, is mediated by self-stigma (Kao et al., 2016).

1.3.2.2.3 'Mental illness is an illness like any other'

As mentioned in Section 1.2.3.2.2 in the positive functions of diagnosis, some research suggests that a psychiatric diagnosis reduces stigma by invoking the sick role (Davis, 2009). However, research has shown that labelling mental health problems as illness and using biomedical causal theories is, in the case of psychosis, associated with perceptions of dangerousness and unpredictability as well as fear, and a desire for social distance from the individual (Read, Haslam, Sayce, & Davies, 2006). A similar study showed that the more people endorse brain disease as the cause of schizophrenia or major depression diagnoses, the more they rate the person as dangerous (Dietrich, Matschinger, & Angermeyer, 2006). These perceptions of dangerousness were associated with increased fear and desire for social distance from the person who was diagnosed (Dietrich et al., 2006). A recent review of the impact of using medical language and the message of 'mental illness is an illness like any other' in anti-stigma campaigns showed that this message entrenches rather than relieves stigma and discrimination (Sayce, 2014). Instead of an individual's identity being of an ordinary person who happens to have an 'illness', the 'mental illness is an illness like any other' narrative reifies differences between individuals as biological, creating an 'other' identity, which contributes to stigmatizing 'us' and 'them' public perceptions of mental health (Tew, 2015).

1.3.2.2.4 Diagnosing the problems or the person?

Emphasising the implications of essentialising psychiatric diagnosis and its association with identity, the BPS report *Understanding Psychosis and Schizophrenia* (BPS, 2014a), highlighted the ways in which some people with a diagnosis of psychosis "felt labelled in society as a 'mental patient' or 'schizophrenic'" (p. 26). This finding suggests that diagnostic labels can impact upon the identity of the individual. Psychiatrists and GPs use diagnoses as way of categorising or describing a person's difficulties, but some people who receive them feel that it is they themselves who are labelled. This issue is discussed further within Section

1.3.3, below, which explores the implications of diagnosis from the perspective of the service user/survivor literature and the social sciences literature.

Mental health services are not immune to essentialising thinking about psychiatric diagnoses. This is perhaps most clearly seen in the diagnosis of ‘personality disorders’, where the fact that life-long character traits and longstanding patterns of behaviour attract diagnostic labels means that many people feel that the person, and not the distress, is being diagnosed. Two recent experimental studies, for example, demonstrate how a label of borderline personality disorder (BPD) can have a stigmatizing influence on clinicians’ assessment of unrelated difficulties (panic and ‘agoraphobia’), over and above a description of a person’s difficulties that matched the diagnostic criteria for BPD. These findings suggest how particular diagnoses may colour clinicians’ assessment of aspects of the person other than those that directly relate to that diagnostic label. The first study shows that a BPD label can negatively impact on clinicians’ ratings of a person’s risk, disability, outlook, response to and compliance with intervention for panic (Lam, Poplavskaya, Salkovskis, Hogg, & Panting, 2015). The second showed that clinicians who were told a client had a label of BPD reported significantly fewer reasons to be optimistic about her treatment than those who were given only neutral information or a description of difficulties that related to a BPD diagnosis without the label itself (Lam, Salkovskis, & Hogg, 2016).

1.3.2.3 c) Psychological ways of conceptualising and working with mental distress

In response to the above concerns, critics from the Division of Clinical Psychology (DCP) in the British Psychological Society (BPS) have made calls to change the ways that mental health services work with and conceptualise mental distress. For example, Kinderman and colleagues have called to ‘drop the language of disorder’ (Kinderman, Read, et al., 2013) in mental health services. The authors’ proposals to use a lexicon of distress to describe experiences and psychological formulation in lieu of diagnosis are discussed below in Sections 1.3.2.3.2.2 and 1.3.2.3.3.1 respectively. Further to this call to action, the DCP published guidance on the use of language (Division of Clinical Psychology, 2015) stating, “[w]e encourage any usages which attempt to describe behaviour and experience in non-medical terms, and within its personal, interpersonal, social and cultural context” (p. 3). The document gives examples of typical medical language in mental health, and offers suggested alternative words and phrases. For example, instead of “personality disorder”, contextualised alternatives are suggested, such as, “Complex trauma, complex trauma reaction, personality difficulties, relationship or attachment difficulties, complex presentation”.

1.3.2.3.1 Empirically driven approaches: Causal networks

The study of causal networks across mental health problems is a novel, empirically driven, conceptualisation that rejects the traditional latent variable modelling approach of diagnosis. Rather than proposing a new classification structure, 'symptoms' or problems are seen as inter-related due to causal links between experiences (Borsboom, Cramer, Schmittmann, Epskamp, & Waldorp, 2011). Underlying latent variables of diagnosis, such as the 'disorder' of 'depression' are seen as redundant when the correlations between experiences that might otherwise be seen as symptoms of an underlying disorder are simply seen as causally related to each other (Cramer, 2012). For example, sleep problems and fatigue, rather than being caused by the underlying disorder 'major depressive disorder', are seen as causally impacting upon one another (Borsboom & Cramer, 2013). The causal network approach is also used to offer a model for comorbidity. The researchers found that half of the symptoms described in the DSM-IV are connected through common 'bridge symptoms' (p. 3) which are shared across diagnostic criteria (Borsboom et al., 2011), for example sleep problems and fatigue, which are also contained within criteria for generalised anxiety disorder. These overlapping symptoms and the fuzzy boundaries between diagnoses are seen as vital in understanding comorbidity (Cramer et al., 2010). The causal networks approach to mental health also links in with research into transdiagnostic mechanisms from clinical psychology, such as rumination (Borsboom, Epskamp, Kievit, Cramer, & Schmittmann, 2011; Nolen-Hoeksema & Watkins, 2011). Such work includes studies of the direct connections between emotion and psychosis, and proposals for a developmental pathway between the two (Freeman & Garety, 2003).

1.3.2.3.2 The scientist-practitioner model

Clinical psychology has a long tradition of being an applied science. The concept of the scientist-practitioner was introduced by Monte Shapiro, who argued that psychologists should apply the scientific method where validated methods of assessment were not available (Shapiro, 2002). The scientific method of observation and generation and testing of hypotheses is applied to the individual client. The scientist-practitioner approach is a technological way of attempting to objectively define difficulties and understand their causes, which is described by Kinderman (2014) as an alternative to diagnosis. The clinician makes a hypothesis against which to manipulate variables and interventions in order to create a particular effect. Kinderman and colleagues (Kinderman, Read, et al., 2013; Kinderman, 2014) have argued that different experiences of distress should be operationally defined using a shared lexicon, and that evidence-based interventions should be planned around these definitions, rather than by diagnosis. This is seen as separate from the use of diagnosis as difficulties are identified without being diagnosed as a disorder. Two of the

proposed psychological alternatives to psychiatric diagnosis also take up this approach, and are described in the following sections.

1.3.2.3.2.1 Symptom-level and problem list pathways

Much like a causal networks-based taxonomy, the symptom or problem list approach rejects the idea of discrete categories of 'disorder' as causing symptoms. Bentall (2003) suggests that in understanding individual 'symptoms' or experiences, the concept of an underlying disorder will become redundant. An argument has been made for the development of a shared lexicon of operationally defined terms in lieu of diagnostic labels (Kinderman, Read, Moncrieff & Bentall, 2013). This approach represents the scientist-practitioner model of clinical psychology when applied to clinical assessment. Introduced in relation to schizophrenia research (Persons, 1986), the focus of this approach has been on the underlying psychological mechanisms and processes that contribute to individual experiences within diagnostic criteria, such as hallucinations and paranoia. This approach's utility is closely linked with psychological ways of contextualising distress. Research into symptom-specific causal pathways (Mojtabai & Rieder, 1998) has already helped inform understanding of the strong associations between social determinants and specific experiences within psychosis (e.g. Bentall, Wickham, Shevlin, & Varese, 2012; Bentall et al., 2014; Wickham, 2015). For example, an association is frequently reported between sexual abuse and hallucinations (Bentall et al., 2012; Kilcommons & Morrison, 2005; Longden, Madill, & Waterman, 2012). Similarly, support for these causal pathways and specific experiences has been found across diagnostic categories, such as voice hearing within the context of a bipolar diagnosis (Hammersley et al., 2003).

1.3.2.3.2.2 Psychological formulation

Psychological formulation is central to the practice of clinical psychologists, and has been established as such since around the mid-twentieth century (Pilgrim & Carey, 2010). In the UK, for example, psychological formulation is highlighted as an important skill for psychologists by both the Health and Care Professions Council's (HCPC) standards of proficiency for the protected title of practitioner psychologist (HCPC, 2015), and the BPS standards for doctoral programmes in clinical psychology (BPS, 2014b). Reflecting the research outlined above, psychological formulation is a way of situating distress within the context of adversities and other life experiences. This approach represents current recommendations to understand these contexts in clinical work, whereby recovery is not seen solely as symptom reduction (Boyle, 2002; Read, Hammersley, & Rudegear, 2007; Tan, Gould, Combes, & Lehmann, 2014). In the BPS report on diagnosis, it is stated that psychologists should be using formulation as the basis for their clinical work (BPS, 2013a). Psychological formulation is a way of linking psychological theory with clinical practice.

Formulation summarises the key problems experienced by an individual (or a family or system, etc.), and uses psychological theory to collaboratively bring together an understanding of how those problems developed and are maintained. A formulation is a flexible guide to intervention based in psychological theory and processes, and is open to revision. In drawing upon psychological, biological and systemic factors, formulation seeks to contextualise distress, whilst incorporating the personal meaning associated with it (BPS, 2011). In this manner, psychological formulation takes an idiographic over a nomothetic approach (Pilgrim, 2014), representing individual experiences of distress rather than using a broader, generalising lens to distinguish between groups of people. This process of conceptualising distress allows for the possibility of understanding individual narratives and personal meaning making which have been described as central to caring and recovery, not least by the recipients of mental health services (Buchanan-Barker, 2004; Casey & Long, 2002; Thomas & Longden, 2013). Formulation, therefore, aims to take a more humanistic stance than psychiatric diagnosis (Johnstone & Dallos, 2014), whereas personal experiences associated with symptoms or problems are excluded from diagnostic categories (Vanheule, 2012). The benefits of the use of psychological formulation have been demonstrated not only in care planning and understanding service users' difficulties, but also across staff teams, with potential for improving staff and service user interactions (Berry, Barrowclough, & Wearden, 2009; Cole, Wood, & Spendelow, 2015; Summers, 2006).

In its critique of the DSM-5, the BPS' Division of Clinical Psychology called for formulation to be promoted as one response to the problems of psychiatric diagnosis (BPS, 2013b). Constructing formulations of clients' difficulties is also part of core psychiatry training in the UK, however such formulations represent a pared down version of psychological formulation, including biopsychosocial factors in the development and maintenance of problems, but not representing personal meaning or psychological theory and processes (Royal College of Psychiatrists, 2010). Psychiatric formulations are generally made in the context of a psychiatric diagnosis, and therefore represent an epistemological tension between the two models (Pilgrim & Carey, 2010).

1.3.2.3.3 Humanistic approaches

There is inevitably overlap between the medical, empirical, scientist-practitioner, and humanistic approaches described in this literature review. For example, it could be argued that, depending on the model used, psychological formulation may represent technologically based scientific practitioner approaches, or a more humanistic approach focused on meaning. The difference might be considered between types of formulation; for example the distinctions between a formulation based theoretically in cognitive behavioural therapy versus one focused on narrative therapy. In a typical '5Ps' cognitive behavioural therapy (CBT) formulation, for example, the contributing factors (presenting issues, precipitating,

perpetuating, predisposing and protective factors), are viewed as variables that describe and explain an individual's current distress (Johnstone & Dallos, 2014). Although such factors would include examples of the individual's thoughts and experiences, the formulation is nevertheless arguably more detached from the individual's phenomenological experience of their distress than other approaches. Johnstone, Boyle, and Cromby (2017), for example, presented their 'Power/Threat/Meaning Framework' at the BPS Division of Clinical Psychology annual conference, in which meaning is seen as integral to shaping the ways that social and societal power and threat operate upon the individual and the ways they experience and respond to these central processes.

1.3.2.3.4 The 'avoidance' of biomedical conceptualisations

With non-diagnostic approaches of mental distress, from a psychological perspective, comes a downplaying of biological factors in its development. A focus on distress as understandable within the context of extreme and painful life experiences reduces to a lesser contributory factor the role of biomedical or neurobiological factors such as brain chemistry or genetics. Critics have argued that such approaches make a claim or assumption that there is no biological pathology behind mental distress (e.g. Coyne, 2015). Boyle & Johnstone (2014), however, emphasise that the approach is not dualist, instead arguing that the role of biology is much more complex than is typically represented by diagnostic models. Harper (2013) and Cromby, Harper, and Reavey (2013), however, use Rose (2005) lifelines approach in order to situate biological factors within cultural, historical, and social contexts. This approach reflects a de-emphasis on biology, which promotes interventions other than drug treatment. Currently, with limited access to other interventions, the common denominator of available treatment is drugs. Frequent treatment with drugs reinforces notions of biological causation, for example social acceptance of the idea that chemical imbalance causes depression (Moncrieff, 2011). However, as described above in Section 1.3.1.2.5, Moncrieff and Cohen (2006) argue that psychiatric drugs create, rather than correct, abnormal chemical states in the brain, and it is these states that provide temporary relief.

1.3.2.3.5 A note on 'alternatives to diagnosis'

The term 'alternatives to diagnosis' has effectively become a technical, even political, term in psychological literature. Strengthened by the debate and controversy surrounding the publication of the DSM-5, the search for 'alternatives to diagnosis' became a mainstay of some of the central figures in the psychological arm of the debate, as part of the campaign against psychiatric diagnosis and calls for a paradigm shift in mental health (Boyle & Johnstone, 2014). Following her seminal book, "Schizophrenia: A scientific delusion?" (Boyle, 2002), Boyle later questioned the use of diagnosis across mental health, exploring

why diagnosis is still used, and calling for the need to discuss alternatives (Boyle, 2007). This discussion was followed up in the same year as the publication of the DSM-5, in which Boyle (2013) addressed ways of preventing the neutralisation of alternatives to diagnosis by proponents of the biomedical model, and avoiding the assimilation of alternatives into the dominant psychiatric approach. Kinderman (2014) has advocated for a continuum model as an alternative to diagnosis, in which mental distress of the type described within diagnostic categories is not seen as qualitatively different from 'normal' behaviour and experience. Johnstone (2013) wrote about alternatives to diagnosis as part of the Global summit on diagnostic alternatives, an international campaign website set up in response to the publication of the DSM-5 and dedicated to the development and dissemination of alternatives to current psychiatric classification systems. She highlighted that we already have alternatives to diagnosis, such as psychological formulation and Open Dialogue, and argued that the notion of having to wait until alternatives to the DSM were developed is a fallacy. Nevertheless, widespread use of formulation or Open Dialogue would represent a radical change to the structure and practice of mental health services. Likewise, it remains to be demonstrated whether any of the proposed 'alternatives' could replace the myriad functions of psychiatric diagnosis.

1.3.2.3.6 Focus on the individual

Considering both psychological formulation and Open Dialogue approaches, each is theoretically driven and has a particular focus on individuals, rather than on classification or technological aspects of mental health. Each approach is already being used clinically, although not, in the UK, as a general method of organising mental health services and conceptualising mental distress. The approaches outlined within the psychological literature have potential limitations in their application across a broader scale in lieu of diagnosis. Open Dialogue, for example, may have limitations in its application to a considerably larger population. The small geographical area of Western Lapland has a population of just 70,000 (Seikkula et al., 2011), and the management of service planning may be very different using this approach in the UK. Formulation with its idiosyncratic approach would need some consideration in adapting it to meet the needs of service planning and commissioning, which currently appears to be broadly diagnostic in nature. Furthermore, psychological literature, in its general approach to mental distress, conceives difficulties not as biomedical deficits or disorders, however difficulties are nevertheless typically located within the individual. Psychological interventions reflect this conceptualisation, such as a continued focus on individual therapy, and thus have a professional interest in maintaining this individualised lens (Boyle, 2011; Smail, 2012). Open Dialogue to some extent widens the context for distress in its systemic family and social network approach, however, its scope is limited beyond these immediate networks. Parker (2015) contextualises this positioning within the neoliberal politics of the early 1980s, arguing that psychology gained popularity as people

were “ideologically corralled into finding individual solutions to the problems they faced” (Parker, 2015, p. 55).

1.3.3 The personal and political implications of diagnosis: Service user / survivor and social sciences literature

The psychological literature around mental health begins to incorporate a contextualised account of people’s difficulties through formulation. Biographical factors such as emotional environment, social situation, and life experiences such as trauma and adversity are acknowledged. In contrast with the psychological literature, the service user/survivor and social sciences literatures are not only about the social context of the individual. These literatures consider the wider societal and political contexts of applying psychiatric diagnoses, and those who are diagnosed, labelled as disordered or disabled. Service user/survivor literature typically bridges between the individual and the political; Jacqui Dillon references the feminist maxim, “the personal is political” (Dillon, 2011). The service user/survivor literature is presented alongside relevant social sciences literature as both share a perspective of exploring the political implications of diagnosis, disablement and the personal impact on individuals. This section is outlined in the following three sections: Power and the construction of difference; Labelling and the creation of a ‘mentally ill’ identity; and Resistance.

1.3.3.1 *Labelling and the creation of a ‘mentally ill’ identity*

According to Foucault’s concept of the production of the psychiatric subject, people who are diagnosed are invited to see themselves as the ‘incontrovertible identity’ (Roberts, 2005, p. 40) created by the diagnostic category. The literature suggests that there may be some positive aspects to this identity, such as the legitimisation of distress (Pitt et al., 2009; Probst, 2015). Diagnostic labels may also enable collective identities, whereby the individual can access networks of support from others with the diagnosis, thus reducing the isolation that may accompany mental distress (Goldstein Jutel, 2011).

However, much of this body of literature concerns the negative impact of this change in identity that is brought about by diagnosis. Foucault, for example, argues that the patient is made dependent by the creation of this identity, thus legitimising psychiatric power (Roberts, 2005). Labelling theory, derived from Mead’s symbolic interaction theory and conflict theory from Marxist and Foucauldian writings, proposes that the way that society responds to particular behaviours, by labelling them as deviant or otherwise different in some way, in turn shapes the way that labelled individuals conceptualise themselves as disordered (Probst, 2015b). Scheff (1966) proposed that the way those in power label minority behaviours

creates the 'disorder', rather than the behaviour itself. As a result of this process of labelling and the essentialist thinking described earlier in Sections 1.3.2.2.2 – 1.3.2.2.4, individuals can be perceived as irrational, actively seen as disordered or pathologised, and socially excluded (Spandler & Anderson, 2015). In Goffman's key text on stigma (Goffman, 1963), he describes the way that society can stigmatise a person once they can be categorised as different:

While the stranger is present before us, evidence can arise of his possessing an attribute that makes him different from others in the category of persons available for him to be, and of a less desirable kind – in the extreme a person who is quite thoroughly bad, or dangerous, or weak. He is thus reduced in our minds from a whole and usual person to a tainted, discounted one (p3).

The creation of a mentally ill identity is not limited to others' perceptions of the stigmatised or 'othered' identity discussed within psychological perspectives (Section 1.3.2.2.3 and 1.3.2.2.4, above). This disordered identity is taken up implicitly by the people who are diagnosed, again raising the question of whether it is the distress or the person that is diagnosed. The following quotes illustrate the ways in which being given a psychiatric diagnosis can dramatically change a person's identity:

I was told I had a disease... I was beginning to undergo that radically dehumanising and devaluing transformation ... from being Pat Deegan to being 'a schizophrenic' (Deegan, 1993, p.7)

I went into that hospital a troubled, confused, unhappy 18-year-old and I came out a schizophrenic...The very first time I met [Pat Bracken, a psychiatrist] he said to me, 'Hi Eleanor, nice to meet you. Can you tell me a bit about yourself?' So I just looked at him and said 'I'm Eleanor and I'm a schizophrenic.' Longden (2010, p.256)

Not only can a diagnosis change a person's identity, "being mentally ill" (as Scheff's (1966) book was titled) constructs a particular social position, a socially shaped identity that leads to multiple forms of disadvantage (Crossley, 2004). The inequalities of this identity act across multiple forms of power across rights and status, in contrast with 'non-disordered' society in general, and with mental health professionals. Oppression, or the exercising of psychiatric authority, is seen as a consequence of the psychiatric model that is responsible for the creation of a victim (Coleman, 1999). Therefore, as Patricia Deegan writes, "[i]t is important to understand that we are faced with recovering not just from mental illness, but also from the effects of being labeled mentally ill" (Deegan, 1993, p. 10).

1.3.3.1.1 The social model of disability and mental distress

Disability studies and the social model of disability (Oliver, 1983) have been applied to mental health. This literature explores the social oppression of disabled people. Originally concerned with physical impairment, the concepts of the social model of disability separate 'impairment' from 'disability'. That is, impairment can be described as a physical problem of body structure, which may cause activity limitations where an individual may have difficulty in completing a particular task or action (WHO, 2017b). Disability, however, is not located within the individual, and instead is seen as socially caused; a form of discrimination whereby society excludes and disadvantages people with impairments through social and environmental barriers (Beresford & Nettle, 2010; Slorach, 2016). In contrast with common discourse of seeing disability as a 'personal tragedy', and disabled people as being in need of 'care', the social model highlights the possibilities for political action to enact social changes in order to end the social exclusion of disabled people (Barnes, 2004, as cited in Slorach, 2016).

In the context of literature arguing that psychiatric labelling itself creates 'disorder', and has a profound impact on those diagnosed, the application of the social model of disability appears well suited. However, this issue is complex. For example, the idea of 'impairment' has been likened to the notion of 'chronic mental illness' that so many survivors struggle against (Tew, 2015). It is also difficult to separate 'impairment' from 'disability' in this sense; causes of mental health difficulties are not necessarily within the individual (as biomedical model psychiatric literature tends towards), or even limited to the immediate social context of the individual, including adverse experiences (as the psychological literature incorporates), but also the critical impact of much further reaching societal oppression and disadvantage. These issues are discussed further in the following section.

Another challenge to the application of the language of impairment and the social model of disability to mental distress is in survivors' reinterpretations of distress not as symptoms but as coping mechanisms in response to traumatic and adverse life experiences (Dillon, 2010). These perspectives ask that experiences of distress should be respected as creative ways of coping in desperate circumstances (Tew, 2015). For example, voice hearing has been conceptualised as representing metaphors used to represent and cope with overwhelming and difficult emotions in response to "painful, unresolved life events" (Longden et al., 2012, p. 62). As Tew (2015) describes, "if they were symptoms at all, they were symptoms of unresolved personal and social issues – a direction of understanding that was profoundly social, but took people beyond the social model of disability as a frame of reference" (p. 74).

1.3.3.2 Societal oppression

Examples of societal oppression and disadvantage include, but are not limited to, systemic discrimination on the basis of ethnicity, gender, and socioeconomic status. Each of these sources of oppression is discussed below. This literature is included in order to represent the systemic issues of discrimination and oppression on the basis of factors such as gender, ethnicity, and socioeconomic status, which the individualised biomedical diagnosis of mental distress overlooks. Neoliberalist ideology, which has been argued to underpin current conceptualisations of recovery in mental health (McWade, 2016), is founded on the assumption that such forms of discrimination no longer exist. This ideology individualises recovery and mental distress, assuming that individuals begin with a level playing field from which to orchestrate their own health and wellbeing. However this assumption is highly problematic when the following literature is considered. Although the clinical psychological literature in the previous section was described as including a wider consideration of the social contexts of individuals' distress, the discipline has nevertheless been criticised for omitting discussion of issues of race. For example, in response to the publication of the BPS document *Understanding Psychosis and Schizophrenia* (BPS, 2014), an open letter (Fernando, 2014) was published online, which argues that a "glaring flaw" of the report is its lack of consultation with black and minority ethnic groups and individuals in the UK, and its failure to address the issue of 'over-representation' of black and minority ethnic people subject to excessive sectioning under the Mental Health Act, placement in seclusion on mental health wards, and over-medication.

1.3.3.2.1 Ethnicity

The nosology of psychiatry is permeated by ideologies prevalent in Western society, and most importantly, psychiatry is based on philosophical concepts, such as materialism and the separation of mind and body, that are present in Western culture. Thus, in considering diagnosis, two facts should be borne in mind: first, psychiatry is ethnocentric & carries in it the ideologies of Western culture including racism; secondly, the practice of psychiatry, including its ways of diagnosing, are influenced by the social ethos & the political system in which it lives & works (Fernando, 1991, p. 61)

The above quote from Fernando (1991) highlights the ethnocentric bias of Western psychiatry and therefore its diagnostic classification. This bias is illustrated, for example, by findings that psychiatric diagnoses given to service users vary according to the recipient's ethnicity. For example, African American and hispanic patients are more likely to receive a diagnosis of schizophrenia than white patients (Garb, 1997), and white psychiatric inpatients were more likely than African Americans to be diagnosed with bipolar disorder, and less

likely to be diagnosed with schizophrenia (Neighbors et al., 2003). Ethnicity is influential in the type of treatment and limits imposed upon service users; for example, it has been shown that black African and black Caribbean service users with psychosis diagnoses are more likely than white service users to have ever been detained under the Mental Health Act (Davies et al., 1996). Black and mixed race men are also several times more likely than the general population to be admitted into a psychiatric hospital (Slorach, 2016). African-Caribbean and black African service users are significantly more likely to be compulsorily admitted to hospital than white British patients, with African-Caribbean men being the most likely group to be forcibly admitted (Morgan et al., 2005). One meta-analysis showed that, the pooled odds ratio comparing black service users with white service users was 4.31 for compulsory admission (Bhui et al., 2003).

Consequently, 'circles of fear' surrounding the engagement of black and minority ethnic service users have been reported by the Sainsbury Centre for Mental Health (Keating et al., 2002), in which mental health and criminal justice systems are seen as coercive and controlling, and as systems that may cost service users their lives. The report stated that services were seen as inhumane and inappropriate, and that service users' were not respected, nor their voices heard.

Debate regarding the reasons for the 'over-representation' of black and minority ethnic people as recipients of this extreme treatment and diagnostic labels has moved on from notions of 'race differences' and the 'pre-disposition' of certain groups to mental distress. Studies have demonstrated and acknowledged the impact of racism and discrimination on people's mental health. For example, studies have shown an association between 'common mental disorders' and unfair treatment and racial insults (Bhui et al., 2005), and discrimination and perceived discrimination (Karlsen et al., 2005). Karlsen and colleagues also showed a similar association with psychosis. A review of racial/ethnic discrimination and health demonstrated that of the 25 included papers that measured associations with psychological distress, 20 reported a positive association between discrimination and mental distress, three reported a conditional association, and just two reported no association. Positive associations were also found between discrimination and diagnoses of depression, generalised anxiety disorder, early substance abuse, and psychosis (Williams et al., 2003).

More recent literature, although it is not always explicitly acknowledged (as highlighted by Fernando, 2014), has explored the racially discriminatory nature of mental health services themselves and the inequalities embedded with service provision and outcome, associated with the adverse experiences of black and minority ethnic groups at the hands of society and mental health services (National Institute for Mental Health in England, 2003).

Taking up Goffman's (1963) theory of stigma, some have proposed that constructions of race within mental health services "imply a sense of black otherness set in juxtaposition to an idealised white self" (Stowell-Smith & McKeown, 2001, p. 159). Others argue more specifically that historical, cultural, and structural social relations, including shared oppression as a consequence of social inequalities, are reframed within psychiatry as biologically mediated risks that individuals must manage in order to improve their mental health (Johnson Thornton, 2010). Metzl (2010) has argued that clinical diagnoses "unconsciously mirror larger conversations about the politics of race" (p. ix), demonstrating that the category of schizophrenia has been altered over the decades, from a transformation of personality into a 'protest psychosis' in the context of the American civil rights movement in the 1960s and 1970s, becoming a diagnosis disproportionately given to black men. Kalathil and Faulkner (2015, p. 22) argue that schizophrenia "is not just a flawed diagnosis but a racialised pathology imposed on black communities".

Furthermore, a recent blog (Race Reflections, 2017) cautions that less biologically focused conceptualisations, such as psychological trauma-informed approaches to mental health care, may also fix the therapeutic lens too narrowly on the individual and their own personal experiences of trauma, rather than acknowledging, making visible, and legitimising the wider psychological impact of racial oppression. Likewise, Nazroo (1998) has argued that technical interventions focused on causal pathways may ignore the roots of health inequalities and wider social inequalities.

1.3.3.2.2 Gender

The impact of gender on mental health has long been recognised (e.g. Showalter, 1987), and hostility and violence towards women and girls puts them at high risk for development of mental distress (Taaffe, 2017). Moreover, authors have argued that not only does gender violence contribute to later distress, but that diagnostic categories themselves contain gender bias that reflects wider societal issues of gender. Ussher (2013), for example, has argued that several diagnostic categories in particular, hysteria, pre-menstrual dysphoric disorder, and borderline personality disorder (BPD), represent psychiatry's response to "difficult women" (p. 63). For example, amidst social and political changes during the last century, both the diagnostic categories of hysteria and homosexuality were associated with non-conformity within gender and sexuality (Kinderman, Allsopp & Cooke, 2017). Although the reasons for hysteria's removal are complex, including diagnostic heterogeneity and changes in conceptualisations of psychosis and neurological medicine (Micale, 1993), a significant contribution to the disuse of the term was the rise and development of women's rights and changing gender roles within the 20th Century (Ussher, 2013). Ussher has also argued that pre-menstrual dysphoric disorder (PMDD) represents a modern medicalisation of female experiences. PMDD may be diagnosed in the presence of both feminised pre-

menstrual changes, such as anxiety, depression, and tearfulness, and changes that conflict with typical feminine attributes, such as anger and irritability. However, Ussher (2013) highlights, pathologising these experiences within the individual ignores their wider relational context. Such experiences may instead be contextualised as responses to over-responsibility or insufficient social support (Ussher & Perz, 2012) or as a ceasing of the self-silencing that is practised during the remaining three weeks of the month (Ussher & Perz, 2010).

BPD has been extensively debated as a diagnostic category. It has been argued that there exists a gender bias in the diagnosing of BPD; the DSM-IV-TR reports that around 75% of those given the diagnosis are female (APA, 2000). Some have suggested that the reasons for this are complex, arguing that it is difficult to ascertain whether the gender differences are a result of sampling bias, biased diagnostic criteria, or sociocultural factors (Bjorklund, 2006). One proposed explanation is that clinicians may have an inclination towards attributing clients' behaviour to individual or internal causes rather than situational factors, and that women may be especially affected by this phenomenon, as environmental causes have been shown to be used to explain men's behaviour more often than women, where personal factors are more likely seen as the cause of symptoms (Becker & Lamb, 1994; Wallston & Grady, 1985). Becker and Lamb (1994) have demonstrated clinicians' sex bias in the diagnosis of PTSD, a diagnosis with clear environmental cause, and borderline personality disorder, a more person-centred diagnosis. The authors found that clinicians were more likely to assign ambiguous descriptions of distress to a BPD diagnosis when the vignette was said to describe a female case, and more likely to assign the diagnosis of PTSD when the case was introduced as male.

Further examinations of the category of BPD, particularly those from feminist literature, argue that conceptualisations of distress should move beyond an internalised, problem-focused account of women's lives, and instead incorporate externalised narratives of power, and to understand distress and behaviours not as symptoms of disorder but as the response of women to societal sexual violence and oppression (Shaw & Proctor, 2005). These arguments propose that the predominance of women diagnosed with BPD, and the nature of the diagnostic category itself, are direct consequences of a societal "attempt to explain away the strategies which some women use to survive and resist oppression and abuse" (Shaw & Proctor, 2005, p. 484) by pathologising these strategies as a symptom of a psychiatric disorder located within the individual's personality.

Evidence has been demonstrated for a causal relationship between childhood trauma and later diagnosis of borderline personality disorder (Ball & Links, 2009). These associations are particularly apparent for sexual trauma and diagnoses of BPD, for example, Meichenbaum (1994) found that 70% of people diagnosed with BPD have been sexually

abused as children. Another study showed that 88% had experienced abuse, of which 70% were experiences of childhood sexual abuse (Castillo, 2000). Consequently, it has been argued that BPD should be re-conceptualised as complex PTSD (e.g. Herman, 1992; Trippany et al., 2006). However, others have argued that reassigning BPD as PTSD still does not address the issues of medicalising women's problems (e.g. Becker, 2000). This re-conceptualisation would also fail to address prejudice that may be both initiated and maintained by clinicians (Nehls, 1998), thus perpetuating blaming, silencing discourses about women.

1.3.3.2.3 Socio-economic status

A growing body of evidence shows that poverty and inequality lead to poor mental health. For example, a review of global health studies across low- and middle-income countries showed that the majority of studies found a positive association between poverty and common mental health problems (Patel & Kleinman, 2003). The authors argued that policy makers should recognise 'common mental disorders' alongside physical diseases that are acknowledged as associated with poverty. Inequality represents the difference between the richest and poorest within society. Evidence shows that the more extreme the levels of income inequality in a country, the poorer that country's health outcomes, including mental health (Pickett & Wilkinson, 2010). Health inequalities have been shown to have an impact on a social gradient, whereby the lower a person's socio-economic status, the poorer their health (Marmot, 2010). For example, one study exploring the health inequalities across the most and least deprived areas of Stockton-on-Tees demonstrated that living in the less deprived area afforded substantial protection against problems with mental health and poor mental wellbeing, with a significant gap in mental health found between the two areas. Poor mental health and wellbeing in the most deprived area was accounted for by multiple psychosocial factors, including living in polluted areas, in homes that are too dark, feeling unsafe walking alone in the neighbourhood at night, being in receipt of housing benefit, social isolation and lack of companionship (Mattheys et al., 2016). Studies have shown that transitioning into poverty increases the odds of children experiencing socioemotional behavioural problems, and the association appears to be partially explained by maternal mental health (Wickham, Barr & Taylor-Robinson, 2016; Wickham et al., 2017), family poverty, and bullying (Straatmann et al., 2017). Welfare reform and government austerity measures in recent years appear to have contributed to rising numbers of mental health problems (Barr, Kinderman & Whitehead, 2015), including an increase in suicides and antidepressant prescribing associated with the Work Capability Assessment used to reassess people on disability benefits (Barr et al., 2016).

In spite of these associations between psychosocial environment and mental distress, it has been argued that the psychiatrisation of distress promotes a separation of mental health and

social context, and that neoliberal values encourage a culture of an individual, self-responsible citizen, whereby poverty becomes linked to insufficient management of the self (Gillies, 2005; McWade, 2016). McWade (2016) argues that by introducing ideals of choice, and the notion that some choices are 'right' while others are 'wrong', the political system and the recovery model of mental health frame some individuals as "failed citizens" (p. 62) who are responsible for their poor mental health. Hansen, Bourgois and Drucker (2014) argue that this process is tantamount to pathologising poverty. The authors suggest that by demanding that people must demonstrate their 'disabled' status by bureaucratically using diagnosis, taking medication, and accepting therapy, those who do not make these 'correct' choices are condemned as the "unworthy poor" (Hansen et al., 2014, p. 82).

1.3.3.3 *Power and the construction of difference*

Central to the issues described above is the exertion of power to the detriment and even oppression of the 'other'. Further to the three types of societal oppression discussed above, McWade (2016) argues that the concept of intersectionality can be used to represent and acknowledge the multiple forms of disadvantage that individuals may experience. McWade argues that psychiatry and the mental health system "continues to repress and restrain impoverished people" (McWade, 2016, p. 64). She argues that 'recovery', by eradicating personal experiences, silences the service user/survivor movement and the history of oppression within mental health services of women, minority ethnic groups and other socially disadvantaged groups.

Differing understandings of distress, such as the spiritual explanations of an individual versus the medical model of a psychiatrist, can be considered different but parallel narratives. Using a social constructionist understanding, neither narrative is more 'true', but they differ in the relative power they hold (Burr, 2003; Lafrance & McKenzie-Mohr, 2013). Language is seen as performative, with the power to create meanings, however some groups have greater power than others in influencing what is accepted as knowledge (Burr, 2003; Lafrance & McKenzie-Mohr, 2013). This has been described as a 'narrative surrender' in which the patient's narrative of their difficulties is conceded in favour of the clinician's version (Frank, 1995, cited in Goldstein Jutel, 2011). Many have argued that the creation of difference through disorder in psychiatry is not merely a neutral administrative exercise but one of the exertion of power, for example, through the expert status of psychiatry as a mechanism of social control (Szasz, 1974). As Pilgrim argues, "although psychiatric knowledge is weak, psychiatric authority is powerful" (Pilgrim, 2013, p. 339). Pilgrim (2014) argues that in this way, the binary approach to psychiatry (sane vs. insane, disordered vs. non-disordered) creates 'othering' of those diagnosed. This idea invokes Derrida's theory of binary opposition in which pairs, rather than being neutral opposites, involve a hierarchical power relationship (Cooper, 1989). By constructing their distressing experiences as

disorders, individuals are immediately placed at the weaker pole of this binary. In drawing the lines of disorder, so too is normality constructed (Crowe, 2000). This process has been described as not simply creating difference but using moral judgements to reify this difference and create categories of disease (Kirk, Cohen, & Gomory, 2015), for example, categorising individuals as sick rather than morally deviant, particularly in the case of personality disorder diagnoses (Sulzer, 2015). Foucault referred to this process as the 'psychiatric test' (Foucault, 2006, p. 268) in which the request for intervention is re-transcribed in terms of symptoms and illness. Foucault's disciplinary power of psychiatry (e.g. confinement of patients) is converted to medical power. Foucault describes the act of diagnosing in psychiatry as not simply informing a person of what their illness is, but legitimising the psychiatrist's position, and in turn, the individual is created as the psychiatric subject (Foucault, 2006; Roberts, 2005). Smail (2012) argues that creating this difference, particularly of the oppressed, may in some way justify their suffering by those in power because "our common humanity rests upon our common embodiment" (p.93).

1.3.3.4 *Resistance*

"Many of us find that recovery means becoming politicised and aware of the social, economic, and human injustices we have had to endure. We find that empowerment and recovery means finding our collective voice, our collective pride, and our collective power, and challenging and changing the injustices we face" (Deegan, 1993, p. 10)

Power relations are called into question by the ways in which resistance is enacted against them. Much of the service user/survivor literature pertains to the resistance to psychiatric power. A significant factor in the initiation of service user/survivor actions of resistance, Campbell (1999) argues, is negative personal experience of formal mental health services. The literature contributes to a rights-based social movement (Crossley, 2004), securing rights for those diagnosed with mental health difficulties but also that seeks to understand and highlight wider implications of societal structure and where this places service users/survivors as a result of their definition as disordered. This civil rights- and liberation-centred approach creates a blurred distinction between personal and political change groups, for example, the Hearing Voices Movement, which aims to influence professional practice (Lindow, 1999). A central theme of resistance to psychiatric practices is to challenge the perceived status of those diagnosed. The shaping of identity plays a key role, with an emphasis on self-definition, representing service users'/survivors' reluctance to impose new terms or labels on each other (Campbell, 1999). Goffman's classic text *Asylums* describes the inhabitants of asylums, and the ways in which they subverted its systems, such as refusing medication. Resistance to psychiatric power and the identity of 'being mentally ill' echoes Goffman's assertion, "to dodge a prescription is to dodge an identity" (Goffman,

1961, p.170). In a play on the title of Scheff's (1966) text, Crossley (2004) refers to this as ways of resisting the psychiatric identity, or, "not being mentally ill" (p. 161).

1.3.3.4.1 Examples of resistance

Part of the service user/survivor literature represents "consciousness raising" (Lindow, 1999, p. 213), or sharing stories and narratives of the oppression experienced by those labelled as having mental health difficulties. Consequently, calls have been made to demand that mental health professionals acknowledge and understand these struggles: "professionals must stop denying our experience" (Coleman, 1999, p. 161). In applying concepts of narrative and understanding of the ways in which mental distress is socially shaped, Thomas and Longden (2013, p. 62) ask that professionals "bear witness to the injustices that shape the lives of those who suffer."

1.3.3.4.1.1 Language

Highlighting the ways in which the language of psychiatry plays a role in the exertion of its power, Burstow (2013) cites Audre Lorde (1984), who said, "[t]he master's tools will never dismantle the master's house". Burstow argues that by using psychiatric or biomedical language in lay discourse, we perpetuate its symbolic power, and accordingly, describes using talk that is 'psychiatry-resistant' or 'psychiatry-free' in order to 'tacitly...undermine psychiatric rule' (Burstow, 2013, p. 80). Echoing the DCP (2015) guidelines on language (discussed in Section 1.3.2.3), non-diagnostic ways of conceptualising and working with mental health difficulties use language that attempts to be non-medical, such as 'distress' over 'disorder', and 'hearing voices' over 'hallucinations' (e.g. the Hearing Voices Movement, discussed below). These ways of using different language to describe distress are in keeping with Dillon's and other service users' representations of distress as coping strategies in response to unbearable emotions and challenging experiences. In this way, changing the language used to describe distress, without labelling, represent ways of "not being mentally ill" (Crossley, 2004). Coleman describes his rejection of the term, and the identity, of a 'schizophrenic':

"In the early 1980s I was diagnosed as schizophrenic. By 1990 that was changed to chronic schizophrenic and in 1993 I gave up being a schizophrenic and decided to be Ron Coleman" (Coleman, 1999, p. 160)

In this political positioning, the literature speaks frequently to issues of power in the psychiatric model, discussed previously. Madness is seen as a historical category, reclaimed for political action (LeFrançois, Menzies, & Reaume, 2013). The term 'Mad' (capitalised) as opposed to 'mad' (non-capitalised) is used as a politicised term to denote an oppressed

identity (Cresswell, 2016). Reclaiming the term Mad, it is argued, symbolises “a positive assertion of alternative identity that distances itself from any biological signifier and which celebrates irrationality rather than seeking to erase it from public view” (Tew, 2015, p. 73), which links back to the rejection of the essentialised consequences of diagnostic categories discussed in Sections 1.3.2.1.1 and 1.3.3.1.

1.3.3.4.1.2 Peer support and recovery

Peer support groups range from formal, structured meetings, to informal social groups. What they have in common, however, is the redressing of power imbalances traditionally seen within mental health services, such as the inequality in the doctor-patient relationship. Members of peer support groups are seen as broadly equal, and decisions are made on this basis. The experiential knowledge gained through having been through similar difficulties of distress is highly valued. The peer support initiative, therefore, not only challenges psychiatric authority but offers members a sense of agency in their lives and in helping others (Beresford & Russo, 2016; Lindow, 1999; Shaw, 2013). In sharing knowledge and understanding, peer support groups can also help to validate and normalise situations and feelings. Alternative perspectives can help individuals to find an understanding that fits with their distress and their experiences, in contrast to having their distress redefined within a model that may not match their own understandings, as in mainstream mental health services (Shaw, 2013).

‘Recovery’, as developed by the service user/survivor movement, has many definitions, but has been described as giving a new sense of self and, importantly, of hope (Deegan, 1988). Often, the idea of recovery has been used to challenge the medicalization of distress and, as with peer support, the power of psychiatry (Morrow, 2013). An acceptance of different viewpoints is central to the idea of recovery within the Hearing Voices Movement, which is an example of one of the most influential user-led challenges to biological psychiatry. Two key assumptions of the movement are normalising voices, valuing personal meaning, and developing agency and expertise. In contrast with psychiatric views of voice hearing as bizarre and abnormal, the movement argues that hearing voices is similar to any other human variation, such as being left-handed. The aim is not to rid people of their voices, but to help them to cope with their voice hearing, or work through the unresolved and painful experiences that led to it. Understanding voices, within the movement, is about non-judgementally helping others to find a preferred means of making sense of their voices, rather than finding the ‘correct’ or ‘true’ understanding. Most importantly, the movement seeks to help people to become empowered and lead the way in their own recovery (Longden, Corstens, & Dillon, 2013).

1.3.3.4.2 Barriers to resistance: Co-option

'Mad Studies' (Menzies, LeFrançois & Reaume, 2013) is a relatively new literature that brings together many of the longstanding ideas explored above, incorporating exploration of oppression of "Mad subjects" (p.1), resistance to psychiatry, and survivor narratives. With the growth of Mad Studies and other social movements within mental health, concern has been voiced that the central ideas of these movements may be taken up by mainstream mental health services and undermined in their message against traditional psychiatric ideas. "[P]oliticians have become adept at 'turning rebellion into money'" Slorach (2016, p. 24) argues, giving the example of the Disability Rights movement's slogan "nothing about us without us" being transformed into the NHS slogan "no decision about me without me" in a policy (Department of Health, 2012a) that Slorach argues further limited disability rights in practice. Just as Slorach describes within the Disability Rights movement, Boyle (2013) argues that new concepts intended to move thought away from the psychiatric model can be assimilated into the existing medical model through the use of language. Such has been the case for user driven initiatives including 'recovery' and 'peer support'. These concepts, which began with hope and empowerment for people with mental distress, have been heavily transformed by their co-option by mental health services. The idea of recovery has been used to drive people back to employment and limit their support, whilst the use of peer support within the NHS has been turned into a source of low or unpaid labour that does not truly value the knowledge of service users (Beresford & Russo, 2016). Morrow (2013) argues that the concept of recovery has been reformatted within neoliberalism, creating the 'healthification' of social problems, such as homelessness and poverty. By reframing social injustices as problems of health, the burden of responsibility is shifted from the state to the individual, and Morrow argues that the concept of recovery has been co-opted to this end.

1.4 The social functions of diagnosis: Historical development of the DSM

The service user/survivor movement literature takes into account the biographical context of distress, as well as some of the things that are produced by diagnosis, including power inequalities and difference, as well as oppression and the political positioning that results from being diagnosed. The social sciences literature presented in this review takes these perspectives wider, by discussing the broader social relations encapsulated by psychiatric diagnosis. This literature demonstrates that categories are not only productive for individuals (whether in positive or negative ways) but also for organisations. Where the previous literatures have focused on the individual and the social relations that allow the individual to be diagnosed or otherwise assessed or 'treated', this latter body of literature moves its focus to classificatory systems themselves. The literature at once returns to classification itself, the DSM and ICD, and highlights the wider social contexts within which these taxonomies were

historically developed, and the drivers for change as it continues to be revised today. Diagnoses are positioned as active categories, constructed to perform particular roles. The socio-political influences on diagnosis are outlined, providing evidence for diagnostic classification as performing a particular set of socio-cultural, financial, and political functions for various groups and organisations, but that need not necessarily look this way. The implications of diagnosis and classification are discussed within the context of these influences.

Both the psychiatric and psychological literatures acknowledge problems of the reification of diagnostic categories, however these ideas are limited to the sense of diagnoses becoming seen as fixed or 'real' categories. Here, these ideas are expanded in order to make visible the 'social relations' of diagnostic classification. The concept of reification within the social sciences literature takes up the Marxist concept whereby human creations are seen as facts or realities of nature and in addition, the social and power relations associated with these creations are made into things (Dahms, 2011). By associating diagnostic categories with the biomedical model, using the language of illness & disorder, psychiatric diagnoses are seen as existing categories out there for the clinician to diagnose and identify, rather than questioning what has gone into producing these categories, why certain decisions have been made, and who was involved in making these decisions. The social is made invisible, in terms of the development of diagnostic classification systems, and the model of where the problem is located, seen as within the person rather than taking into account and understanding the wider social context. Taussig (1980) describes this process as masking social relations as "natural things, concealing their roots in human reciprocity" (p. 3). He describes this concept of the 'reification of the patient', but it can be applied to the diagnostic categories themselves. The social relations of diagnostic categories are masked, leaving the categories to be seen as 'natural kinds', rather than embedded within relationships between individuals and their experiences. Taussig's analysis also incorporates the political context of diagnoses, discussed within both the service user/survivor and social sciences literature. The categories "reproduce a political ideology in the guise of a science of (apparently) 'real things'" (p. 3).

Within the context of reification, the following review of the historical development of the DSM is oriented towards diagnostic classification as a 'thing'. Psychiatric literature frames diagnostic categories as neutrally descriptive and non-aetiological, or atheoretical (see Section 1.2.2, Aetiological agnosticism). However, the social sciences literature reviewed here embeds the classification within its socio-political context, revealing the specific needs and interests that psychiatric diagnoses have been developed to meet. Diagnoses are not discovered so much as designed in reflection of the needs and influences of particular groups and stakeholders, such as political, economical, and public interests (Manning, 2000). Psychiatric diagnostic classification is seen, therefore, as consisting of productive,

rather than merely descriptive, categories. The following section outlines the ways in which diagnosis is reflective of social, cultural, political, and financial norms and values over scientific progress in the field of psychiatry. Diagnostic categories are therefore flexible; open to influence rather than ever-refined mirrors of nature (Hyman, 2007; Rosenberg, 2002). Diagnosis reflects a particular set of conceptualisations about mental health that need not look this way.

1.4.1 Early influences on classification

From Durkheim's (1951) understandings of suicide as a social fact in 1897, there is a history of literature arguing that there is a need for the social to be acknowledged within mental health. Likewise, as long as this literature has existed, it has been contested alongside more biomedical understandings. For instance, the DSM-I and II (APA, 1952, 1968) were strongly psychodynamic in approach (American Psychiatric Association, 2015), reflecting the growth of psychotherapy in supporting soldiers returning from the Second World War. Not only was this approach psychodynamic, it also recognised the impact of social and environmental factors. A conceptualisation of mental health was popularised that represented a spectrum of difficulties beginning with the general population, in contrast with earlier ideas of the 'insane' kept separate to society, both literally and figuratively (Grob, 1991).

As Kinderman, Allsopp & Cooke (2017) describe, however, the factors preceding the development of the DSM-III marked what has been described as a 'crisis of legitimacy' for psychiatry (Lafrance & McKenzie-Mohr, 2013; Mayes & Horwitz, 2005; Wilson, 1993). This crisis stemmed from the problems of poor reliability described in Section 1.3.1.1. Psychiatry was not clearly separating between the mentally 'ill' and mentally 'well' (Wilson, 1993). This criticism was made infamous by Rosenhan's (1973) now classic study in which colleagues reporting hearing a voice saying 'empty' or 'thud' were diagnosed with schizophrenia and admitted into hospital. Rosenhan concluded that hospitals could not distinguish between the sane and insane. Anti-psychiatrist movements argued that if the line between 'sick' and 'well' was fluid, and distress was psychosocial in nature, then diagnoses could not be said to be diseases, and mental health should be conceived of as social and political rather than medical (e.g. Szasz, 1974). There was concern that psychiatry's methods of assessment and treatment, in contrast with medicine, were too fluid and unstandardized, representing problems for professional accountability and insurance companies (Wilson, 1993). The DSM-III 'revolution' therefore represented a desire to align mental disorders more closely with physical illnesses that eventuated a shift in power away from psychodynamic approaches within the APA. The DSM-III was transformative in the sense that it moved from a clinically based biopsychosocial model to research-based medical model, which incorporated descriptive operational criteria and information about how to distinguish between categories. This shift in structure fulfilled a number of political and financial

functions. For example, more formal diagnostic classification created discrete illness categories against which to make insurance claims and to enable the greater involvement of pharmaceutical companies (Mayes & Horwitz, 2005; Tsou, 2011). In their analysis of the discourse of the introductory sections of the DSM, Romelli and colleagues (2016) highlight the ways in which the language of early editions of the DSM self-legitimises, establishing the APA as the central actor in the development of psychiatry. The DSM-III and DSM-IV, they argue, build upon this position politically to establish psychiatric hegemony by presenting the DSM as a source of valid categories of knowledge and central to education within mental health (Romelli et al., 2016).

1.4.2 The removal of homosexuality

Homosexuality was included in the first edition of the DSM in 1952, originally as a sociopathic personality disturbance. Its removal is a key event in the history of the DSM, illustrating that some of the most significant changes to psychiatric classification have occurred as a result of social and cultural values rather than scientific advances. In 1962 and 1967 respectively, the first acts were passed to decriminalise homosexuality in the US and England and Wales, yet it still remained a category of mental disorder. Activism grew progressively; the Stonewall riots in 1969 helped the movement gather momentum. In 1974, under huge social and political pressure from gay rights campaigners, homosexuality was removed in its previous format. Kutchins and Kirk (1997, p. 56) argue, “the dispute over the inclusion of homosexuality in DSM was not about research findings. It was a 20-year debate about beliefs and values”. However, ‘ego-dystonic homosexuality’ took its place, which represented persistent distress associated with unwanted homosexual arousal. Ego-dystonic homosexuality was removed from the DSM-III-R in 1986, although again there was no theoretical change in the DSM’s definition of ‘disorder’ that encompassed the removal of homosexuality from its pages (Kinderman, Allsopp & Cooke, 2017). Perhaps as a result of this lack of clarification, further work is still in progress to declassify other diagnoses that relate to homosexuality. The WHO have published a bulletin calling for the removal of disease categories in the forthcoming ICD-11 that relate to sexual orientation (Cochran & Drescher, 2014).

1.4.3 The making of a diagnosis

1.4.3.1 *Post-traumatic stress disorder*

In contrast with homosexuality, where activism drove a shift towards depathologisation, PTSD was introduced in large part as a result of pressure from veterans of the Vietnam war to recognise their traumatic experiences. First introduced in the DSM-III (APA, 1980), rather than an appeal to civil rights being used to depathologise experiences such as voice hearing

and homosexuality, PTSD presents an example of individuals invoking diagnostic infrastructure in order to access their civil rights to medical or psychological care (Kinderman, Allsopp & Cooke, 2017). By minimising the impact of the Vietnam war, as part of a policy of returning soldiers to combat as quickly as possible, those who experienced difficulties such as flashbacks were dismissed as having delusional thinking about the war. As Sarah Haley, a social worker at the Veterans Association, and later part of Vietnam Veterans Working Group, reported in 1969, “these professionals denied the reality of combat...They were calling reality insanity!” (Scott, 1990, p. 298). In creating the diagnostic category, experiences were legitimised that had previously been seen as malingering, or simply not recognised as part of the denial of the impact of particular experiences of warfare. Post-trauma experiences were dismissed as pre-existing psychotic tendencies or delusional beliefs about the war (Galatzer-Levy & Bryant, 2013). Further demonstrating the impact of a set of socio-political influences on the creation of diagnoses, the eventual diagnosis of PTSD was created as a compromise. It described a broader experience that could be used for anyone who had experienced extreme stress, rather than the ‘post-Vietnam syndrome’ originally proposed (Helzer, Robins, & McEvoy, 1987). In part this compromise acted to reinforce the argument by incorporating evidence from Holocaust survivors, as well as achieving a critical mass of interested parties in order to effect change. This process has been described as a ‘transformation’ of activism that allowed human interests to be reconceptualised as ‘science’ and therefore legitimised (Kutchins & Kirk, 1997).

1.4.3.2 *‘Dangerous and severe personality disorder’*

As described by Kinderman, Allsopp and Cooke (2017), whilst introduced as an ‘administrative category’ (Burns et al., 2011) rather than a clinical diagnostic category, ‘dangerous and severe personality disorder’ (DSPD) was created in the UK in 2001. Its creation was a response to public anxiety around high-profile cases of people being attacked by individuals diagnosed with ‘severe personality disorder’, in order to provide treatment with the aim of reducing reoffending (Ministry of Justice, 2011). Thus the impetus for introducing such a category was largely political, combining risk aversion and public protection, punishment, and treatment (Manning, 2002). The label served to identify individuals who met three main requirements, two related to risk and reoffending, and the third rested on being diagnosed with a ‘severe disorder of personality’, established through various diagnostic instruments and a minimum score on a psychopathy assessment (Trebilcock & Weaver, 2012). Four DSPD units were set up in the UK, based in both high secure hospitals and prisons, and a treatment programme established. Although administrative, in that it was never introduced into psychiatric classification, it is clear that the label was taken up both from research and lay perspectives as if it were a diagnosis, for example, journal articles that have written about ‘a pilot programme for the treatment of individuals with dangerous and severe personality disorder’ (Völlm & Konappa, 2012) and in a House of Commons debate

'To ask the Secretary of State for Justice how many (a) adult and (b) juvenile prisoners have been diagnosed with dangerous and severe personality disorder' (Parliamentary Written Answers, 2008).

The DSPD programme has since been disbanded, and absorbed into the Offender Personality Disorder Pathway, initiated in 2011 (Department of Health, 2011). The programme lacked on-going interest as a result of problems with efficacy, discrimination from other personality disorders, and cost (Department of Health, 2011; Tyrer et al., 2009) but also due to difficulties around the legal implications of detention without treatment in that there was an argument that people meeting the criteria for DSPD are 'untreatable', despite ways around this being established in tribunals (Trebilcock & Weaver, 2012). Manning notes this disjunction between treatment and public protection, arguing that the need to achieve particular social and political goals create opportunity for innovation where the existing means (existing categories and treatment pathways) are insufficient; "...in such a situation, a cherished goal will virtually justify any means" (Manning, 2000a, p. 635).

1.5 The actions and practices of classification

The following sections are drawn from science and technology studies, and sociology of classification literature. These literatures, although not typically associated with psychology, psychiatry, and mental health, are included as they provide important insights and an alternative perspective to psychiatric diagnostic classification. These concepts are presented below within the context of psychiatric diagnosis, and will be picked up in the analysis of data across the five empirical chapters that follow.

1.5.1 Diagnostic categories as active constructs

As is described above in the social functions of diagnoses and their construction, diagnostic categories are seen as created or developed, and are active in the sense that they are productive, and responsive to needs. That is, diagnostic categories have been developed to meet specific and varying needs by the individuals, systems, and organisations that take them up. As Brown (1995, p. 37) describes, "[r]ather than a given biomedical fact, we have a set of understandings, relationships, and actions that are shaped by diverse kinds of knowledge, experience, and power relations, and that are constantly in flux". Diagnoses are seen as active categories with multiple functions across the multiple social worlds described in this review; clinical, social, and personal spheres.

1.5.2 Stabilising categories

In the traditional model of scientific research, data are wrapped into a paper that produces a generalizable truth – after which the scaffolding can be kicked away and the timeless truth can stand on its own (Millerand & Bowker, 2009, p. 149)

Where new categories, such as PTSD, are introduced into diagnostic classification, the boundaries of these categories must be identified and criteria agreed upon. As discussed, there may be political contributions to this process, such as the eventual inclusion of other types of trauma within the PTSD category, not solely that caused by the Vietnam War. However, and particularly with mental distress where categories are purely descriptive, the boundaries of the infrastructure of diagnosis are frequently blurred. Psychiatric diagnostic categories are actively shaped to perform particular functions and perform specific roles. Their use and the literature surrounding them subsequently act to stabilise these categories. Below is a brief exploration of two types of fact stabilisation discussed by the social sciences literature; the construction of certainty, and the creation of standards.

1.5.2.1 *The construction of certainty*

In their classic text, 'Laboratory Life', Latour and Woolgar (1986) explicate the ways in which scientific activity constructs facts, for example, the process of reducing complex laboratory findings into simplistic forms for scientific publications. This process of simplification is described as the pragmatic production of ordered versions of observation and discussion, for consumption by others. Latour and Woolgar describe how scientists ignore alternative readings and explanations of their data in order to consistently produce an ordered account. Messy fieldwork is transformed into textbook categories (Bowker & Star, 1999). This reductionism can be associated with the reification of diagnoses, the acceptance of diagnostic categories as representing illnesses 'out there' in the world. Related to categorisation within science, Star (1989) describes the development of the model of localization of regions within the brain, as an attempt to manage and contain uncertainty. Star's study moves beyond the immediate setting of the lab, and considers the longer-term construction of theory, which can be applied to the development of psychiatric diagnosis. As has been hinted towards in this chapter, the development of diagnosis is the result of accumulated creation of certainty gathered from multiple forms of research evidence. Certainty is created when local uncertainties are put aside or otherwise resolved. Transforming local uncertainty into certainty, Star (1989) argues, is central to research organisation. Over time, and through accumulated evidence and specialist consensus, diagnostic uncertainty is transformed into developed taxonomies and lists of criteria consisting of definitive symptoms. Diagnosis is a standardised tool, a property particularly

pushed by the DSM-III with the introduction of specific diagnostic criteria with the aim of improving reliability between clinicians. Standardised tools have been described as 'powerful tools for ensuring fact stabilisation' (Fujimura, 1992, p. 204).

1.5.2.2 *The creation of standards*

Standards such as human weight charts, blood types, and electrical current now appear fixed and neutral, although this inert quality obscures the enormous amount of work needed to stabilize knowledge, freeze action, delete outliers and residuals, and facilitate use (Star & Lampland, 2009, p. 10)

Once scientific certainty has been forged, information may be organised into agreed upon rules, or 'standards'. Diagnostic categories are one example; the DSM and ICD classification systems are the two central standards of psychiatry (Pickersgill, 2012). A standard is used across more than one site of activity and is used to make disparate and heterogeneous systems or components work together (Bowker & Star, 1999). For example, diagnostic categories are used as both a way of communicating to service users and a bureaucratic means of recording and capturing data from NHS electronic health records. Standards are often enforced or mandated by professional organisations, such as the American Psychiatric Association and the World Health Organization. In becoming a standard language, a critical role of standards is in information stabilisation (Star & Lampland, 2009). The creation of a 'shared information infrastructure' (Millerand & Bowker, 2009, p. 150) means that when a diagnosis is recorded, this clinical information is coded in a way that it can be used beyond what is needed for the individual clinician's use. In this way, classifications such as the DSM and ICD are used by multiple social worlds or communities, and have been described as objects that allow communication and cooperation across these worlds, or 'boundary objects' (Bowker & Star, 1999; Star & Griesemer, 1989). Boundary objects occupy various social sites and at the same time meet the information requirements of each of these sites (Star & Griesemer, 1989). In time, standards may become so embedded that they become very difficult to change. The DSM, for example, has been described as 'impermeable' to new information (Patrick & Hajcak, 2016, p. 416), 'locked-in' (Cooper, 2015, p. 1), and as described above, reified.

1.5.2.2.1 Material diagnosis: Formal recording of diagnoses

Diagnostic classification has both symbolic and material forms. Diagnoses are integrated into clinical and social environments not solely through the academic or professional conceptualisations of the people who use them, but also via their physical forms. For example, psychiatric diagnoses are ubiquitous across electronic health records and Mental Health Act paperwork. Each of these physical formats of diagnosis has accompanying

conventions about how these standards work in practice within these environments (Bowker & Star, 1999). Additionally, the same diagnostic formats may have multiple associated conventions according to the stakeholder in question. For example, a diagnosis on an electronic health record will be used differently by a clinician taking on a new client to an NHS Trust using it for data capture and monitoring purposes.

1.5.3 Diagnostic classification as infrastructure

As standards that facilitate the sharing of knowledge across sites and systems, diagnostic classification becomes an infrastructure in itself. This infrastructure becomes part of the much wider infrastructure of mental health care and support within the NHS and across social care systems, including housing and welfare benefits. Bowker and Star (1999) define infrastructure using several central factors. Applied to psychiatric classification, these factors demonstrate the ways in which the diagnostic infrastructure becomes intricately woven throughout systems and processes such as the wider infrastructure of the ways our society works with mental distress. Diagnostic classification is embedded within NHS services, for example, their organisation and commissioning, and their electronic health records systems. It is embedded within our welfare system and within lay discourses about mental distress. Diagnostic classification reaches across time and space; the DSM and ICD classifications have formed widely established conceptualisations of mental distress since the mid-twentieth century. Spatially, classification reaches across health services, academia and lay uses across the Western world. In a community of practice that uses an infrastructure such as diagnostic classification, the artefacts or arrangements of that classification are taken-for-granted by members. Outsiders must learn about diagnostic classification and new members, such as trainee clinicians, develop familiarity with its features. Infrastructure can become largely invisible, and the meanings assigned to it by different users can be taken for granted. Infrastructure does not need to be recreated or compiled for each use, and so is effectively rendered transparent. Diagnostic classification invisibly supports a clinician in referring a client to another service, for example. Infrastructure becomes most obviously visible when it breaks down or fails to function for its users. For example, it becomes visible when a residual category such as 'eating disorder not otherwise specified' is the diagnosis applied to up to 70% of outpatients with eating difficulties (Fairburn & Bohn, 2005). The infrastructure of diagnosis can be made visible by considering both its symbolic and material forms. Understanding how the symbolic and material forms are used can make visible the meanings that different users associate with diagnosis, and how and whether the physical forms of diagnoses work with the conventions and conceptual arrangements associated with them (Bowker & Star, 1999).

1.5.4 Diagnoses in practice

1.5.4.1 *The rift between protocol and practice*

As a 'standard' within psychiatry, diagnostic criteria represent the planned or idealised use of psychiatric classification, a protocol of sorts for clinical assessment. In a study of the human-artefact interaction between people and Xerox machines, Suchman (1987) explores the tensions between plans and 'situated actions'. Diagnostic classification can be considered as such an artefact or technology, and Suchman's work highlights the potential rift between these protocols for assessment and the application of diagnostic categories in everyday clinical practice. Situated actions must necessarily incorporate unpredicted contingencies and respond to the actions of others. Star and Lampland describe this as the 'slippage between a standard and its realization in action' (Star & Lampland, 2009, p. 15). It is from this slippage that we can better understand how standards such as diagnostic classification are interacted with in clinical practice, and how standards themselves may shift in response, both in the categories themselves or in people's conceptualisations of them. In discussing their redefinition, Millerand and Bowker (2009) describe standards as a black box that is opened, "not always in the same way, across the set of sites" (p. 164).

1.5.4.2 *Flexible local practices*

The tension between the needs of the taxonomist and the needs of the practising clinician has been acknowledged (Kupfer, First, & Regier, 2002). This tension is one example of the need to determine the ways in which diagnosis and other methods of assessment and categorisation are used in day-to-day practice. Where standards such as diagnostic classification are imposed, for example in health settings, work-arounds are inevitable (Bowker & Star, 1999). That is, because classification systems are standardised, they cannot take account of local idiosyncrasies or individual needs. Consequently people create their own flexibility by working around the formal restrictions of the standard.

For example, in exploring the diagnostic practices of psychiatrists in the US, Whooley (2010) uses Merton's (1976) idea of 'sociological ambivalence' to describe the ways in which an individual is subject to "structurally induced contradictions" (Whooley, 2010, p. 455), which create cognitive dissonance owing to competing interests and demands that result from the individual holding a particular role. Psychiatrists experience ambivalence that results from being at once an individual clinician and a member of a professional body; working within the complex structure of the mental health system and autonomously within their own clinic room. Not only do psychiatrists work within these tensions, Whooley argues that the DSM contributes uniquely to this state of ambivalence. The DSM is both the justification of the position of psychiatry within the mental health world, yet simultaneously the tool by which the

psychiatrist's work is bureaucratically monitored. Whooley explored the ways that psychiatrists attempted to resolve this ambivalence and subvert the impositions of the DSM on their autonomy by finding ways of working around the official protocol of the DSM where it hindered their work. For example, the most common work-around reported by Whooley's study was "fudging the numbers" (p. 460). In the insurance-dominated healthcare system of the US, Whooley found, insurance companies had a very concrete conceptualisation of diagnoses, and required that a diagnostic category be recorded before treatment commenced in order for reimbursement to be arranged. In managing their own clinical practice whilst complying with this bureaucratic requirement, psychiatrists would 'fudge' or 'disorder' (p. 460) the diagnosis recorded on the form in order to choose a diagnosis that would be acceptable, "so everybody has a major depressive illness...", one psychiatrist explains.

To better understand the local adaptations inevitably employed at individual and health service levels would be to more fully understand the ways in which classification and assessment systems are used in practice. In exploring the practice of diagnosis, its implications for the stakeholders involved, not least users of mental health services, can be highlighted.

1.5.4.3 Multi-directional influence between classification and its practices

It has been argued that Latour and Woolgar's framing of the production of scientific knowledge is limited in its representation of science as an active agent from which knowledge flow is unidirectional to passive recipients in the world outside the laboratory (Martin, 1994). Martin argues that this representation is overly simplified, and cannot capture the complexity of how scientific knowledge operates and interacts with the social world. She therefore represents the multi-directional influence between classification and practices by moving between institutional settings where scientific knowledge is produced, and beyond the laboratory into settings within wider society.

Likewise, Bowker and Star (1999) argue that infrastructure shapes, and is shaped by, the conventions of the communities in which it is taken up and of the practices with which it is associated. An example of this bi-directional influence between psychiatric diagnostic classification and clinical practice is seen in the recent revision of the DSM-5 criteria for a bipolar disorder diagnosis. To reflect clinical practice and to formalise clinicians' recordings of experiences of distress that fall outside of a diagnostic category, a diagnostic specifier for 'anxious distress' was added to the diagnostic criteria so that co-occurring 'anxiety symptoms' (p. 4) can be formally identified on individuals' health records (APA, 2013b). Consequently, this specifier creates a new category through which research can be organised.

1.5.4.4 *Representing multiple voices and perspectives*

Systems of classification (and of standardization) form a juncture of social organization, moral order, and layers of technical integration (Bowker & Star, 1999, p. 33)

As an example of classifications changing over time, Bowker and Star (1999) cite the changes in conceptualisation of the category of the AIDS virus. The authors highlight the multiple voices in the category's history, between the technological, organisational, social, and moral. These included, for example, epidemiological narratives, personal and public narratives about living with the disease, public health stories, and virology stories. Multiple voices can also be seen in our conceptualisations and categorisations of mental distress, some of the narratives of which are touched upon within this chapter. Categorisation of mental distress began in statistical and public health roots, with narratives from biomedical psychiatry, psychotherapy and psychology, the pharmaceutical industry, and service users/survivors of the mental health system.

This review sought to organise an overview of the literature on psychiatric diagnosis widening out from the technological and taxonomic view often taken by psychiatric literature, and from there increasingly incorporating wider perspectives as to the social relations involved in the development, use, and implications of diagnosis. Nevertheless, each of the literatures covered in this review tend to view diagnosis from their own perspective with limited scope for the consideration of the other literatures. This focus on singular perspectives of diagnosis is reflected in some of the published debates regarding the DSM. In a Maudsley debate published in the British Medical Journal (BMJ), for example, the article by-line made this limitation clear; "Felicity Callard and Pat Bracken argue that a psychiatric diagnosis can disempower people rather than help them, but Anthony David and Norman Sartorius think that the diagnostic framework ensures that resources are allocated appropriately" (Callard et al., 2013). The academics on each side of the debate have clear arguments to make, however these do not exactly oppose one another. Debates such as these highlight the multiple functions and implications of diagnosis, and therefore multiple perspectives and positions that can be taken up by participants. However, as the BMJ debate reveals, what the existing literatures fail to do is sufficiently engage with a range of these views and functions in order to take a crosscutting approach to understanding why diagnosis is used, and what might be different ways of conceptualising and viewing mental distress.

2 Chapter 2: Methodological background

2.1 Overview

The four key bodies of literature outlined in Chapter 1 inform the methodological approach and theoretical questions asked by this thesis. Understanding the diverse functions, and ways in which diagnosis taken up across multiple perspectives, including personal, clinical, legal, and business spheres, is seen as central to exploring its implications, and how diagnostic alternatives might be conceptualised.

The following chapter seeks to offer the reader an understanding of the overall philosophical and methodological approach of the thesis. This approach underpins each of the methods of data collection used within this thesis. The areas that will be outlined are: personal and political positioning, epistemology and language, and the overall research design and theoretical questions that the research sought to answer. The chapter closes with an outline of how the following empirical chapters are organised and the findings presented.

2.2 Personal and political positioning

To develop reflexive awareness of myself as a researcher and how this shapes my research, it was important to ensure that this thesis was grounded within an understanding of its theoretical and epistemological starting points and assumptions, as well as an awareness of its wider social and political context (Green & Thorogood, 2014). The current political climate of psychiatry is rooted in a long history of critical approaches such as the anti-psychiatry movement that began in the 1960s, stemming both from clinicians (such as Laing and Szasz) and survivor movements of those who had 'survived' treatment within the psychiatric system (raised in Section 1.3.3). More recently, the controversy surrounding the publication of the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5, American Psychiatric Association, 2013) brought the debate more directly into the public eye, with high profile pieces in the media on both sides of the Atlantic (e.g. Doward, 2013; Jaslow & Castillo, 2013). The responses of two significant professional bodies, the US National Institute of Mental Health (NIMH) and the Division of Clinical Psychology (DCP) of the British Psychological Society (BPS) both called to reject existing diagnostic classification in mental health. These calls for change diverged significantly in their proposed direction of travel for mental health, one towards research into biological drivers (Insel, 2013) and the other towards more psychological ways of assessing and understanding difficulties (Division of Clinical Psychology, 2013). Nevertheless, the result was to spur forward research and discussion of alternatives to diagnosis (Boyle & Johnstone, 2014; Bracken et al., 2012; Kinderman, Read, et al., 2013). The context of the publication of the DSM-5 and public

debate surrounding it, underpinned by a history of debate and service user/survivor activism around mental health care allowed this research to be carried out at this time.

This thesis engages with these calls for alternatives from a broadly psychological perspective. My supervisors, Professors Kinderman, Corcoran and Read, each work within clinical psychology. Professors Kinderman and Read are both qualified clinical psychologists who are known for being sceptical, and at times openly critical, of psychiatric diagnosis (Kinderman et al., 2013; Kinderman, 2016; Read, 2015; Read, Dillon, & Lampshire, 2014). My PhD research in the Institute of Psychology, Health and Society is part-funded by the Institute and part-funded by Pearson, a publisher of psychological assessment tools. My working background is within mental health services as part of nursing and psychology teams and within psychological assessment research at Pearson. Alongside this experience, and throughout my PhD, I have been involved in a DCP working group within the BPS, and have contributed to a document that is being prepared by the group that outlines the problems with psychiatric diagnosis and aims to establish alternatives, particularly on an individual clinical basis (document in preparation; see Johnstone, Boyle & Cromby, 2017, for information). I am not, however, trained as a clinical psychologist, nor medically trained. Likewise, I have not, to my knowledge, been given a psychiatric diagnosis, although I would consider myself to have experienced at certain times what might be labelled as mental health difficulties.

Reflexivity is an attitude of attending to the relationship between the researcher and what is being studied, with the assumption that the two mutually influence and affect each other throughout the course of research (Alvesson & Sköldberg, 2000). By not taking a positivist position (see Section 2.3, below) I neither consider it possible to separate myself from my research nor maintain researcher neutrality as is pursued within positivist paradigms (Alvesson & Sköldberg, 2000). I acknowledge that my interpretation of findings will be shaped to some extent by my particular position (Davies & Harré, 1990; Goffman, 1974). However, I have maintained an awareness of this personal and political positioning throughout the research process and made efforts to question and challenge my assumptions, and ensure that my framing of the findings are closely grounded within the research data. These issues are further discussed in later chapters where relevant.

2.3 Epistemology

This thesis is underpinned by a position of critical realist social constructionism, which incorporates ontological realism and epistemological relativism (Harper, 2012). There is no single, encompassing, description of social constructionism (Burr, 2003), so in this section I aim to define how I understand it, and how it fits with my research. In contrast with positivism and empiricism, which are theoretical positions that argue that the nature of the world can be

revealed through scientific observation (Snape & Spencer, 2003), social constructionism is critical of these ways of understanding the world (Burr, 2003). Rather than taking the positivist position that scientific tools can be used to uncover the reality of the world, social constructionism seeks to understand the ways in which knowledge is produced or constructed (Harper, 2012). This stance is particularly interested in the language used to construct knowledge, and takes the perspective that individuals' experiences are mediated by culturally understood and shared meanings (Harper, 2012). That is, our understandings of the world are socially and culturally specific, and situated within our current historical context. Knowledge is seen as being produced via culturally specific interactions between people (Burr, 2003). Harper (2012) describes two positions within social constructionism; relativist social constructionism and critical realist social constructionism. The relativist, or radical, position argues that we cannot comment on the nature of reality because it is not possible to be in direct contact with it, instead we can only study text or talk, and that the researcher should not look beyond the text in its interpretation. This position suggests that different researchers will not necessarily interpret data in the same ways. Critical realist social constructionism adopts a similar epistemological position of relativism, accepting that there are multiple perspectives and ways of interpreting things such as data. In contrast with the relativist position, however, this position goes beyond texts to incorporate an understanding of wider historical, social, and cultural contexts. Additionally, by taking a stance of ontological realism, this position draws on critical realist assumptions of there being a reality, albeit one that we cannot understand directly (Harper, 2012).

I have taken up the stance of critical realist social constructionism in order to incorporate an acceptance of and acknowledgement that people experience very real distress. The world 'out there' is seen as real, with real events that have real effects, such as trauma and distress, but that these experiences of distress are mediated by language, by the ways of expressing this distress that are culturally recognised or accepted. Pilgrim (2013) describes mental illnesses as not really existing, but he argues that since problems such as "unintelligibility, interpersonal dysfunction and common human misery" (p. 336) recur throughout life, they therefore amount to real problems for society and for those affected. The utility of incorporating a critical realist stance is in not 'denying' the existence of the 'real', such as distress, or social structures. A criticism levelled at strong social constructionism is that this stance can become nihilistic, rendering thinking to discourses about discourses by being sceptical of any reality (Pilgrim, 2013). Smail (2005, p. 16) argues, "to understand how we come to suffer avoidable psychological distress we are going to have to extend our gaze beyond the 'inner world' of individuals to take account not only of social structure, but also of the limitations placed on our imaginings by the real world". The position taken within this thesis, therefore, was used to ground the research within both the reality of distress and its psychosocial and political contexts beyond the individual.

In the philosophical position I have taken, whilst the feelings and experiences that people have are seen as real, by contrast, the 'second order' ways that we choose to talk about and conceptualise 'mental health' are not seen as fixed or real, or even approximations of a reality, and are mediated through language and discourse. I include within this description both the way that individuals talk about and ascribe meanings to their own experiences, and the more formal ways in which groups and organisations conceptualise mental health, for example, the establishment of mental health care services and diagnostic classification. Psychiatric diagnoses and ideas of 'disorder', for example, are categories that have some shared meaning for people, however I view them as just one way of conceptualising and categorising mental health which are constructed in order to meet varying functions and needs. They are productive categories in that they have been developed in order to produce certain effects and serve various functions, such as granting access to mental health services, categorising for research, and service planning. In this sense, our conceptualisations and categorisations of mental health (such as we choose to use them) need not necessarily look this way (Foucault, 1967), and individuals' and groups' experiences and conceptualisations of these categories are shaped by their own experience, by personal, social, and political contexts.

As discussed in Chapter 1, one of the key limitations of psychiatric diagnosis is the potential for its essentialised location of problems within the individual, to the exclusion of consideration of the social, relational, and environmental factors in the development of personal distress. Drawing upon a social constructionist epistemology allows a redressing of the balance between individual perspectives and an understanding of the ways in which these are influenced by and take shape as a result of the shared meanings that are culturally and socially available to individuals (Harper, 2012) and the ways in which these meanings are impacted by power relations and social context across social structures (Georgaca, 2013).

2.3.1 A note on language

The language of 'mental health difficulties' and 'mental distress' is used throughout this thesis. These common terms are used in an attempt to strike a balance between invoking a shared understanding of what the thesis is about, and avoiding the medical model language of mental health. Terms such as 'disorder', and 'illness', and diagnostic labels themselves, can presuppose a biomedical illness model of mental health. As discussed in the preceding literature review, this model can be stigmatising, as well as having other implications such as minimising the biographical context of distress. These types of terms, therefore, are avoided or qualified, following the BPS guidelines on language in relation to so-called functional psychiatric diagnosis (BPS, 2015). Although it could be argued that by choosing language that is not necessarily of the dominant discourse in mental health (such as using 'hearing

voices' rather than 'hallucinations', 'difficulty' instead of 'disorder'), is a political statement or point of resistance in itself (Burstow, 2013), I have made this decision in an attempt to use neutral language rather than choose to represent a particular alternative model.

Nevertheless, it is also recognised that this thesis takes a particular stance on these types of experiences. These experiences are situated within mental health 'care'. Medical model language is avoided where possible, however, to some extent experiences are still seen as 'problems' that are likely to warrant support and potentially more formal 'interventions' such as psychological therapy. Mental health difficulties are situated within a particular psychological and philosophical tradition. As referred to earlier, use of this language shapes the ways that these experiences are conceptualised and responded to. Although this language is revisited and considered throughout the thesis, use of the term 'mental health difficulties' by definition problematises these experiences, compared with other cultural or alternative ways of viewing them, such as the ways that hearing voices might be conceptualised in, for example, the Hearing Voices Movement, or shamanism (Corstens, Longden, McCarthy-Jones, Waddingham, & Thomas, 2014; Johnson, 1993). This issue will be further discussed within the thesis.

Chapters 4, 6, and 7 describe the findings of a series of interviews with participants including clinicians and people who have been given a psychiatric diagnosis who are currently involved with mental health services. A specific term was needed to distinguish between these participant groups throughout the thesis. Varying terms used in the literature include 'patient', 'client', 'consumer', 'survivor', and 'service user', each representing different identities and power dynamics in the relationship between person and clinician/professional (McLaughlin, 2009).

Some surveys have found that people prefer the term 'patient' to 'client' or 'service user' (McGuire-Snieckus, 2003; Simmons, Hawley, Gale, & Sivakumaran, 2010), although the terms are still debated. Historically, mental health activists have rejected the term 'patient' since the 1970s, arguing that it denotes someone who is passive, and therefore incapable of doing things for themselves, or worthy of being listened to. Following this backlash, mental health professionals increasingly began to use the term 'consumer' (Reaume, 2002). However, Burstow (2013) describes what she sees as the underhand way in which governments and organisations have introduced terms like 'consumer' that use the "language of the marketplace" (p.86), and how this seemingly neutral phrase minimises critiques of the medical model. In the context of being subjected to forcible drug treatment, the term 'consumer' has been powerfully rejected by some, "I did not *consume* psychiatric drugs. They were forced down my throat" (Millett, 1991, as cited in Burstow, 2013). Burstow suggests 'survivor' as an alternative, however she describes terms such as these as framed within activism, as "refusal terms" (p.82) of those resisting psychiatric language. Whilst some

of the participants in this research identify as activists against the current mental health system and its conceptualisations, I do not feel that this represents all of the people I spoke to, and therefore find it inappropriate to use as a catchall term.

For Burstow, the importance is that people can identify in any way they choose, and that the presumptuous way of telling a person what they should call themselves should be avoided. Nevertheless, whilst acknowledging the individual differences in the group of participants that chose to help with my research, I feel that a collective term is necessary in order to avoid confusion, and so I have chosen to use the term 'service user' for my research participants and to refer generally to those using services. This was chosen as a descriptive term, however, I do not with this imply that people are passive recipients of services. Instead, I use the term in the sense adopted by the Social Care Institute for Excellence (2016) and the Shaping Our Lives National User Network (Shaping Our Lives, 2012, cited in Beresford, 2012), whereby the term is seen as positive and active, whilst acknowledging that people should self-identify with whatever term they feel is appropriate for them.

2.4 Overall research design

The structure of the overall research design was drawn from Wengraf's (2001) model of top-down progression. Wengraf's model has been adapted from Maxwell (1965, as cited in Wengraf, 2001) for semi-structured interviewing methods, and incorporates opportunities to include other research methods such as the document analysis used in this thesis. The model outlines a process of moving from an overall research purpose or interest, via the conceptual frameworks that underpin the research, and narrowing down to a central research question that gives light to a set of theory questions, and later interview questions and other focused questions for data collection and analysis.

The following sections outline the process of research design, beginning with the refining of the overall research purpose and the central research question. Three theory questions derived from the central research question are then outlined. Together these questions form the aims and objectives of the thesis, which each empirical chapter was designed to answer.

2.4.1 Refining the central research purpose

2.4.1.1 Original central research purpose

As discussed in the previous chapter, Bentall (2003) suggests, based on his extensive research in psychosis, that mental health care should take a symptom level or 'complaints-based' approach to assessment and intervention, where people's specific experiences of mental distress are seen not as symptoms that indicate the presence of a disorder, but as

'complaints'. Bentall argued that once the individual causal mechanisms are identified for individual 'symptoms' or experiences contained within diagnostic criteria, the diagnostic category itself (e.g. schizophrenia) will cease to have utility, as it adds no further value (Bentall, 2003). Informed by Bentall's research, Kinderman has written frequently about the use of a problem list approach to mental health assessment. In his book, '*A prescription for psychiatry*', Kinderman, (2014) outlines a manifesto for reforming mental health services, in which he supports the use of a list of well-defined problems over diagnosis as a means of assessment. Based on these ideas, and my background in the development of psychological assessment tools, the initial aim of this thesis had been to explore and develop an assessment approach that comprised phenomenological descriptions of distress in a problem or complaints checklist. However, this original central research question was revised in light of the reasons outlined below. The updated central research purpose is described below in Section 2.4.1.3.

2.4.1.2 *Reasons for refinement*

The reasons for revising the research purpose were twofold. First, following the textual analysis of the DSM, the decidedly heterogeneous nature of mental health was highlighted. As such, different experiences would need very different approaches to how these are assessed; therefore a standardised assessment tool attempting to measure each of these within the same measurement framework would be inappropriate. For example, assessing the nature, frequency, and severity of self-harm versus the nature, meaning and impact of unusual beliefs could not be done using the same measurement scale. Second, a qualitative phase began which intended to inform the assessment development by better understanding the functions that psychiatric diagnosis had on an individual level. I began interviewing clinicians and users of mental health services, and through an iterative process of moving between data collection, scientific literature, and the assumptions of my research, it soon became clear upon speaking with both clinicians and service users that from their perspectives, needs, and uses, a problem list might not suffice. This process highlighted the biases inherent in the original framing of the research aim. The problem list approach is framed from a research perspective, reflecting its proponents' foremost academic interests. The approach was limited by its focus on two aspects of diagnosis; research into the causes of distress, and eliciting a person's difficulties in an individual clinical assessment. However, these perspectives do not take into account the many other perspectives and facets of diagnosis and assessment in mental health that were brought to the fore during the initial qualitative interview phase.

2.4.1.3 *Central research question*

The aims of the shift in research purpose, described above, were to better take account of the multiplicity of perspectives involved when considering diagnosis and its many functions. Furthermore, this research focus also addresses the implications of diagnosis and assessing and conceptualising mental health in these ways. I consider these factors essential to understanding what alternatives to psychiatric diagnosis could look like. As noted in Chapter 1 the existing proposals for alternatives to diagnosis tend to stem from one or other perspective rather than multiple perspectives, for example the clear divide between taxonomic- and assessment-based alternatives. Early interviews highlighted the research bias in the original conceptualisation of a complaint or problem list approach, and many other functions that diagnosis has for individuals when they make sense of their own or another's difficulties.

The central research question for this thesis, therefore, was: From multiple perspectives, what are the functions of psychiatric diagnosis?

2.4.2 Theory questions

The following theory questions build upon the literature and conceptual frameworks outlined in Chapter 1 to elaborate on and inform the central research question. Theory questions ask specifically what the researcher wants to understand by doing the research (Wengraf, 2001), and therefore what questions the research attempts to answer. The theory questions for this thesis are as follows:

- 1) What are the conceptual underpinnings of diagnostic categories, and are these consistent across contexts and practices?
- 2) How are psychiatric diagnostic categories used in practice?
- 3) What do diagnostic categories produce? What are their implications?

2.4.2.1 *What are the conceptual underpinnings of diagnostic categories, and are these consistent across contexts and practices?*

Psychiatric diagnoses as they are presented in the classification systems of the DSM and ICD represent descriptive criteria without, with some exceptions, including information about the cause of difficulties, as would be typically seen in physical medicine (see Section 1.2.2, Aetiological agnosticism). However, historically, in the language of the DSM and in the disciplines largely responsible for its shaping, there has been a shift from the use of psychodynamic models of mental health towards the biomedical. Psychiatric diagnoses, therefore, are on the one hand described as descriptive categories with clinical utility (e.g. Kendell & Jablensky, 2003), and on the other representations of a biomedical model of

mental health. In asking about the conceptual underpinnings of diagnosis and the ways it is taken up and used in a variety of ways, by both clinicians and service users, this research sought to explore the ways that theoretical and conceptual understandings of diagnosis may or may not be represented both in the language of the categories themselves, and in the ways that people speak about and make sense of them. The conceptual ideas behind diagnostic categories themselves are often described and debated (e.g. Hyman, 2010; Jablensky, 2012; Kendell & Jablensky, 2003; Kendler, Zachar, & Craver, 2011; Pilgrim, 2013; Probst, 2015a). However, the aim of this research was to take this further by understanding in what ways people's conceptualisations of mental health and diagnoses are represented in the ways that they talk about them, and to see how conceptualisations can help to explain the uses of diagnoses in practical ways. For example, would participants describe diagnoses in ways that represented them as:

- descriptive categories that perform useful functions (Kendell & Jablensky, 2003)
- categories that represent real illnesses (Hyman, 2010)
- moral judgements (Hill, 2010)
- a combination of these ways of thinking

2.4.2.2 *How are diagnostic categories used in practice?*

This question looks at the differences between diagnosis as a protocol for clinical use, and the ways it is taken up and used in practice by multiple stakeholders, including individuals outside of the clinical world. If adaptations to the diagnostic protocol are made in practice, these work-arounds can help us to see how conceptualisations of mental distress might be adapted to reflect real world needs.

2.4.2.3 *What do diagnostic categories produce? What are their implications?*

Diagnoses are considered to be active categories, constructed to perform particular functions. In performing these roles, the literature review in Chapter 1 considered some of the consequences of using diagnosis in these ways. This research aimed to understand the implications of conceptualising mental distress in diagnostic way from multiple perspectives. It asks if diagnosis has negative implications, and what it is about diagnosis that has these undesirable consequences.

2.4.3 From theory to data collection: Using multiple sources of data

In order to answer the above theory questions, three different sources of data were used. The sources of data collection were: 1) sections of the DSM-5; 2) service eligibility and entry criteria for NHS adult mental health services in the north of England; and 3) semi-structured interviews with clinicians (GPs, psychiatrists, and clinical psychologists) and users of mental

health services who had been given psychiatric diagnoses. These data were used to explore the functions of diagnostic classification from multiple perspectives, addressing the central research question and the three theory questions described above. The rationale for using each data source and the individual methodological details for each are outlined in the relevant empirical chapters that follow.

2.4.3.1 Organisation of empirical chapters

The following five empirical chapters present the findings from the analysis of each of the three sources of data. Rather than organising the following empirical chapters by data source, the sequence was chosen to represent the consequential process of the travel of diagnosis, its practices, implications, and changing conceptualisation across different contexts. The organisation of the following chapters is represented by the flowchart in Figure 2-1, below. The empirical chapters begin with analysis of the text of diagnostic classification itself (Chapter 3), expanding outwards to explore the uses and practices of diagnostic classification within clinical spheres. Clinical diagnostic practices are explored from the perspectives of clinicians making individual clinical assessments (Chapter 4) and at a service level from the perspective of trust - and service-defined mental health service entry and eligibility criteria (Chapter 5). The analysis then examines the ways in which diagnosis travels beyond clinical spheres and into business, legal, and social arenas (Chapter 6). The final empirical chapter explores how people who have received diagnoses take up and use, or do not use, diagnoses (Chapter 7). Each empirical chapter focuses on a particular source of data (e.g. interview data), however, the findings from different chapters also inform each other, reflecting the consequential process between the chapters.

Reflecting the epistemological approach used, the social and organisational contexts of the data are acknowledged throughout, and the uses and conceptualisations of diagnosis are contextualised within the wider systemic uses of classificatory categories. For example, the NHS policy data from the service eligibility and entry criteria was used to provide context for clinicians' uses of diagnosis for referrals into adult mental health services. Likewise, in Chapter 6, which explores the ways in which diagnosis travels beyond the clinic by being formally recorded, the interview findings are contextualised using information about the systemic and organisational uses of diagnostic categories.

The findings of each of the empirical chapters are brought together and discussed in Chapter 8.

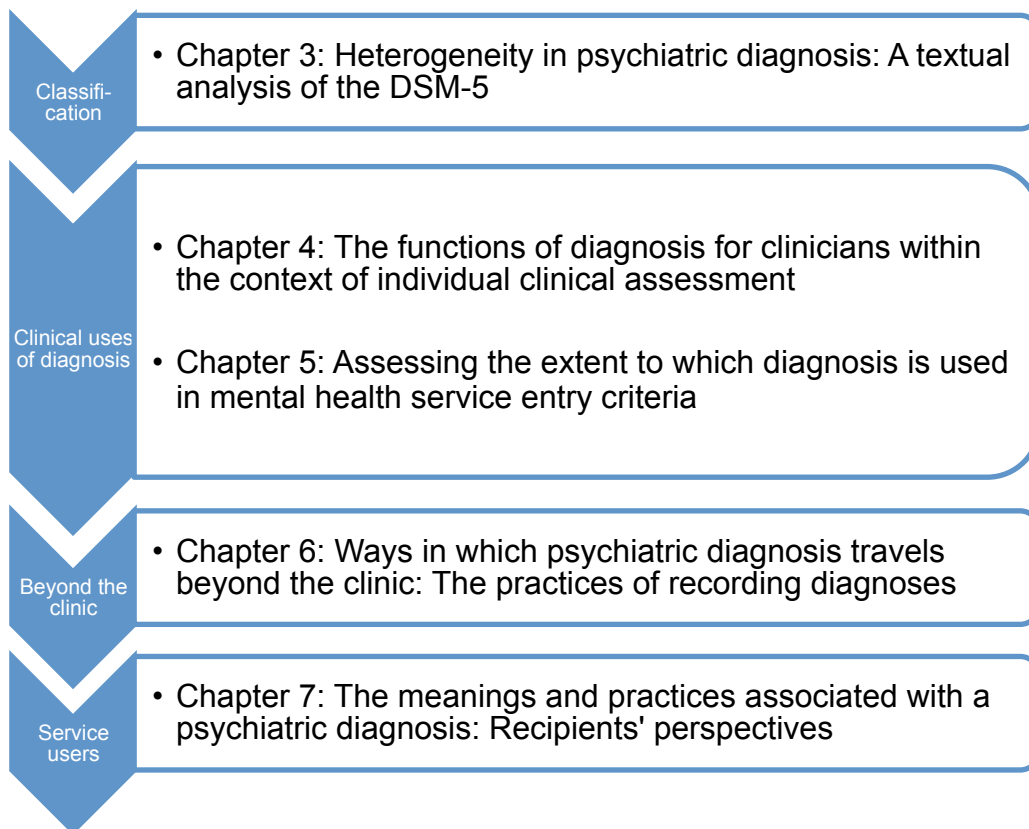


Figure 2-1: Flowchart representing organisation of the following empirical chapters

For reference, a thematic map showing all the themes and subthemes of the following five empirical chapters is shown on the following page in Figure 2-2.

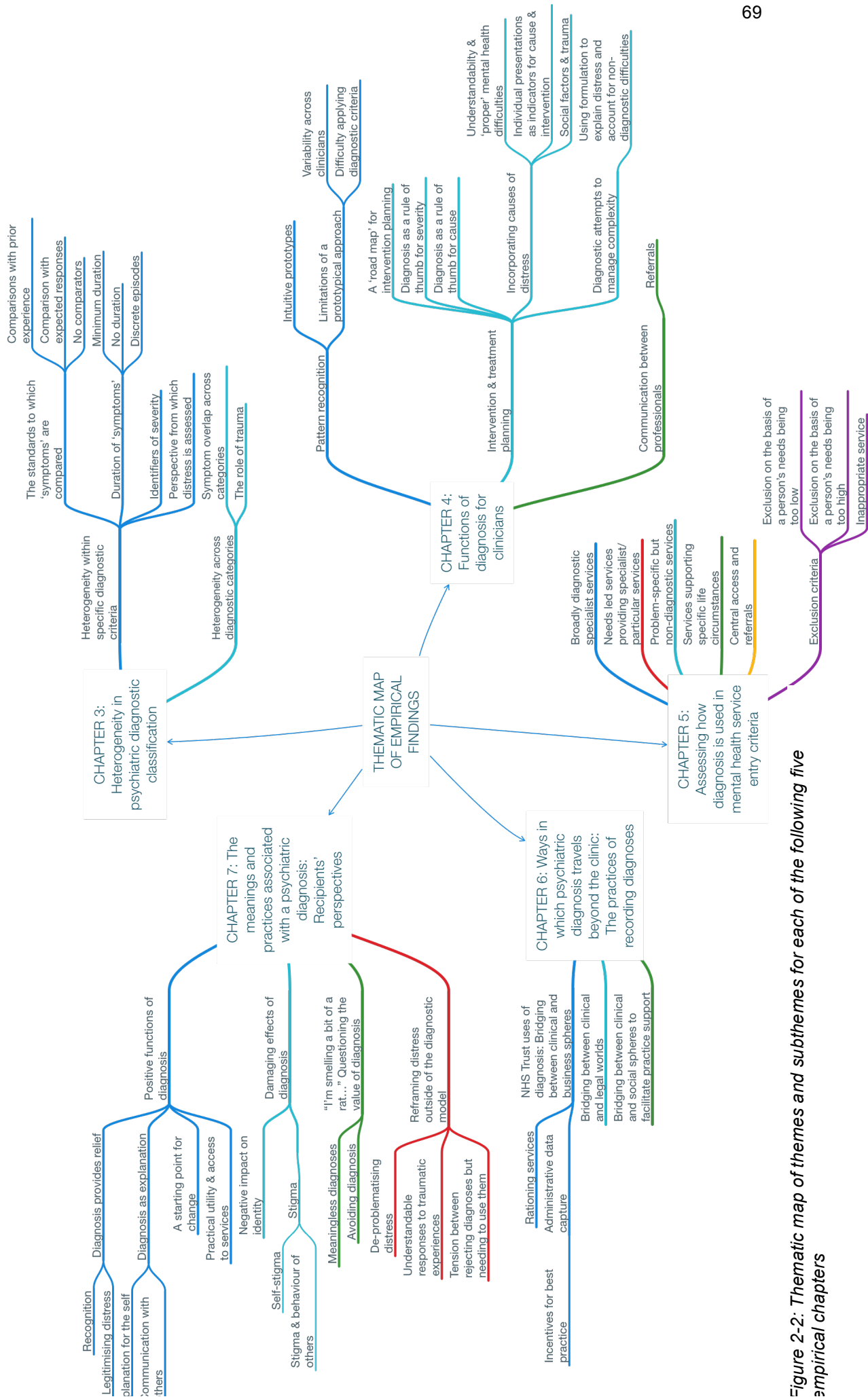


Figure 2-2: Thematic map of themes and subthemes for each of the following five empirical chapters

3 Chapter 3: Heterogeneity in psychiatric diagnostic classification: A textual analysis

3.1 Abstract

This chapter examines the heterogeneous nature of the phenomena described within the DSM-5, and the ways in which it reflects attempts to impose coherent structure upon these phenomena. Selected chapters of the DSM-5 (APA, 2013) were thematically analysed, with the purpose of examining the DSM-5 as a protocol for practice, exploring the ways heterogeneity is represented across diagnostic criteria, and what is produced as a result. The themes identified heterogeneity across specific diagnostic criteria, including symptom comparators, duration of difficulties, indicators of severity and the perspectives used. Wider variations across diagnostic categories examined symptom overlap across categories, and the role of trauma. The findings are discussed in terms of what is constructed by the discourse of the DSM-5, including the notion of inherently disordered experiences, such as voice hearing, and the implications for psychiatric authority. Pragmatic criteria and the representation of experiences of distress that overlap across diagnostic criteria offer flexibility for the clinician, but undermine the model of discrete categories of disorder. This model nevertheless has implications for the way that cause is conceptualised; trauma is seen as involved in only a limited number of diagnoses, discrete categories may lead to common 'transdiagnostic' causes being missed, and individual differences within diagnostic categories may be obscured.

3.2 Introduction

As discussed in Chapter 1, developments and amendments to systems of psychiatric classification can be conceptualised within the perspective of wider social and cultural developments (Foucault, 1967). Amongst other consequences, these socio-political and historical roots have resulted in considerable inherent heterogeneity in a wide range of psychiatric diagnoses during their piecemeal development. For example, stark differences are demonstrated between highly specific diagnostic criteria and those with more flexibility around symptom presentation, resulting in almost 24,000 possible symptom combinations for panic disorder in DSM-5, compared with just one possible combination for social phobia, which itself can be a manifestation of or the foundation of panic (Galatzer-Levy & Bryant, 2013).

In addition, Olbert and colleagues (2014) report considerable heterogeneity within the criteria of individual diagnoses, showing that in the majority of diagnoses in both DSM-IV-TR and DSM-5 (64% and 58.3% respectively), two people could feasibly be given the same

diagnosis without sharing any common symptoms. Such 'disjunctive' categories have been described as scientifically meaningless. Bannister, for example, pointed out as early as 1968 that the 'schizophrenia' construct was '[a] semantic Titanic, doomed before it sails, a concept so diffuse as to be unusable in a scientific context', largely because '[d]isjunctive categories are logically too primitive for scientific use' (Bannister, 1968, pp. 181–182). Categories such as schizophrenia remain disjunctive in DSM-5. Young and colleagues memorably calculate that in the DSM-5 there are 270 million combinations of symptoms that would meet the criteria for both PTSD and major depressive disorder, and when five other commonly made diagnoses are seen alongside these two, this figure rises to one quintillion symptom combinations - more than the number of stars estimated in the Milky Way (Young et al., 2014).

3.2.1 Rationale: Analysis of the DSM-5

As section 1.5.4.1 of Chapter 1 highlights, an important consideration in the study of diagnostic classification is the move from the protocol of the classification itself, to its use in practice. Diagnostic heterogeneity is therefore considered in this context. As diagnostic categories are seen within this thesis as active categories, developed to perform particular functions, this chapter considers how heterogeneity is represented across diagnostic categories, the functions it meets, and what is produced by diagnostic criteria.

As is introduced in Sections 1.2 and 1.4.1, the DSM-5 is the latest edition of the APA's diagnostic classification in psychiatry. The DSM has led the way in making significant changes to psychiatric diagnosis, such as the overhaul of psychiatric classification with the introduction of specific descriptive diagnostic criteria in DSM-III (as described in Section 1.4.1.1.), following which the ICD and the DSM became very similar (APA, 2009). Since then, the WHO and the APA have collaborated to ensure that the ICD and DSM are compatible (Sartorius et al., 1995).

The ICD-10 is the psychiatric classification that the NHS formally uses, however the influence of the new DSM-5, for example, on current clinical conceptualisations of mental health has been noted (NHS Choices, 2013). The last major revision of the ICD was the publication of the ICD-10 in 1994; as the new edition of the ICD is not due to be published for two years (World Health Organization, 2017b), the DSM-5 represents the formally published and most current understandings of psychiatric classification. Debate around the publication of the DSM-5 was covered by the UK national press (e.g. Doward, 2013), and a position statement was made by the BPS (Division of Clinical Psychology, 2013). Royal College of Psychiatry good practice guidelines have been updated to include information from the DSM-5 (e.g. Royal College of Psychiatrists, 2014), and an international conference

about the DSM-5 (“DSM-5 and the Future of Psychiatric Diagnosis: Where is the roadmap taking us?” Institute of Psychiatry, 2013) was held at the UK Institute of Psychiatry in 2013. Consequently, it was concluded that analysis of the DSM-5, rather than the ICD-10, would best represent current debates in mental health and formal conceptualisations of diagnosis in psychiatry. Analysing the most current version of Western diagnostic classification was thought to be important in order to reflect debates that were raised in interviews with clinicians and service users (the findings of which are presented in Chapters 4, 6, and 7).

3.3 Aims

This chapter addresses the first and third theoretical questions outlined in Chapter 2 (Section 2.4.2); 1) what are the conceptual underpinnings of diagnostic categories, and are these consistent across contexts and practices, and 3) what do diagnostic categories produce; what are their implications?

Within the thesis context of considering diagnostic categories as active categories, developed to perform particular functions, the purpose of this chapter was to analyse the DSM-5 as a protocol for practice, exploring the ways heterogeneity is represented across diagnostic criteria, and what is produced as a result. As part of this analysis, this chapter also aimed to consider the embedded taken-for-granted assumptions of the DSM-5, their implications.

3.4 Methodology

3.4.1 Included chapters

For the purposes of manageability, selected chapters were analysed from the text of the DSM-5 (see Section 3.4.2, Method of analysis, below, for further information). Five chapters of the DSM-5 were chosen for analysis: schizophrenia spectrum and other psychotic disorders; bipolar and related disorders; depressive disorders; anxiety disorders; and trauma- and stressor-related disorders. These chapters were chosen in order to reflect commonly reported ‘functional’ (compared with organic or neurologically-based diagnoses such as dementia) psychiatric diagnoses as highlighted by the Adult Psychiatric Morbidity Survey (McManus, Bebbington, Jenkins, & Brugha, 2016a). These included ‘common mental disorders’, including different diagnoses of depression- and anxiety-related difficulties (Stansfeld et al., 2016) and PTSD, bipolar, and psychotic disorder diagnoses (McManus, Bebbington, Jenkins, & Brugha, 2016b). To reflect the differences in heterogeneity across diagnostic criteria, highlighted by Galatzer-Levy and Bryant (2013), these chapters also contained some of the diagnoses with the most (e.g. PTSD) and least (e.g. social and specific phobias) heterogeneous diagnostic categories.

3.4.2 Excluded chapters

One common diagnosis that is not contained within the chapters that were analysed is 'obsessive-compulsive disorder'. This diagnosis is both common (McManus et al., 2016a) and included in Galatzer-Levy and Bryant's (2013) analysis, however, although previously listed within anxiety disorders in the DSM-IV-TR (APA, 2000), the DSM-5 lists this diagnosis within its own chapter (obsessive-compulsive and related disorders), which contains numerous other diagnoses that are new and less common, such as 'trichotillomania' (hair pulling) and 'excoriation' (skin picking). This chapter, therefore, was excluded for the purposes of this analysis.

To enable consideration of diagnostic categories with the potential for consistency across assessment and reporting (for example, self-reporting of distress), diagnoses concerning childhood were excluded from the analysis. For example, 'reactive attachment disorder' and 'disruptive mood dysregulation disorder' were excluded.

3.4.3 Method of analysis

Thematic analysis (Braun & Clarke, 2006) was used to code themes or patterns of meaning across the diagnostic categories being analysed, with a particular focus on the heterogeneity or differences across the types of diagnostic criteria. Drawing from McKee's (2003) concept of post-structural textual analysis, selected chapters were analysed rather than the whole of the text. McKee (2003) describes this approach as identifying information in the text about its sense-making practices to respond to the questions asked of the text. Thematic analysis was used to identify the ways in which heterogeneity was represented across diagnostic categories, and to organise this heterogeneity into central themes of differences across the criteria.

The analysis was therefore both deductive and inductive. The first phase of the analysis deductively focused on identifying heterogeneity or differences between the diagnostic criteria of each category within the five chapters analysed. Following reading and re-reading of the data within the listed diagnostic criteria for each diagnosis, six areas of heterogeneity were identified that represented differences across criteria. Four of these themes related to heterogeneity within specific diagnostic criteria, and there were two broader themes that related to heterogeneity that spanned across diagnostic categories. These six themes are listed below:

- **Heterogeneity within specific diagnostic criteria**
 - The standards to which 'symptoms' are compared
 - Duration of 'symptoms'

- Identifiers of severity
- Perspective from which distress is assessed
- **Heterogeneity across diagnostic categories**
 - Symptom overlap across categories
 - The role of trauma

The second phase was inductive in that each of the themes outlining heterogeneity was grounded within the text of the criteria, and the coding of the data within each of these themes was likewise data driven. During this phase of coding, data was extracted from the diagnostic criteria for each diagnostic category in each of the five chapters, and coded line by line to the themes above. Subthemes were generated from the information within two codes (Standards to which 'symptoms' are compared, and Duration of 'symptoms') as different ways of representing these themes emerged across diagnostic categories. At each stage of coding, the themes were discussed with my research supervisors in order to consider and question my interpretations of the data.

3.5 Findings

The following findings section will demonstrate that heterogeneity in diagnostic criteria is found across the chapters of the DSM-5 that were examined. Unless otherwise specified, page numbers throughout this section refer to the DSM-5. Heterogeneity was identified within diagnostic criteria, concerning the standards to which symptoms or experiences are compared, the duration of symptoms, identifiers of severity, and the perspective from which distress is assessed. These inconsistencies in diagnostic criteria suggest ways in which different experiences are constructed within the DSM-5. Two wider themes illustrate how some chapters emphasise the similarities between diagnoses, whilst others create distinctions. These themes relate to symptom overlap across diagnostic categories, and the role of trauma in the DSM-5. The findings section is organised by the themes and subthemes outlined in Table 3-1; each of these will be explored in detail below.

Table 3-1

Outline of themes and subthemes

Heterogeneity within specific diagnostic criteria

The standards to which 'symptoms' are compared

Comparisons with prior experience

Comparison with expected responses

No comparators

Duration of 'symptoms'

Minimum duration

No duration

Discrete episodes

Identifiers of severity

Perspective from which distress is assessed

Heterogeneity across diagnostic categories

Symptom overlap across categories

The role of trauma

3.5.1 Heterogeneity across specific diagnostic criteria

3.5.1.1 *The standards to which 'symptoms' are compared*

A key element of heterogeneity in the description of disorders and their constituent criteria within diagnostic systems relates to differences in the ways in which the experience of 'symptoms' are compared with normal functioning (or the omission of such comparators). Comparators are identified here as a point of contrast for a particular experience, for example, a requirement of a change in mood that is distinct from previous or usual experience, or compared to an approximation of what is considered 'normal' within society. Diagnostic criteria in the chapters analysed were represented either by no comparator, or a change from previous functioning, behaviour, or mood.

3.5.1.1.1 Comparisons with prior experience

Most criteria associated with change or comparisons with prior functioning or experience were mood-related. Some descriptions of change implied a comparison with previous mood, for example, Criterion A for persistent depressive disorder (dysthymia) requires "[d]epressed mood for most of the day..." (p. 168), and Criterion A for a manic episode requires "[a] distinct period of abnormally and persistently elevated, expansive, or irritable mood and abnormally and persistently increased goal-directed activity or energy" (p. 124). Certain criteria for manic, hypomanic, and major depressive episodes included implied comparisons with previous mood or behaviour. For example, Criteria B2 and B3 for both manic and hypomanic episodes are "decreased need for sleep..." and "more talkative than usual..." (p. 124) respectively. Criterion B6 for a major depressive episode requires "[f]atigue or loss of energy nearly every day". Each of these implied comparisons suggest the presence of a usual or acceptable behaviour or mood, such as sleep or irritable mood, which is altered to a problematic extent. As well as the bipolar and depressive disorders chapters, mood components from the schizophrenia and psychosis chapter were also included for three diagnoses. Schizophreniform disorder and schizophrenia both include 'negative symptoms',

which are described as “diminished emotional expression or avolition” (p. 99), implying a change from usual mood or motivation. Finally, schizoaffective disorder incorporates the mood comparisons made in the major depressive or manic episodes outlined in the mood disorder chapters. Other symptoms within the diagnostic criteria for psychotic disorders had no comparators; this is described in the following section.

Other descriptions explicitly noted a comparison, for example, Criterion A for a major depressive episode states, “[f]ive (or more) of the following symptoms have been present during the same 2-week period and represent a change from previous functioning” (p. 160). Criterion B2 for panic disorder, the only anxiety-related diagnosis to include comparators, requires “a significant maladaptive change in behavior related to the attacks (e.g. behaviors designed to avoid having panic attacks, such as avoidance of exercise or unfamiliar situations)” (p. 208). In the case of the criteria for panic disorder, the behaviour is constructed as unusual or unacceptable by this criterion’s description as ‘maladaptive’.

3.5.1.1.2 Comparison with socially expected responses

Within mood episodes, and criteria for some anxiety and trauma-related diagnoses, there is a notion of ‘excessive’ behaviours or responses, suggested a comparison with a socially expected response. For example, Criterion B7 of manic and hypomanic episodes requires “excessive involvement in activities that have a high potential for painful consequences (e.g. engaging in unrestrained buying sprees, sexual indiscretions, or foolish business investments)” (p. 124). Criterion B7 of a major depressive episode assesses “feelings of worthlessness or excessive or inappropriate guilt...” (p. 125). Separation anxiety disorder similarly assesses “persistent and excessive worry” (A2, p. 190). In another way of assessing a person’s response in comparison with expected responses, specific phobia and adjustment disorder both require the response to be “out of proportion” (pp. 197 and 286), with either the object or situation (social phobia) or the stressor (adjustment disorder). A subjective judgement is required to assess whether a person’s experiences are out of line with typically expected responses. This is discussed further in Section 3.5.1.2.2, Perspective.

3.5.1.1.3 No comparators

By contrast, other symptoms or experiences within the diagnostic criteria did not acknowledge a comparison with any previous experience. For example, barring the negative symptoms described in the previous section, none of the psychosis-related symptoms were given a comparator. The presence of delusions and hallucinations, for example, is always stated in the diagnostic criteria with no qualification.

There is a similar absence of comparators for some of the criteria within the mood disorders chapters. For example, “feelings of worthlessness” or “recurrent thoughts of death...” (Criteria A7 and A9, respectively, of a major depressive episode), and “flight of ideas...” or “distractibility...” (Criteria B4 and B5, respectively, of manic and hypomanic episodes). The criteria for manic, hypomanic, and major depressive episodes, therefore, give a mixed presentation of criteria with both comparators and no comparators. Three or more of the experiences described in Criterion B must be present for identification of a manic or hypomanic episode, meaning that presentations of these episodes might reflect either discontinuous, disordered experiences, or within a continuum with ‘normal’, or a mixture of the two. A function of comparators may be the pragmatics of differentiating problematic experiences from experiences that are generally considered ‘normal’ or within an acceptable range. For example, more comparators are given for a hypomanic episode compared with a manic episode (such as “(t)he disturbance in mood and the change in functioning are observable by others”, Criterion D, p. 125), perhaps because a ‘hypomanic’ experience is more similar to ‘normal’ mood fluctuations therefore more difficult to differentiate.

The criteria for PTSD and acute stress disorder notably omit comparators. For example, “[r]ecurrent, involuntary, and intrusive distressing memories of the traumatic event(s)” (B1, e.g. p. 271) and “dissociative reactions (e.g. flashbacks)...” (B3, e.g. p. 271) are examples of criteria for both PTSD and acute stress disorder that are compared to neither expected responses nor prior functioning. These omissions are perhaps surprising given the severity of the experienced trauma or stressor described in Criterion A for both PTSD and acute stress disorder; “exposure to actual or threatened death, serious injury, or sexual violation in order (or more) of the following ways...” (pp. 271 and 280). This description of the severity of stressors gives an expectation that the trauma would have some emotional impact on the individual.

3.5.1.2 *Duration of ‘symptoms’*

There were three subthemes for the duration of symptoms or experiences described by diagnostic criteria in the DSM-5: no duration, discrete episodes, and a minimum duration. In effect, these timeframes construct different ‘kinds’ of disorder categories.

3.5.1.2.1 Minimum duration

Most diagnostic categories in the analysed chapters had a specified minimum duration requirement. For example, Criterion C for schizophrenia requires continuous signs of disturbance to continue for at least 6 months, or at least 2 years of depressed mood (Criterion A) for persistent depressive disorder (dysthymia). In the absence of other indicators of ‘disorder’ (such as biomedical markers), a minimum duration requirement

constructs a definition of severity. Giving a minimum duration criterion creates a way of separating between 'everyday' distress and that that is considered 'clinical', or otherwise abnormal and therefore in need of support.

3.5.1.2.2 No duration

The criteria for certain diagnoses offer no timeframe, which suggests that no particular duration is needed to meet criteria. Diagnoses in this category include difficulties due to other medical conditions for each of the chapters (with the exception of trauma-related disorders). Each of these diagnoses is coded as an additional diagnostic category alongside the diagnosis for the medical condition. The diagnostic criteria suggest that a timeframe may not be necessary as the experiences must be the 'direct pathophysiological consequence of another medical condition' (e.g. p. 120). This use of physiological signs sets these diagnoses apart from other functional diagnoses, suggesting that other diagnoses use timeframes to bolster descriptive diagnoses in the absence of physiological tests. This form of diagnostic criteria indicates that the presence of symptoms is itself sufficient for diagnosis.

Other diagnoses that do not require a particular duration are 'other specified' and 'unspecified' diagnoses at the end of each of the chapters analysed. Specifically included to incorporate difficulties that do not meet the criteria for other diagnoses in their respective chapters, these diagnostic categories have very broad criteria. The experiences must be characteristic of other diagnoses in their chapter, and cause clinically significant distress or impairment in functioning (discussed in Section 3.5.1.2.1, Identifiers of severity). However, the 'unspecified' diagnoses for each chapter do not list any experiences that may be included, or their duration, leaving these categories entirely open to clinical judgement. The 'other specified' diagnoses for the schizophrenia spectrum and other psychotic disorders, bipolar and related disorders and anxiety disorders chapters give options, that do not contain timeframes, for specified difficulties, for example, 'persistent auditory hallucinations occurring in the absence of any other features', a much briefer criterion than those included in the other diagnoses for the schizophrenia spectrum and other psychotic disorders chapter.

3.5.1.2.3 Discrete episodes

Least common are diagnoses that represent discrete episodes, with a specific duration such as one day to one month (e.g. brief psychotic disorder). Acute stress disorder ("Criterion C: Duration of the disturbance (symptoms in Criterion B) is 3 days to 1 month after trauma exposure", p. 281) is similarly brief, whilst the symptoms associated with adjustment disorders must occur within 3 months of a stressor and not persist for more than 6 months "once the stressor and its consequences have terminated" (Criterion E, p. 287). These

episodic diagnoses suggest an expectation of an end point that is not present for those with a minimum duration.

Bipolar and depressive disorders are treated differently again; the bipolar and related disorders chapter (including, e.g. cyclothymia) and the category of major depressive disorder are unique in that several episodes are combined in various ways to produce disorders presented as distinct from one other. Major depressive and manic episodes are the two key episodes from which hypomanic episode (shorter duration and lesser severity than manic episode) and a mixed features specifier (criteria are met for one episode, with features of another during the same timeframe) are derived. The three episodes are then variously combined to create eight different diagnostic categories (seven bipolar-related diagnoses, and major depressive disorder).

3.5.1.3 *Identifiers of severity*

The theme of identifiers for severity incorporates statements regarding how severity is identified, and if present, what measures are used. Different diagnoses within DSM-5 show marked heterogeneity in this respect. In some cases, severity indicators override duration requirements, for example, within the criteria for manic episodes and Bipolar and related disorder due to another medical condition, any duration is applicable if hospitalization is necessary, or there are psychotic features.

Most categories within the analysed chapters stipulate a criterion of “clinically significant distress or impairment in social, occupational, or other important areas of functioning” (e.g. Criterion B, major depressive disorder, p. 161), which is used to establish a particular threshold at which a disorder should be diagnosed (p. 21). However, no definition of this threshold is provided, therefore representing a subjective judgement, presumably the clinician's.

In contrast, there is a separate idea of a marked change in functioning in both schizophrenia and a manic episode, represented in social, occupational or other areas of functioning. These criteria indicate that the experiences themselves (e.g. hallucinations or delusions, elevated mood) do not have to be distressing, although the person does have to meet an overall criterion of socio/occupational dysfunction. By using social, interpersonal, or occupational functioning, this criterion makes space for a judgement whereby the behaviours experienced by the individual may not be distressing for that person but, rather, distressing or disruptive for others (see Section 3.5.1.4, Perspective from which distress is assessed, below). These variations across criteria offer practical flexibility for the clinician, demonstrating the pragmatic nature of diagnostic categories and their use as a clinical tool.

DSM-5 contains a dimensional severity rating of 0-4 for each Criterion A symptom for delusional, brief psychotic, schizophreniform and schizoaffective disorder criteria. This may, for example, relate to either the pressure to respond to voices or delusions or to what extent the individual is bothered by this experience. For other experiences, such as disorganised speech, the rating is pragmatically based on clinical observation rather than the individual's experience of these difficulties. Other mood-related diagnoses (bipolar, major depression, and related disorders) are rated using a broad dimensional specifier of mild, moderate, severe, or with psychotic features.

3.5.1.4 Perspective from which distress is assessed

The theme of perspective describes the point of view from which distress or other diagnostic criteria are assessed, for example, from the account of the individual being assessed, others around them (e.g. family or friends), or the assessing clinician. Diagnostic categories and their constituent symptoms display considerable heterogeneity with respect to whether the information comes from the individual whose experiences are being assessed or an observer. Many diagnostic criteria do not state a perspective, simply that particular symptoms are present, such as "...there have been numerous periods with hypomanic symptoms" (Criterion A, cyclothymic disorder, p. 139) or "[t]he presence of one (or more) delusions..." (Criterion A, delusional disorder).

In general, the DSM-5 represents a shift towards the perspective of the observer, whereas several DSM-IV-TR diagnoses relied on the individual as the principal (or only) source of information. For example, in the case of DSM-IV-TR social phobia (now social anxiety disorder in DSM-5), reference was made to "marked distress about having the phobia" (Criterion E) and that the "person recognises that the fear is excessive or unreasonable" (Criterion C). In comparison, whilst the fears themselves are self-reported in the DSM-5 version of social anxiety disorder, the criteria otherwise rely on the perspective of the observer. The distress criterion is removed and the individual need not recognise that their fear is excessive, as the clinician makes this judgement. As raised in Section 3.5.1.1.1.2 (Comparators), there are likewise multiple references to the 'excessive' nature of some criteria, such as "excessive involvement in activities that have a high potential for painful consequences (e.g. engaging in unrestrained buying sprees, sexual indiscretions, or foolish business investments)" (manic and hypomanic episodes, p. 124). As well as representing a comparison with an expected response, this use of perspective constructs a socially accepted level at which the behaviours are considered normal versus abnormal. The perspective here demonstrates the power the assessing clinician (or others, such as family) holds by virtue of the diagnostic criteria sanctioning the making of a value judgement.

For other diagnoses, this person's perspective is strongly implied but not explicit, for instance in the case of PTSD, of which Criterion B refers to experiences such as distress and distressing memories, flashbacks and physiological reactions. Likewise, the perspective for information regarding the trauma itself is somewhat unclear; although likely to stem from self-report accounts, it could also be derived from formal police, military or clinical reports of the events.

Finally, in many cases, the question of perspective (who is making the judgment as to whether the criterion is met) is unambiguously ambiguous, as in the case of major depressive episode; "as indicated by subjective report... or observation made by others". In a pragmatic approach, information is collected, from a range of sources, to assess whether or not the diagnostic criteria are met.

3.5.2 Wider heterogeneity across diagnostic categories

3.5.2.1 *Symptom overlap across categories*

The data demonstrated considerable overlap of symptoms; whereby the same experiences occur in multiple diagnostic categories. Major depressive episode, for example, features within the criteria for major depressive disorder, bipolar and related disorders, and can be included within the criteria for schizoaffective disorder (Criterion A of schizoaffective disorder requires the occurrence of "a major mood episode (major depressive or manic)", p. 105). Likewise, hallucinations can occur in schizophrenia and other psychotic disorders, but also in major depressive disorder with psychotic features, bipolar and related disorders (except cyclothymia), and PTSD.

DSM-5 explicitly refers to bipolar disorders bridging between psychotic disorders and depressive disorders, and likewise that schizoaffective disorder bridges several diagnoses. Despite this repetition of symptoms or experiences, there is no explicit statement provided in the DSM about the phenomenological or qualitative experience of symptoms across different diagnoses. The DSM-5 acknowledges,

Although DSM-5 remains a categorical classification of separate disorders, we recognize that mental disorders do not always fit completely within the boundaries of a single disorder. Some symptom domains, such as depression and anxiety, involve multiple diagnostic categories and may reflect common underlying vulnerabilities for a larger group of disorders... (p. xli)

Ten specifiers are provided with the DSM-5 to allow the clinician to represent other patterns not contained within the main diagnostic criteria for bipolar and major depressive disorders,

such as with anxious distress, rapid cycling (for bipolar and related disorders), or psychotic features. The range of experiences incorporated within these specifiers acknowledges the heterogeneity of diagnoses. Depressive episodes are no longer required in DSM-5 criteria for bipolar I, and the diagnostic criteria for cyclothymic disorder incorporates only experiences that are sub-threshold for both hypomania and a major depressive episode. These changes and the additional specifier of ‘anxious distress’ for bipolar and MDD diagnoses represents a shift towards broadening the range of experiences captured by the same diagnostic labels. The ‘mixed features’ specifier further blurs the boundary between depression and bipolar diagnoses in that it can be added to episodes of depression within the context of major depressive disorder where there are symptoms of mania or hypomania present. Likewise, panic attacks can be used as an adjunct to any DSM-5 diagnosis, and catatonia can be specified across various diagnoses spanning several chapters (including neurodevelopmental, psychotic, bipolar, and depressive disorder diagnoses, and other medical conditions).

3.5.2.2 *The role of trauma*

The DSM-5 states at the outset the atheoretical nature of diagnostic categories, and generally avoids discussion of aetiology, stating, “[s]ince a complete description of the underlying pathological processes is not possible for most mental disorders, it is important to emphasize that the current diagnostic criteria are the best available description of how mental disorders are expressed and can be recognized by trained clinicians” (p. xli). In the absence of traditional medical aetiology, the disorder may effectively be seen as causing the difficulties (as described in Section 1.3.2.1.1, Epistemological confusion). Diagnoses in the DSM-5 are at times described in this way, for example, “the disturbance... is not better explained by another mental disorder” (Criterion E, delusional disorder, p. 90).

One chapter of diagnoses, however, is explicitly framed as caused by or directly influenced by external factors; trauma- and stressor-related disorders. Trauma in the DSM-IV-TR was represented only by PTSD and acute stress disorder, and housed within the anxiety disorders chapter. This delineation is made even more distinct in the DSM-5 by the creation of a separate chapter, ‘Trauma- and stressor-related disorders’. The latent variable model of distress being ‘caused’ by the diagnosis or disorder itself is maintained within this chapter. However, the conceptualisation constructed by this addition of causal information is a notable difference from the other analysed chapters. For example, despite contextualising PTSD as a response to an extreme traumatic stressor that would be distressing for anyone to experience (“Exposure to actual or threatened death, serious injury, or sexual violence...” Criterion A, p. 271), in assigning the diagnosis the individual’s response is categorised as disordered.

A related dilemma can be seen in the remarkable semantic similarity between various criteria for schizophrenia and PTSD diagnoses in DSM-5. These include affective flattening and avolition, as well as illusions, hallucinations, and dissociative flashback episodes, restricted range of affect, and markedly diminished interest or participation in significant activities. All of these experiences would, in the presence of a traumatic event, be broadly consistent with a diagnosis of PTSD.

3.6 Discussion

This chapter analysed the text of the diagnostic criteria from five chapters of the DSM-5 to address the first and third theoretical questions outlined in Chapter 2 (Section 2.4.2); 1) what are the conceptual underpinnings of diagnostic categories, and are these consistent across contexts and practices, and 3) what do diagnostic categories produce; what are their implications? The findings demonstrate heterogeneity in diagnostic criteria across the chapters of the DSM-5 that were examined. Heterogeneity, or variation, was found across the standards to which symptoms or experiences are compared, the duration of symptoms, identifiers of severity, and the perspective from which distress is assessed. Diagnostic criteria in some chapters of the DSM-5 acknowledge similarities or overlap in experiences of distress, despite being presented as discrete categories of disorder. One chapter of diagnoses acknowledges the causal role of trauma, however this sets these chapters aside as distinct from the other chapters analysed. The following discussion explores these findings, and is organised by the following points:

- Construction of disorder
 - Power and the impact on the individual
- Threats to the model of discrete disorders
 - Symptom overlap
 - Pragmatism
- Implications for understanding cause
 - The role of trauma
 - 'Transdiagnostic causes'
 - Specific causal pathways obscured by diagnostic categories

3.6.1 Construction of disorder

The heterogeneity demonstrated by findings can be likened to 'variations' highlighted by discourse analysis. Language is understood within discourse analysis in terms of its functions, and the ways in which it is constructed, that is, rather than reflecting or representing reality, reality is created by language (Georgaca & Avdi, 2012). The constructive aspect of language assumes that objects of study, such as the DSM-5, are

constructed by the text used to describe them. The findings from this chapter can be interpreted in this way to understand how the text of the diagnostic criteria contained within the chapters of the DSM-5 constructs the diagnoses, and beyond the categories themselves, how mental distress is constructed and conceptualised by the text (Georgaca & Avdi, 2012).

A consequence of the inconsistent use of comparators is in what is constructed by their presence and absence. A divide is created between those experiences (such as mood) that are seen as problematic only at a particular threshold, and those experiences whose presence alone is indicative of disorder. By not comparing a person's experiences, such as hallucinations, delusions, or dissociation, with any previous occurrences of such experiences, these experiences are set up as inherently disordered or pathological for both the clinician and the individual being assessed. Furthermore, the diagnostic criteria for PTSD and acute stress disorder require a change in thoughts, behaviours and emotions following trauma. The criteria are also explicit about the severity of trauma experienced, after which it would be expected that most people would experience distress. However, there are no comparators to identify what a 'normal' or 'appropriate' response to such a severe stressor would entail. That is, the criteria do not provide information about how to identify at what point someone has a 'disordered' response as opposed to one that is 'normal'. In the case of the criteria for panic disorder, behaviour change related to panic attacks is constructed as unusual or unacceptable by the 'maladaptive' criteria, despite this behaviour (such as "behaviors designed to avoid having panic attacks", p. 208) arguably representing attempts to cope with the experience of panic attacks.

3.6.1.1 Power and the impact on the individual

Crowe (2000) argues that the DSM constructs normality via societal assumptions based on values such as productivity and rationality, suggesting ways in which experiences such as hallucinations come to be unquestioned as disordered. In her seminal paper, "K is mentally ill", Smith (1978) analyses the discourse of a person who constructs a 'factual account' defining her friend as mentally ill. Smith describes the "complex conceptual work" (p. 26) required to construct this account, and the heterogeneity seen across diagnostic categories in the DSM-5 reflect these complexities. These variations hinge on the figure-ground effect (Smith, 1978) of the underpinning concept of disorder. For those experiences seen as inherently pathological, such as hallucinations, Smith's argument is applicable; "[t]he rules do not have to be further elaborated presumably because they may be taken to be known at large. Unlike other features they are 'obvious' without having to be declared as 'obvious'" (Smith, 1978, p. 47). The rules or comparators of inherently pathological symptoms do not have to be elaborated because they are socially accepted as deviant or otherwise not fitting with typical standards of behaviour, ways of being. The clinician is told in the reading of the diagnostic category that these types of behaviours or emotions are abnormal, owing to both

the language of the diagnostic criteria and the socio-political positioning of the DSM-5 as a manual for diagnosing mental disorders. Where the DSM-5 views certain experiences such as voice hearing as inherently pathological, and do not require the perspective of the individual and their experience, the clinician is placed in a position of power.

Clinical implications of this type of discourse may include a focus on symptom reduction, on reducing those experiences seen as inherently disordered, such as voice hearing, rather than on removing only the distress associated with the experiences. In addition, labelling distress as abnormal may in itself create further distress. For example, flashbacks in the context of trauma are distressing in themselves, but the diagnosis potentially makes the experience more distressing because they are seen as abnormal.

Although the diagnostic classification is a technological document or tool (Bowker & Star, 1999), the DSM-5 nevertheless places emphasis on being “first and foremost a useful guide to clinical practice” (APA, 2013a, p. xli). This function is highlighted in the pragmatic nature of several of the diagnostic criteria. For example, the ‘other specified’ or ‘unspecified’ categories at the end of each chapter are included as categories to be used where a diagnosis must be assigned in order access treatment or release insurance funding in the interest of the service user, in spite of an unclear presentation; the unspecified diagnosis criteria in the DSM-5 suggest it may be used where insufficient information is provided, such as “in emergency room settings” (APA, 2013, p. 122). These distinct, codable disorders have clinical and administrative utility, however they are for the individual diagnosed potentially life changing as a result of stigma and impact on the person’s identity (e.g. Hayne, 2003; Pitt et al., 2009; and this issue is explored further in Chapter 7). Although these categories are pragmatic tools used to meet administrative requirements or gain access to treatment, these diagnoses nevertheless use psychiatric discourse to place the individual who is given the diagnosis in a pathological subject position (Georgaca and Avdi, 2012).

Similarly, where the individual is not immediately distressed by their behaviour or experiences (for example in the case of delusions or ‘excessive’ spending), flexible diagnostic criteria still allow a clinician to identify these behaviours as problematic even without the individual’s agreement. These criteria are in one sense pragmatic; the clinician is enabled to take steps to limit the risk of the individual to themselves or others around them. However, the authority constructed within this discourse nevertheless renders service users powerless to contribute or negotiate the diagnostic label assigned to them when clinicians can make judgements about behaviours and whether these are seen as normal or abnormal. The technological discourse of the DSM-5 allows the clinician to disregard the meaning the individual ascribes to their experiences. In this situation, it can be questioned who decides that the ‘symptoms’ are present, and what happens if there is a disagreement, for example between the service user and a psychiatrist.

3.6.2 Threats to the model of discrete disorders

3.6.2.1 *Symptom overlap*

As noted in Section 3.5.2.1, the DSM-5 acknowledges that experiences do not always fit within the boundaries of a specific disorder; its rules are therefore internally inconsistent. The manual presents a classification of discrete, homogeneous disorders, yet acknowledges that this structure cannot always be followed due to the overlap between diagnostic categories. For example, the specifiers described in Section 3.5.2.1, used across diagnostic categories, such as “with anxious distress”, and the episodes that make up mood disorder categories represent heterogeneity and enable more specific labelling of presentations that is not otherwise possible with the basic diagnostic categories, to develop clinical utility and possibilities for formal record-keeping. Such specifiers allow the possibility of categorising extraneous symptoms that do not fit neatly within a diagnosis. As a result, the diagnoses’ inherent heterogeneity is effectively increased, while retaining an appearance of homogeneity through the use of a single diagnostic label. However, these over-arching specifiers struggle to fit within a model of discrete disorders. The function of incorporating heterogeneity, therefore, has a consequence of deteriorating the underpinning model. This structure highlights the non-Linnean nature of such diagnostic categories, as well as the oddities of relationships between non-exclusive, but non-hierarchical phenomena within diagnostic groupings.

3.6.2.2 *Pragmatism*

The specifiers described above provide an example of pragmatism in DSM-5 criteria, which was also demonstrated in other ways across diagnostic categories, such as the allowance for distress to be judged as distressing or disruptive for others despite not necessarily being distressing for the individual being assessed (described in sections 3.5.1.3, identifiers of severity, and 3.5.1.4, perspective). These pragmatic decisions introduce flexibility and therefore utility for the clinician, but they may also have consequences for the individual diagnosed (as discussed in Section 3.6.1.1), and for the diagnostic model itself. For example, information can be gathered from different perspectives, from a range of sources, to assess whether or not the diagnostic criteria are met, as discussed in Section 3.5.1.4. Likewise, in each of the chapters the ‘other specified’ or ‘unspecified’ categories offer flexibility for difficulties that “do not meet the full criteria for any of the disorders in the schizophrenia spectrum and other psychotic disorders diagnostic class” (p. 122, for both ‘other specified’ and ‘unspecified’ diagnoses). Criteria for these diagnoses are minimal, and therefore largely open to clinical subjectivity. What is introduced in these pragmatic criteria is heterogeneity; the same diagnostic criteria may be applied in different ways by the clinician

to suit individual situations and presentations. Whilst practical, this detracts from the DSM-5's presentation of diagnoses as rigorously and consistently applied criteria that represent stable, homogeneous disorders.

3.6.3 Implications for understanding cause

The findings demonstrate three ways in which DSM-5 diagnostic criteria have implications for how the cause of distress is conceptualised. The following sections discuss the role of trauma in diagnostic categories other than those within the trauma- and stressor-related disorders chapter, the ways in which a model of discrete disorders limits understandings of transdiagnostic causes, and, conversely, the ways in which diagnoses may obscure specific causal pathways within categories.

3.6.3.1 *The role of trauma*

The diagnostic model, which presents experiences as symptomatic of and caused by the disorder or diagnosis itself, results in limited consideration of the cause of an individual's difficulties. By making reference to trauma or stressors only in one dedicated chapter, the DSM-5 implies that the diagnostic categories in the other chapters are unrelated to trauma. The consideration of social, psychological, or other adversities in relation to other diagnoses is minimised. Returning to her account of the construction of K's mental illness, Smith (1978) describes this as "cutting out" (p. 47) an account of mental illness so as to construct behaviours and experiences as disordered. Smith argues that, "[c]utting out' is done by constructing relationships between rules or definitions of situations and descriptions of K's behaviour such that the former do not properly provide for the latter. The behaviour is then exhibited as anomalous" (p. 47). Smith's analysis can be applied to diagnoses within the DSM-5; symptoms are constructed as anomalous or disordered, rather than potentially understandable in relation to a person's life experiences. The DSM constructs a situation whereby the definition of a 'normal' response to trauma is that a person should respond in a particular way. When a person does not respond in this way, and has other experiences such as dissociation or flashbacks, the rule or definition of the response to trauma cannot account for these other experiences, therefore the behaviour is construed by the DSM as anomalous, i.e. disordered. Even within the trauma- and stressor-related disorders chapter, the experiences assessed, despite being specifically linked with trauma, are seen as symptomatic of a disordered or inappropriate response to that trauma. The reverse of the implications of singling out one trauma-related chapter is acknowledged by Spitzer and First (2005), who have been instrumental in the development of the DSM. In their response to a suggestion that diagnostic categories be clustered according to cause, they stated:

Most problematic is the characterization of the first cluster as patients with "brain

disease.” Psychiatry has abandoned the reductionist “organic” vs “functional” distinction and now regards all mental disorders as disorders of brain function. It would be a big leap backward to delineate a subgroup of DSM disorders as involving “brain disease” with the implication that in other mental disorders brain functioning is unimpaired. (Spitzer & First, 2005, p. 1898)

By the same logic the same can be said of the role of trauma; for the majority of the DSM-5 diagnostic categories, the criteria suggest to clinicians that these difficulties are caused by the disorder (and implicitly that these disorders are associated with brain function), and may therefore limit exploration further than identification of the disorder. However, just as Wakefield (2013) describes how stressors other than grief might also be reasonably and expectably related to experiences of low mood and depression, accumulating evidence demonstrates that trauma or adversity is involved in the development of many conditions and symptoms including psychotic experiences. Growing and persistent evidence to the contrary to this assumption of a separation between trauma-related diagnostic categories and other diagnostic categories is outlined in Sections 1.3.2.3.2.1 and 1.3.2.1.2.

3.6.3.2 *‘Transdiagnostic’ causes*

On the one hand, the DSM-5 acknowledges crossover of experiences such as those related to mood and anxiety, and the potential for “common underlying vulnerabilities” across diagnoses (see Section 3.5.2.1), but on the other, splitting experiences into diagnoses limits opportunities for understanding transdiagnostic mechanisms and causes. Frances and Widiger (2012) argue that the “DSM is a splitter’s system, with the diagnostic pie divided into many small pieces” (p. 113) in order to meet a need for reliability, gained through the creation of “clearly demarcated homogeneous constructs” (p. 113). The authors argue that each category represents a description rather than a distinct disease, and that “multiple diagnoses are better conceived as modular building blocks, each of which adds precision and information” (p. 113). However, aside from the ways in which separate diagnostic categories are perceived and used (explored further in Chapters 4, 5, and 7, regarding the practices of diagnosis), these separated categories are also problematic from a theoretical standpoint. In the drive to create unique diagnostic entities by separating collections of experiences from each other, potentially important similarities in the experiences, or even processes, that exist across diagnoses may be lost. An example of this may include similar causal mechanisms for voice-hearing by individuals diagnosed with either bipolar disorder or schizophrenia (e.g. Hammersley et al., 2003).

3.6.3.3 *Specific causal pathways obscured by diagnostic categories*

At the same time as limiting research into common causes that do not respect diagnostic

boundaries, by obscuring heterogeneity in the experiences described within a single diagnosis, psychiatric diagnoses arguably obscure causal heterogeneity or other key differences between individuals (Olbert et al., 2014). Evidence already suggests that there may be distinct pathways in the development of specific experiences identified within the diagnostic criteria of schizophrenia, for example strong associations between childhood sexual abuse and hallucinations, compared with childhood neglect or institutionalisation and paranoia (Bentall et al., 2014).

3.7 Conclusions

This chapter analysed the text of the diagnostic criteria from five chapters of the DSM-5 to explore the diagnostic criteria as a protocol for practice, analysing the ways heterogeneity is represented across diagnostic criteria, and what is produced as a result. The findings demonstrate that heterogeneity can be found across diagnostic criteria. Differences in the way that symptoms are presented in the DSM-5 construct disorder or inherently pathological experiences of distress. Pragmatic criteria offer flexibility for the clinician but consequently tend to shift power to the professional. Some of the heterogeneity is a consequence of this flexibility, which demonstrates the multiple contexts and applications of psychiatric diagnosis. However, alongside the symptom overlap across diagnostic criteria, these findings undermine the notion that the DSM-5 is a list of mental disorders, and instead supports the concept of psychiatric classification as a human system attempting to respond to distress and non-conforming behaviour. The model of discrete categories of disorder also has implications for the way that cause is conceptualised; trauma is seen as involved in only a limited number of diagnoses, discrete categories may lead to common 'transdiagnostic' causes being missed, and individual differences within diagnostic categories may be obscured. These findings contextualise the following chapters, which explore the practices of diagnostic classification when it is taken up by stakeholders including clinicians, services, and people who are given psychiatric diagnoses.

4 Chapter 4: The functions of diagnosis for clinicians within the context of individual clinical assessment

4.1 Abstract

Detailed diagnostic criteria emphasise rigorous application in clinical practice. Yet, the psychiatric literature advises clinicians to understand diagnostic categories as works in progress, concepts or tools with clinical utility. This chapter uses data from interviews with thirteen psychiatrists, ten GPs, and eleven clinical psychologists (a total of thirty four clinicians) to explore the ways in which diagnosis is used and made sense of in clinical practice, at the level of the clinician carrying out individual assessments. The findings demonstrate that diagnostic categories are used as heuristics that guide clinical functions such as pattern recognition, intervention planning, and communication. However, these heuristics are fallible, and limitations are seen within each of these functions. Local flexibility in diagnostic practices is seen across services and clinical disciplines owing to the pragmatic, and therefore often idiosyncratic, uses of diagnosis. The findings showed that individualised information beyond diagnostic criteria is also a central part of clinical assessment. Taken-for-granted understandings of diagnosis and its epistemology are explored, and these are seen to differ across clinicians. Implications for both clinical practice and wider data capture are discussed.

4.2 Introduction

The functions and limitations of psychiatric diagnosis, outlined in Chapter 1, apply generally to the 'ideal' use of psychiatric diagnosis, as diagnostic classification is intended to be used. Similarly, the examination of DSM-5 categories in Chapter 3 represents diagnostic categories as a protocol for use. This chapter explores the ways in which diagnosis is used and made sense of in clinical practice, within the context of the individual clinical assessment.

Psychiatric diagnoses are often framed as discrete, biologically based illnesses, despite the evidence for this supposition being lacking. As Kupfer, the chair of the DSM-5 taskforce stated; "We've been telling patients for several decades that we are waiting for biomarkers. We're still waiting" (APA, 2013). In spite of this disease framing, clinicians, it is argued, should use diagnoses with an awareness of the history of their development and limitations; "[n]o sensible mental health professional thinks such systems are anywhere near perfect or complete; they are interim summaries with practical aims awaiting clarification" (Callard et al., 2013, p. 2). Diagnoses are frequently discussed in psychiatric literature as a practical tool with utility for clinicians, with proponents arguing, "[t]houghtful clinicians have long been

aware that diagnostic categories are simply concepts, justified only by whether they provide a useful framework for organizing and explaining the complexity of clinical experience in order to derive inferences about outcome and to guide decisions about treatment” (Kendell & Jablensky, 2003, p. 5). Frances and Widiger (2012, p. 113) assert, “[m]ental disorders are no more than useful constructs”. These statements seem to confirm, as Kendell and Jablensky (2003, p. 7) argue, that there appears to be “...a growing assumption, *at least within the research community* [emphasis added], that most currently recognized psychiatric disorders are not disease entities”. However, these statements are in contrast with other public conceptualisations, comparing categories of mental distress with physical illnesses. For example, the website for the Australian government’s Department of Health states, “mental illnesses... are illnesses just like any other, such as heart disease, diabetes, and asthma” (Australian Government Department of Health, 2007).

Some flexibility in making diagnoses is assumed by diagnostic manuals, and the literature encourages clinicians to use their clinical judgement alongside clinical utility of diagnostic categories with an awareness of their construction. However, in spite of this, an emphasis is nevertheless placed on meeting the full diagnostic criteria in order to make a “confident” diagnosis (WHO, 1992). Systematic checking of diagnostic criteria, it is asserted, “will assure a more reliable assessment” (APA, 2013, p. 19). The DSM-5 itself states that its diagnostic criteria “are intended to summarize characteristic syndromes of signs and symptoms that point to an underlying disorder...” (APA, 2013, p. 19).

In practice, Moncrieff (2010) argues that diagnostic labels embody an assumption that service users’ behaviours and experiences are symptomatic of an underlying biological disease. Yet at the same time, she argues, these labels mask the complex decision-making and judgements that precede the affixing of a diagnosis to a health record. Beyond the officially endorsed use of diagnosis as a useful tool or concept, in practice, Bowker and Star (1999) described ways in which people ‘subvert’ formal structures of ICD-10 classification with ‘informal work-arounds’ (p.54). Both Whooley (2010) and Rafalovich (2005) describe the ambivalence that practising clinicians feel towards psychiatric diagnostic categories. In his interviews with psychiatrists in the US, Whooley found further evidence of explicit work-arounds in clinical practice, including fudging the diagnostic codes on official paperwork and using alternative typologies (Whooley, 2010). Rafalovich argues that attention deficit hyperactivity disorder (ADHD) diagnoses “are not automatic, mechanical phenomena, but rather, are preceded by processes of negotiation and interpretation” (Rafalovich, 2005, p. 318), and that diagnostic protocols are not perfectly applied in clinical practice.

4.2.1 Rationale: Clinical diagnostic practices

As Blaxter (1978) argues, diagnosis is both a category and a process. The process of diagnosis, and its implications, has been given limited attention in psychiatric literature. Three central clinical groups are both qualified to make and use psychiatric diagnoses and come into contact with psychiatric diagnoses in their day-to-day clinical practice; psychiatrists, clinical psychologists, and GPs. Psychiatrists and clinical psychologists were included in the study as they represent two of the key literatures outlined in Chapter 1; psychiatrists as the predominantly diagnosing group of professionals within mental health care, and psychologists, who are professionally in a position to utilise diagnosis to perform functions such as communication and research, yet also typically use psychological formulation as a means of assessment and intervention planning, thus providing an alternative perspective (British Psychological Society, 2013b). GPs were included as a group of clinicians who represent often people's first contact with health services regarding their mental distress, and GPs act as a gatekeeper for most specialist mental health services as a formal referral from primary care is required (NHS Choices, 2016). Their views and practices of psychiatric diagnosis were therefore seen as important to the central research purpose.

4.3 Aims

Within the context of the overall research purpose of examining the functions of psychiatric diagnosis from multiple perspectives, this chapter addresses the first and second theoretical questions outlined in Chapter 2 (Section 2.4.2); 1) what are the conceptual underpinnings of diagnostic categories, and are these consistent across contexts and practices? And 2) how are psychiatric diagnostic categories used in practice?

The purpose of this chapter was to explore the ways in which clinicians use and encounter psychiatric diagnosis in the individual clinical context, both in terms of its explicit functions, and more implicit concepts for which diagnosis acts as a proxy. In light of the previous chapter exploring diagnostic classification as a protocol for use, this chapter sought to examine diagnosis in practice, and how protocol and practice compare.

4.4 Methodology

As part of data collection for the overall thesis, semi-structured qualitative interviews were carried out with GPs, psychiatrists, clinical psychologists, and a group of mental health service users who had been given a psychiatric diagnosis (or diagnoses). The following methodology section describes the overall research methodology for the data collection with each of these participant groups, and goes on to describe specific information about the clinicians who were interviewed.

Details of service user participants and methodology specific to interviews with service users can be found in the methodology section of Chapter 7 (Section 7.4).

The data from interviews with clinicians and service users were analysed as one dataset, so that links between the data would not be lost. This methodology section therefore outlines the methods of analysis (Section 4.4.5) that were applied across the whole dataset. Some reference is therefore made to interviews with service users, as this is relevant to the analysis as a whole.

The findings from interviews with clinicians are presented in this chapter, Chapter 6, and the data contribute to Chapter 7. The findings of the interviews with service users can be found in Chapter 7. Further details about the presentation of the findings of the interviews across the thesis can be found in Section 4.4.5.8, below (Presentation of interview analysis findings).

4.4.1 Design: Using qualitative interviews as a source of data

Semi-structured interviews were chosen as an appropriate method of collecting data with which to answer the theoretical questions outlined in Chapter 2 (Section 2.4.2). Reflecting the overarching epistemological position of thesis (Section 2.3), this approach aims to access how the ways that people talk about diagnosis construct the ways that they are used. By talking about the ways that they use diagnosis, people are not showing how they use diagnosis in practice but instead offering a window into the ways that language and discourse used about diagnosis shapes their conceptualisation, and the implications of this. Bringing together these accounts is to describe the commonalities in the ways that people articulate their relations with the world, shared sense-making processes that are presented by individuals as describing or explaining mental health and diagnosis. These processes are not seen as 'real' in the sense that they are not mirrors of nature or even an attempt to get close to how things 'really are' in the world, but as an approximation of the common elements of shared discourses; the explanations and descriptions that people take up and use when articulating their relation with personal and societal representations of mental health.

Rather than a phenomenological approach, which seeks to represent individuals' perspectives through their feelings and thoughts (Harper, 2012), in conducting interviews with different stakeholders (clinicians, service users), individuals' accounts are seen as serving a variety of functions, both interpersonal and social or cultural (Harper, 2012). I am interested in understanding how people represent, talk about, and make sense of psychiatric diagnosis and experiences of mental health, holding an assumption that people's language

shapes and makes possible these concepts (Burr, 2003) when contextualised within wider social, political, and other environments. Social constructionist understandings of diagnosis view the act of diagnosing an individual as a transformation of a person's distress into the model of disorder, which is then used as an explanation. Georgaca (2013) argues that studying the process of diagnosis, therefore, is a valuable way of understanding how this transformation of distress is achieved. By interviewing clinicians and service users, this methodology allowed the study of both process of diagnosis (and other assessments of distress) and its implications for the individuals who are diagnosed.

4.4.2 Ethics

4.4.2.1 *Ethical approval*

The University of Liverpool Research Support Office sponsored the study carrying out semi-structured interviews with NHS clinicians and service users (see Appendix 1; Sponsorship approval confirmation letter). The study underwent full ethical review by the NHS National Research Ethics Service (NRES) Committee North West - Greater Manchester East, and was granted ethical approval (see Appendix 2; Confirmation of favourable ethical opinion). Individual NHS trust approval was given by the two individual trusts from which participants were recruited (Trust 1 and Trust 2).

4.4.2.2 *Anonymity and confidentiality*

All the interview data gathered during this research was anonymised. Each participant and their interview data were assigned an identifying number, and their names removed. Clinicians were identified according to their profession, for example, 'Psychiatrist 1'.

Audio recordings of the interviews were transcribed for the purposes of analysis (see Section 4.4.5.1, Data preparation, below). A portion of the interviews was transcribed by a freelance worker within the University of Liverpool. The audio files were transferred to the freelancer directly using a password-protected USB data stick. Audio files were labelled using only the participant ID number. A confidentiality agreement was signed by the freelancer confirming that no information about the data would be disclosed to third parties (Appendix 3).

Following transcription, any reference in interviews to identifying information, such as names, places, NHS trusts or services, were removed and replaced with a brief description, for example '[NHS Trust]'. Some participants gave examples of their own experiences or, in the case of clinicians, information about clients or the services in which they worked, that provided information for context for my understanding, but which they did not wish to appear in the transcript of the interview. In these instances, sections of the transcript were redacted

prior to analysis, and in one case, a copy of the redacted transcript was sent to a clinician to ensure that they were happy with the anonymisation.

4.4.2.3 *Data storage*

Electronic audio recordings of interviews were stored using anonymised participant ID numbers. Interview transcripts were anonymised, password-protected, and stored using anonymised participant ID numbers. All electronic files were stored on a password-protected computer and will be destroyed at the end of the study, as stated on the participant information sheets. Participants' personal information, such as contact details, will also be destroyed at the end of the study. Signed, hard copies of participant consent forms were stored in a locked filing cabinet in the Institute of Psychology, Health and Society, University of Liverpool, throughout the study, and at the end of the study will be transferred to university archiving for a minimum of five years. Any potentially identifiable information will be removed from interview transcripts and the transcripts will be stored anonymously and confidentially in the university archive for the same period of time.

4.4.3 Participants

4.4.3.1 *Sampling*

Purposive, or criterion based, sampling (LeCompte, Preissle, & Tesch, 1993; Mason, 2002; Patton, 1988) was used in the recruitment of participants for this research. This method of sampling selects participants with particular characteristics that are of relevance to the research and furthermore will allow the gathering of detailed data that can offer a rich understanding of the theory questions designed as part of the overall research approach. GPs work within private practices, therefore were selected by region. Psychiatrists and psychologists were invited from a wide range of service types, from primary care to tertiary services, mild and moderate to complex presentations, and from open to secure services. These variations were chosen purposively in order to gain a wide understanding of the ways that diagnosis is used across clinical groups and services.

4.4.3.2 *Inclusion criteria*

Currently practising psychiatrists, GPs and clinical psychologists were invited to take part in the study. These three groups of clinicians were interviewed in order to gather data from a range of perspectives from individuals with that were thought to have different views and uses of psychiatric diagnosis.

4.4.3.3 *Recruitment*

It was expected that there would be some overlap between professional groups of the clinical participants, as a result of training and NHS working practices. There would also likely be differences in the ways that the different clinician groups used and encountered diagnoses in their practice, for example, owing to the differences in their positions in the care pathway and across service types. Therefore, a separate sample of participants was sought for each professional clinical group (Green & Thorogood, 2014).

Psychiatrists and psychologists were invited from a range of mental health services in order to gather a range of perspectives to compare and contrast how diagnoses might be used in different ways across service types. Different services and settings from which clinicians were invited included primary, secondary, and tertiary care, therefore representing a range of out-patient and in-patient care, general adult and specialist services, and a range of severity and risk in the client populations with which those services worked. Invitations to take part in the study included a brief summary email, recruitment information, and the participant information sheet for clinicians (Appendix 5).

For Trust 1, the majority of clinicians were contacted directly and invited to take part in the study. The advice of the Local Clinical Research Network for the NHS National Institute for Health Research was sought regarding recruitment, and the network assisted with sending out study information to the trust psychiatrists. One of the lead psychologists for the trust sent out the information to all the psychologists in the trust. For Trust 2, an invitation to take part in the study was sent out to psychiatrists and clinical psychologists by the trust research office.

A list of the local GP surgeries was compiled and each surgery was contacted and invited to disseminate study information to their doctors. I was also invited to attend a GP conference to speak to individual attendees to give them the study information. Recruitment of GPs was difficult; feedback was received from some interviewees about the limited time that GPs have available in their working day. In order to reflect this, the length of the interviews was cut to 30-40 minutes (reduced from one hour). The same interview questions were asked, however there was less follow up discussion. Academic GPs within the University of Liverpool were also approached and invited to take part; three of the GP sample of ten worked at the university as well as practising as GPs. The limitations of these steps taken to increase recruitment are twofold. First, due to the shortened length of some GP interviews, the data gathered is inevitably less rich. Second, the academic GPs worked in mental health as part of their roles of the university, thus introducing some bias to the data.

Clinicians who were interested in taking part in the research interview contacted me directly and an interview date was arranged. All of the clinician interviews took place at the clinicians' places of work, with the exception of two clinicians, who chose to come to the University of Liverpool for ease, for example, due to working in a secure service where visitor access was difficult.

4.4.3.4 Demographic information

In order to preserve participant anonymity, the clinicians' demographic information is divided into separate tables. Tables 4-1 to 4-3 give the participants' age, gender, and ethnicity. Ethnicity was self-identified. Where the clinician preferred not to identify with a particular ethnicity, the field is left blank.

Table 4-1

GP demographic information

Participant ID	Age	Gender	Ethnicity
GP 1	51	F	White British
GP 2	54	M	White British
GP 3	59	M	-
GP 4	63	M	White Irish
GP 5	57	M	White European
GP 6	42	M	British Pakistani
GP 7	34	F	Indian
GP 8	37	F	Mixed white Asian
GP 9	53	F	-
GP 10	46	M	Asian British

Table 4-2

Psychiatrist demographic information

Participant ID	Age	Gender	Ethnicity
Psychiatrist 1	51	F	White British
Psychiatrist 2	52	M	Indian
Psychiatrist 3	42	F	Asian Indian
Psychiatrist 4	50	M	Asian Pakistani

Psychiatrist 5	39	M	White British
Psychiatrist 6	43	F	White British
Psychiatrist 7	39	F	White British
Psychiatrist 8	43	M	Indian
Psychiatrist 9	39	M	White British
Psychiatrist 10	39	M	White non-British
Psychiatrist 11	59	M	White British
Psychiatrist 12	51	F	White British
Psychiatrist 13	40	M	British Indian

Table 4-3

Clinical psychologist demographic information

Participant ID	Age	Gender	Ethnicity
Psychologist 1	41	F	White British
Psychologist 2	55	M	White British
Psychologist 3	50	F	White British
Psychologist 4	52	F	White British
Psychologist 5	54	F	White British
Psychologist 6	39	F	White British
Psychologist 7	36	F	White British
Psychologist 8	28	M	White British
Psychologist 9	31	F	White British
Psychologist 10	34	F	White British
Psychologist 11	43	F	White British

Table 4-4, below, gives the areas of specialty of the psychiatrists and clinical psychologists interviewed, and the numbers of clinicians working in those areas. All of the GPs worked in private GP practices. Both psychiatrists and clinical psychologists are represented within the table in order to protect participant anonymity. The frequency total numbers more than the total number of clinicians due to split-post working across more than one speciality. In calculating frequencies, the area of specialty was prioritised over the age of the client group; for example, hypothetically, a clinician working in an older adults learning disabilities service would be counted under learning disabilities only.

Table 4-4

Area of speciality within with psychiatrists and psychologists worked, ordered by descending frequency

Area of Specialty	Frequency
Early intervention in psychosis (EIP)	5
Secure / forensic	5
Prison / probation	3
Community mental health team (CMHT)	3
Older adults	2
Eating disorders	2
Child & adolescent mental health services (CAMHS)	2
Improving access to psychological therapies (IAPT)	1
Learning disabilities	1
Acute inpatient	1

4.4.4 Procedure

4.4.4.1 *Consideration of ethical issues*

On arrival, all participants were given a verbal introduction to the interview, which included an overview of the participant information sheet (Appendices 5 and 6 for clinicians and service users respectively), participant consent form (Appendices 7 and 8 for clinicians and service users respectively), and a reminder that the interview would be audio-recorded for the purposes of transcription for analysis, to ensure that participants were happy with this arrangement. Participants were also given a brief description of the types of questions that would be asked during the interview.

Participants were then given another copy of the participant information sheet, which had previously been given to each individual prior to the interview meeting. Participants were then asked to read through the information sheet and consent form. Care was taken to ensure that participants understood the process of the interview, what would be involved, and how their data would be used. It was made clear to participants that they did not have to answer any question if they chose not to, and that they need not disclose more than they felt comfortable with. Participants were reassured that their data would be anonymised and their responses kept confidential. All participants were informed that they could request a copy of the interview transcript if they wished.

Following this introduction to the interview, participants were asked if they had any questions about any stage of the process. Participants were then asked to read the consent form, and, if they agreed to the statements, to initial the box for each statement of the consent form and sign and date the form, which I then signed and dated.

4.4.4.2 *The interview*

Interview questions were developed to direct participants' responses towards the theory questions of the research in order to provide appropriate material for analysis. The questions were adapted differently for service users and clinicians, reflecting the differences in the use of diagnosis as a clinical tool for clinicians, compared with lay uses. However, a common thread was a focus on examples of participants' diagnostic practices, both clinical and personal, in order to provide rich data that went beyond participants' opinions. Service users were all asked the same set of questions. Two slightly differing sets of questions were developed for clinicians; one set for those who reported using psychiatric diagnosis as part of their clinical practice, and another set for those who did not. Clinicians were asked an initial question ("Do you make psychiatric diagnoses as part of your clinical practice?"), the answer to which determined which of set of questions was asked. The interview questions can be found in Appendix 4.

Once written consent was given to participate in the study, it was ensured that participants were ready to begin the interview, and the digital audio recorder was started. The interviews took a semi-structured approach (Wengraf, 2001), in which the interview guide consisted of several key questions, which were asked in every interview, and throughout the interview follow up and clarifying questions were asked as appropriate to elicit further information. The interview questions can be found in Appendix 4 alongside some brief demographic questions, which were asked at the end of the interview.

After all the interview questions from the schedule had been asked, participants were asked if they would like to say anything more about the topics discussed, and they were given the opportunity to bring up any other experiences or thoughts that they felt were relevant to the study, or if they had any questions that they wanted to ask me. When both the participant and I agreed that we had finished the discussion, the interview was ended and the audio recorded stopped.

The mean interview length for psychologists was 60 minutes (ranging from 44-86 minutes), and psychiatrists, 51 minutes (ranging from 33 to 62 minutes).

The mean interview length for GPs was 47 minutes (ranging from 27 to 65 minutes, reflecting the shortened interview time due to recruitment difficulties, discussed in Section 4.4.3.3, Recruitment).

4.4.4.3 *Debrief*

Following the interview, participants were thanked for their time. A verbal 'debrief' was given to each participant, explaining again the purposes of the study of understanding the functions of diagnosis and the ways that different individuals use it, in order to inform the development of different ways of conceptualising and assessing mental health.

4.4.5 Methods of analysis

As outlined above at the start of Section 4.4, the data from interviews with clinicians and service users were analysed as one dataset, so that links between the data would not be lost. This section therefore outlines the methods of analysis that were applied across the whole dataset. Some reference is therefore made to interviews with service users, as this is relevant to the analysis as a whole.

4.4.5.1 *Achieving data saturation or theoretical sufficiency*

The aim of qualitative research is not to gather data that is representative of the population of study (Green & Thorogood, 2014), but to gather "information-rich cases for in-depth study" (Patton, 1990, p. 182, as cited in Green & Thorogood, 2014, p. 121). Data was collected until it was considered that the data had reached 'saturation'. Data saturation involves collecting data until an increasing sample size no longer offers new information (Green & Thorogood, 2014). Charmaz (2012), a proponent of grounded theory, has described this process as theoretical saturation, whereby no new insights emerge in the theoretical categories of the data, and the categories are robustly supported. The practicality, and therefore attainability, of theoretical saturation, however, has been questioned (Dey, 2007). Dey (1999) argues that the idea of theoretical saturation relies on the researcher's conjecture that categories are saturated; whereas he argues that the theoretical categories are *suggested* by the data. Dey's preferred term is 'theoretical sufficiency' (Dey, 1999, p. 257) instead of claiming data saturation. This notion refers to data adequacy (Charmaz, 2006). Data collection for this research, therefore, was ceased when no new theoretical insights were gained from the interviews, and in light of the concept of theoretical sufficiency, when thoroughness of data had been achieved.

4.4.5.2 *Thematic analysis*

Thematic analysis (Braun & Clarke, 2006) was used to analyse the interview data. This method is used to identify and analyse patterns or themes in the data, and to give a map or outline of these themes across the interview dataset (Braun & Clarke, 2006; Green & Thorogood, 2014). The thematic analysis used in this thesis was underpinned by the critical realist social constructionist epistemology described in Chapter 2 (Section 2.3). This type of analysis was chosen as the most appropriate method in respect of the interview data, and the theoretical questions asked by the research design (outlined in Chapter 2, Section 2.4.2). The central research question for this thesis asks what are the functions of psychiatric diagnosis from multiple perspectives. The theory questions for the thesis relate to the conceptual underpinnings of psychiatric diagnosis, how diagnostic categories are used in practice, and what are the products and implications of their use. In exploring themes or patterns of meaning within the data, thematic analysis allows for these multiple functions and uses to be explored and compared across perspectives. Reflecting the different stances of the theoretical questions, which relate to both practical and conceptual uses of psychiatric diagnosis, thematic analysis allows the researcher to analyse both manifest and latent content in the data (Joffe, 2012). Manifest content refers to that which is observable directly from the data, for example, explicit mention by participants of diagnostic categories being viewed as biologically-caused disorders, as compared with latent content, which is implicit, for example, participants describing diagnoses in an essentialised way but without directly referring to the conceptual model that they are using to understand diagnostic categories. The concept of manifest and latent content was also taken up in exploring the different functions of diagnosis, for example, the manifest functions described, such as clinical assessment and treatment planning, and latent functions, in the sense of for what is diagnosis a proxy when clinicians say that diagnosis is used for referrals, for example. A combination of inductive and deductive analysis was used, where inductive findings are data-driven, emerging from the data itself, compared with deductive analysis, which is derived from theoretical ideas that are brought to the research (Joffe, 2012). This combination allowed the analysis to place first the themes and understandings that had emerged directly from the interview data, and contextualise and interpret this using the existing bodies of literature that were outlined in Chapter 1.

Central to the methodological approach of this research is using the four literatures outlined in Chapter 1; psychiatry, clinical psychology, service user/survivor literature, and social sciences literatures. The focus of the research is in understanding diagnostic practices from a wider perspective than the individual clinical situation. The focus of this approach is in observing and understanding why particular practices happen. Just as my understandings of mental distress are not limited to within the individual themselves, neither are my understandings of the ways that people take up diagnostic, and non-diagnostic, practices.

The analysis was grounded in the ways that people talk about the practices of diagnosis, and what they do in different clinical situations that can shed light on the uses, benefits, and limitations of diagnosis.

Contextual information was also an important part of the analysis and in understanding participants' diagnostic practices. Reflecting the epistemological stance underpinning the thematic analysis, and to ensure that clinicians' responses were understood within the wider context of their practice, it was important to understand why it is that these practices are taken up, what are the constraints imposed upon clinicians, what are the organisational and clinical contexts that produce particular ways of doing things. For example, exploring the space between diagnosis as protocol and diagnosis in practice is not about being critical of clinicians 'not doing what the manual says', but instead understanding the ways in which diagnosis may be difficult to apply in practice, for example, and the ways in which particular organisational contexts or requirements may impose particular ways of carrying out clinical practice. This contextual information therefore made up an important part of later analysis.

The interviews from the three groups of clinicians and the group of service users were deliberately coded and analysed together, and one coding framework was generated that applied across all four groups of participants. This method of analysis was chosen such that links could emerge across the participant groups in order to develop cohesive analytic findings from multiple perspectives.

4.4.5.3 *Researcher positioning*

This section outlines the ways that I used the analytical approach of this research to maintain an observational and analytical stance to the research question and to avoid a position of judgement of participants' interviews. As is described in Chapter 2 (Section 2.2, Personal and political positioning), in approaching this area and in relation to the participants I interviewed, I come from a stance akin to Schuetz's 'stranger' (Schuetz, 1944). My background experience relates to both clinical psychology and psychological assessment, however, I have neither been formally trained in this area nor received a diagnosis myself. I am therefore in a position to, as Schuetz (1944) describes, question or make visible "thinking as usual" (p.501), the common sense knowledge of participants' sense making processes and their potentially unquestioned "scheme of reference" (p.502) or taken-for-granted understandings.

4.4.5.3.1 Management of researcher position across the data analysis phase

An issue that I considered throughout the research was my positionality regarding psychiatric diagnosis and conceptualisations of mental distress. As is discussed in Section

2.2, in being aware of my own stance and opinions in this topic, I was conscious of how this might be brought into my analysis of the interview data. In order to directly address this, a log of reflections was kept throughout the analysis process in order to expand upon particularly interesting codes or reflect upon coding decisions. These reflections served to illuminate assumptions and interpretations made during coding, to ensure transparency and to recognise that coding represented an inductive reading of the data but nevertheless unavoidably involved a level of interpretation. This process of reflecting was to ensure that during later coding and further progression from descriptive to explanatory accounts of analysis, the ways in which interpretations were made were transparent, and yet accountable to the data. Reflective memo writing during the coding process also helped to highlight and reflect upon connections, parallels, and tensions within and across codes, as well as to note similarities and differences between different participant groups. The memos were used to note interpretations that were made from the data, and to question and challenge these, and to try to see the findings from different perspectives. These reflective memos contributed to the shaping and revising of the central research purpose, which was described in Chapter 2 (Section 2.4.1).

The analytic findings, reflections, and interpretations were shared and discussed with colleagues in order to explore alternative explanations and interpretations to challenge my perspectives on the data. The transcripts and the coding framework were discussed with my supervisors, and I presented sections of my transcripts at a regular data analysis group, which was a small group of PhD students in other areas of psychology and in public health, and researchers in sociology and public health. The group reviewed and compared sections of my transcripts and the group's interpretations and reflections were discussed.

4.4.5.4 Data preparation

Interviews were transcribed verbatim, although the level of detail of transcription did not include non-verbal information, owing to the type of analysis used (Green & Thorogood, 2014). As described in Section 4.4.2.2, a portion of the interviews was transcribed by a freelance worker within the University of Liverpool. The transcripts were anonymised as described in Section 4.4.2.2.

4.4.5.5 Data organisation

Data was imported into and organised using QSR International's NVivo 10 Software (NVivo, 2014). The NVivo package of computer-assisted qualitative data analysis software (CAQDAS) was used as a way of organising data. As Spencer and colleagues (Spencer, Ritchie, & O'Connor, 2003) caution, nVivo was used not as a substitute or method of performing data analysis, but as a support tool for organising and archiving data. It has been

argued that the use of CAQDAS offers greater transparency of analysis, because a record is made of how coding schemes are developed (Green & Thorogood, 2014).

4.4.5.6 Data coding

The coding of interview data involved several steps, which are described in the following sections. First, initial open coding was carried out on a sub-section of data. A coding framework was then developed by consolidating the codes generated from open coding into main themes, themes and subthemes. The consolidation of open coding into a coding framework are illustrated by Figure 4-1, below. The full dataset was then applied to the coding framework, and explanatory accounts of the data were generated.

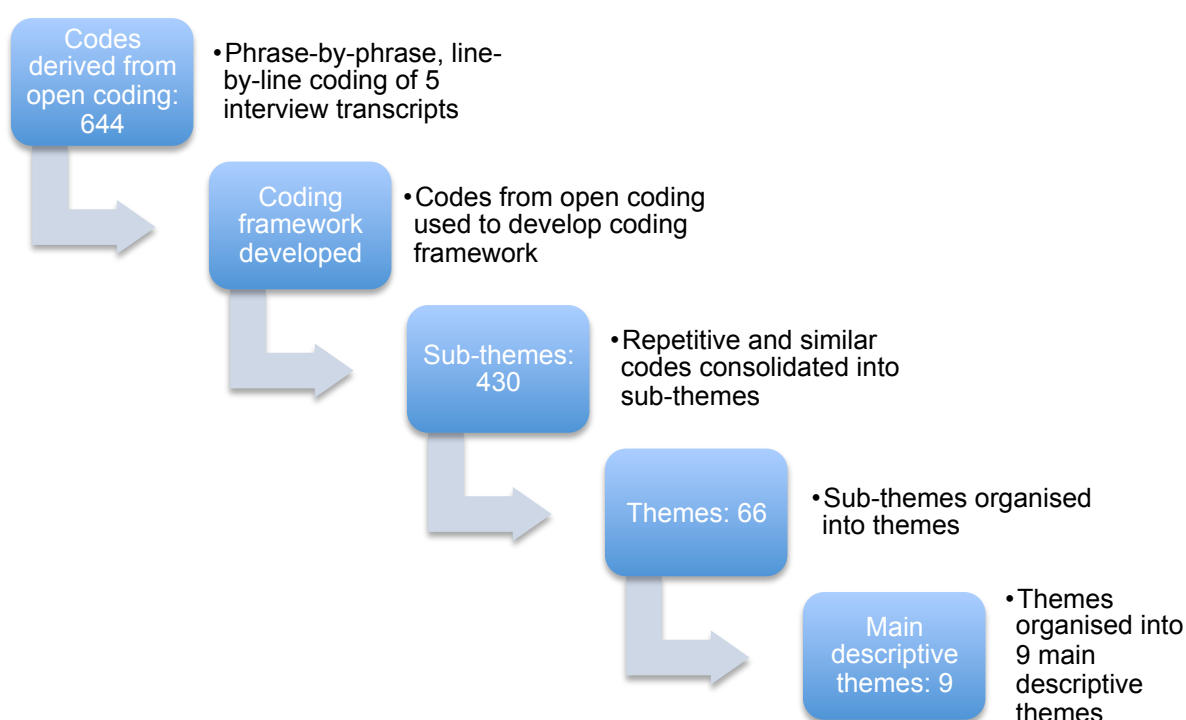


Figure 4-1: Flowchart detailing consolidation of data codes to create coding framework

4.4.5.6.1 Initial open coding

Initial open coding is a technique drawn from grounded theory (Charmaz, 2006). Initial coding ‘fractures’ the data into segments; small units of coding that are phrase-by-phrase, and line-by-line (Boyatzis, 1998). Each segment of data is assigned a new descriptive code. The aim of this detailed analysis is to avoid making “conceptual leaps” (p. 48) and applying existing theories and ideas before the necessary analytic work has been carried out. Initial open coding was used to allow new thinking to emerge from the data (Charmaz, 2006). By maintaining a close focus on the data, the analytic framework is inductive, with theory

emerging from the data. This is in contrast with a deductive approach, which uses the data to test existing theory (Lewis, 2003). An inductive approach was chosen in order to ensure that findings are grounded in the data rather than shaped by pre-conceived ideas or theory. Open coding (Green & Thorogood, 2014) was carried out on a subsection of interview data to fracture the data and open up avenues for enquiry. In particular, acknowledging my positioning as coming from within a particular set of assumptions, I wanted to give the data the opportunity to challenge these assumptions, and for alternative meanings and explanations to arise.

Drawing from Bowker & Star's (1999) methodology in their exploration of the ICD-10, this approach used participants' practice as an analysis rather than starting from a theory and applying that to the data. Charmaz's (2006) approach to open coding uses Glaser's (1978) concept of using gerunds to label codes to invoke action. The aim of this approach is to access actions, practices, and meanings rather than topics and themes. This method of coding was used to reflect the mapping of practices across the participant groups interviewed. It was decided that open coding in this manner would help focus the analysis on processes, practices, and meanings, in order to later move to explanation and theory.

Following initial reading and re-reading of the data, 'versus coding' (Saldaña, 2013, p. 115) was incorporated into the initial open coding as an additional way of exploring what was initially seen as potentially opposing uses and functions of diagnosis. This type of coding was used to explore the contradictions and conflicting ideas or tensions that participants discussed, and how these might relate to the different perspectives of individuals and the different diagnostic functions being taken up. Seeking out tensions and disagreements was used as a method of giving equal weight to the different diagnostic practices. The reasons for this were twofold: to represent different perspectives and uses across individuals, and to try and minimise confirmation bias towards my own perspective.

Due to the detailed nature of open coding, of separately coding each data segment within a line, open coding generates a large number of codes. Therefore, for reasons for manageability, a subsection of the interview dataset was open coded during the first phase of data coding (e.g. Samuels, 2010). Five transcripts were chosen for detailed open coding in order to represent subsamples of the samples used in the research as per Boyatzis' recommendations for developing data-driven codes (Boyatzis, 1998). The transcripts included in this phase were therefore chosen to reflect rich and varied data, representing a diverse range of practices, experiences, and opinions about diagnosis. One transcript from each of the three clinician groups was used; these transcripts were chosen because they were thought to be broadly representative of the practices of their clinical group. Two transcripts were open coded from the service user group. Two service user transcripts were used because unlike the clinicians' interviews, these data did not have a common thread of

professional identity or model of practice, which tended to consolidate the clinicians interviews. There was, therefore, a wider range of practices across the service user interviews. The two transcripts were chosen because they represented differing views, each at a different end of a spectrum across the service users in terms of practices that represented alignment with, or distance from, the diagnostic model of conceptualising mental distress.

644 codes were generated from the open coding phase.

4.4.5.6.2 Development of the coding framework

4.4.5.6.2.1 Generation of subthemes from the codes generated from open coding

Following the initial open coding stage, a coding framework was developed against which the full dataset of transcripts was coded. The coding framework was developed through a process of consolidating the codes generated from open coding into subthemes. A section of the list of codes (alphabetically organised by nVivo) generated from the open coding phase can be found in Appendix 10. This list was examined and organised in Microsoft Excel; codes referring to similar concepts and descriptions were grouped together and labelled as a subtheme. Codes that appeared to be unique and did not relate to any other codes were labelled as their own subtheme. An example of this organisation phase is given in Appendix 11.

This process of organisation consolidated the codes derived from open coding into 430 subthemes. These subthemes were organised under 66 themes. These 66 themes were then organised under 9 main descriptive themes used to describe and organise the data. An example of this process of organisation is given in Appendix 12, which shows the themes and subthemes under the main theme 'Uses of diagnosis and other assessments'.

4.4.5.6.2.2 Coding transcripts according to the coding framework

When the codes derived from the initial open coding were organised into a coding framework of main themes, themes, and subthemes, the full dataset of transcripts was then applied to this framework. Each interview transcript was examined line-by-line within the nVivo software. Phrases, lines, or paragraphs were assigned to one or more subthemes within the coding framework. Where there was not a suitable subtheme in the coding framework, a new subtheme was created.

Multiple iterative cycles were used to move between the coding framework and the data, reviewing the data extracts that were coded to each subtheme in the framework in order to

ensure that the themes and subthemes represented the interview data. Boyatzis (1998) refers to this process as “compare-and-contrast” (p. 42), whereby the information anchored within the coding framework from initial open coding is compared and contrasted in order to extract differences across the dataset. The coding framework was updated where necessary to reflect the data and so consolidation of themes and subthemes continued throughout the application of data to the coding framework. Where appropriate, additional subthemes were added, and subthemes with very limited data assigned to them were removed. Subthemes that contained descriptively or conceptually similar data were merged where appropriate.

The transcripts were worked through across sampling groups, rather than coding all of the psychiatrists’ interviews first, for example. The aim of this process was to ensure that the spread of data was considered at all times, particularly when updating the coding framework. A further aim of this coding approach was to focus on diagnostic practices rather than on making potentially artificial divides between participant groups. The same coding framework was applied to all the data from each of the sampling groups in order to deliberately consider the different uses and experiences of diagnosis alongside each other, as well as to explore the ways in which these uses interact across the clinician and service user groups. Constant comparative methods were used at each analytic stage (Glaser & Strauss, 1967); a constant re-reading of data and comparison of codes to data, data to codes, and codes to codes (Charmaz, 2006) to best fit the coding framework to the data. The constant comparative methods helped abstract the analysis from descriptive to explanatory accounts.

4.4.5.7 Moving to explanatory accounts of the data

Where the initial open coding and the coding framework described the processes and practices within the data, the process of coding all of the interviews according to the coding framework helped to move the analysis from descriptive to explanatory accounts of the data. Spencer and colleagues (2003, p. 213) describe this as the “analytic hierarchy” in which analysis moves from data management, to descriptive accounts, and finally to explanatory accounts consisting of increasingly refined, abstracted concepts, with which data is associated in order to create meaning. An iterative process was used throughout the consolidation of the codes from the open coding, the coding of interviews using the coding framework, and the later analysis.

Repeatedly moving between data and the analytic concepts emerging from the consolidation of the coding framework allowed further movement from descriptive to explanatory accounts of the data. Spencer and colleagues’ (2003) process of moving from data management to descriptive accounts, to explanatory accounts was used in the iterative analysis approach. Data management created initial themes, labelled data, and sorted data by themes and

subthemes. Descriptive accounts emerged through assigning the interview data to themes to convey meaning, refined categories, and distilled abstract concepts.

In order to produce explanatory accounts of the data, preliminary thematic maps (Braun & Clarke, 2006) were used to visually map out the data to examine cross-cutting themes and analytical concepts across the dataset and the coding framework, in combination with the log of reflections kept throughout the analytic process. Patterns were identified across the data, and used to develop explanations for the findings. These explanatory accounts were used to move beyond the data assigned to the coding framework to use the data to answer the theory questions outlined in Section 2.6.5, and to seek application to wider theory and policy.

Having coded the data and examined the themes across participant groups, this allowed the analysis to situate clinicians' and service users' uses of psychiatric diagnosis within the context of how the other participant groups understood diagnostic concepts. Coding and conducting analysis across participant groups enabled an examination of the relational aspect between different participant groups' conceptualisations and uses of diagnosis, and the tensions between these. To reflect these findings, a concept was developed regarding the travel of psychiatric diagnosis from clinicians to service users, and beyond into different social worlds. In order to represent this central conceptual finding, it was decided that the findings would be best presented within chapters that focused on first, clinicians, and second, service users, in order to reflect the different uses and conceptualisations of psychiatric diagnosis between these groups. A third findings chapter was included between these chapters to explicitly represent the travel of diagnosis between clinicians and services, service users, and other social worlds, through an examination of the recording of psychiatric diagnoses. The descriptive themes generated from the open coding and coding framework phases of analysis were reorganised according to these three domains in order to develop the explanatory accounts presented in each of the following chapters. Examples of the themes and subthemes reorganised within the three domains of findings – 1) clinicians, 2) the travel of psychiatric diagnosis, and 3) service users – can be found in Appendices 13, 14, and 15, respectively.

The names of themes and subthemes within these domains were refined during the write up of the findings chapters in order to produce a coherent explanatory narrative within each chapter.

4.4.5.8 Presentation of interview analysis findings within the thesis

The three domains described above are represented by the following interview findings chapters:

1. Diagnostic practices used by clinicians in the individual assessment setting: Findings presented in this chapter.
2. The travel of psychiatric diagnosis beyond the clinic through formal records: Findings presented in Chapter 6.
3. The ways in which service users take up and use (or do not use) their diagnoses: Findings presented in Chapter 7.

These three domains that were derived from the analysis of interview data are presented in the thematic map in Figure 4-2, on the following page. This figure illustrates the three domains alongside the themes and subthemes presented in the three findings chapters. A wider thematic map incorporating all the themes and subthemes from the findings of the five empirical chapters within this thesis is shown at the end of Chapter 2 (Figure 2-2).

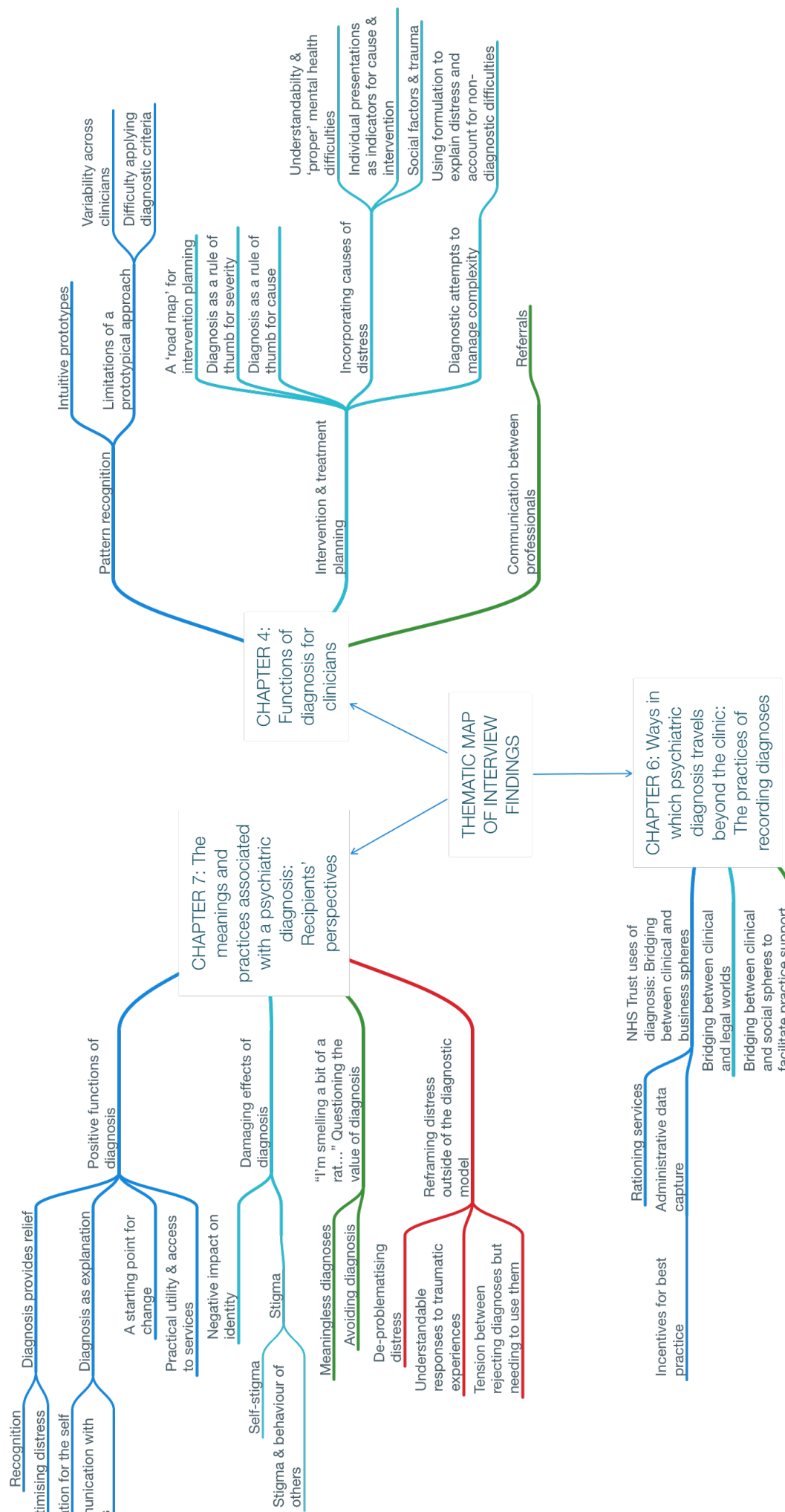


Figure 4-2: Thematic map showing themes and sub-themes from the three domains of findings of the interview data analysis

4.5 Findings

The following findings section presents data specific to the first area described above: diagnostic practices used by clinicians in the individual assessment setting.

These findings will demonstrate that diagnoses are used within clinical assessments for functions such as pattern recognition, a road map for interventions, and for communication, documentation and referrals. Throughout the process of the individual clinical assessment, diagnoses are used as prototypical rules of thumb, offering clinicians a heuristic approach to assessment and management of clients' distress. These broad uses of diagnosis simplify thinking about mental distress; yet, within each of these functions diagnosis has limitations. Heuristics are fallible, and more individualised information is needed, particularly for treatment planning and for understanding complex cases.

A range of explicit clinical uses of psychiatric diagnosis was reported. Pattern recognition, intervention planning, and communication, including record keeping and making referrals, are described below. The use of diagnosis was often described pragmatically, such that diagnostic categories were applied in flexible ways depending on what the clinician felt would benefit the individual the most. The purpose of diagnosis as informing, enabling, or otherwise justifying treatment and intervention was seen as an integral function. For example, diagnosis was described as in and of itself not making a difference without the additional pathways that it might open up: "it helps tell people what's wrong with you, it helps to inform, but at the end of the day...giving them a fancy diagnosis doesn't really explain things to them, doesn't heal their pain at all" (GP 3). Another participant stated, "...it's a balance...are you going to be able, actually be able to offer some specific treatment for this, otherwise it's kind of pointless to make a diagnosis..." (Psychiatrist 10).

The value of diagnoses was identified in clinicians' descriptions of what it enables, "rather than the exercise being just making the diagnosis for its sake" (Psychiatrist 11):

I suppose I'm thinking at the back of my head about what would be useful so I'd want to give somebody a label or a formulation if I thought it was gonna help with planning treatment, or understanding prognosis and outcomes... (Psychiatrist 1)

The findings section explores these uses of psychiatric diagnosis reported by clinicians. The themes and subthemes are illustrated by the thematic map in Figure 4-2, above, and the organisation of the findings is shown in Table 4-5 on the following page. Each of the themes is explored in detail below.

Table 4-5

*Outline of themes and subthemes***Pattern recognition**

- Intuitive prototypes
- Limitations of a prototypical approach
 - Variability across clinicians
 - Difficulty applying diagnostic criteria

Intervention and treatment planning

- A 'road map' for intervention planning
- Diagnosis as a rule of thumb for severity
- Diagnosis as a rule of thumb for cause
- Incorporating causes of distress
 - Understandability and 'proper' mental health difficulties
 - Individual presentations as indicators for cause and intervention
 - Social factors and trauma
- Diagnostic attempts to manage complexity
 - Using formulation to explain distress and account for non-diagnostic difficulties

Communication between professionals

- Referrals

4.5.1 Pattern recognition

Clinicians discussed a need to group individuals or their difficulties in order to identify which pathway to follow for the next steps beyond assessment; "you need to have some idea of how you want to class it, to group it together" (Psychiatrist 10). Assessment is used to "build up a picture" (GP 9) of clients' experiences, and clinicians described identifying patterns over time, rather than a momentary 'snapshot'. Diagnosis was seen as not simply gathering a list of symptoms or experiences, but was described as providing a formalised way of recognising patterns.

Clinicians' descriptions of straightforward assessments reflected the identification of patterns. For example, clinicians recognised a "neat presentation" (Psychologist 7) of difficulties that fit within a familiar or typical pattern that they had seen before. Such a pattern might represent a "classical case" (Psychiatrist 13) where, "on examination they had erm, features that all fitted with a particular pattern and nothing that erm was ambiguous, or didn't fit" (Psychiatrist 7). A straightforward case to assess might not necessarily represent mild difficulties; clinicians described more severe presentations often being easier to identify

owing to less ambiguity; “in some ways a more easy to assess case might be somebody who is quite acutely psychotic because it becomes quite apparent quite quickly” (Psychiatrist 5). A good response to a particular package of treatment or intervention was included within recognised patterns; “it almost makes it easier if it’s a psychotic illness and you treat them for that and so they get better...it adds to the evidence” (Psychiatrist 10).

4.5.1.1 *Intuitive prototypes*

Pattern recognition was represented by clinicians both as matching difficulties to diagnostic criteria and in recognising similar presentations that have been seen. Diagnostic criteria initially offer ‘pre-set’ patterns on which clinicians base their own clinical experience. As this develops, their reliance on the patterns within diagnostic criteria is superseded by those recognised from their own experience: “...when you have worked enough years and have seen enough people presenting with the same sorts of presentations, the same sorts of patterns, then this is your clinical knowledge making sense of these repetitive patterns of symptoms and behaviours” (Psychiatrist 4).

As clinicians became familiar with these patterns, the ways that they spoke about assessment of clients used descriptions more closely associated with their internal representations of patterns, rather than checking off diagnostic criteria against a manual such as the ICD-10. A broad assessment of diagnosis was described as “intuitive” process (Psychiatrist 10). Clinicians described getting “a feeling” (e.g. GP 9, Psychiatrists 2 & 7) or a “sense” (GP 6) of an individual’s difficulties. Psychiatrists described a process of “hom[ing] in on the bits that seem important” (Psychiatrist 11):

Sometimes you can get quite a strong feel for a diagnosis but not necessarily be so conscious of what it is behind that that’s making you er, it’s probably, I think it’s it’s probably something that comes out of developing expertise, you know I think erm, you do tend to build up a kind of erm, internally held representation of what something looks like and sort of match things to that rather than being there kind of looking at your ICD-10 criteria and matching whether someone fits that. (Psychiatrist 7)

I might hold a template of ICD-10 in my head...so often as you’re speaking to somebody, who, it’s fairly clear which of those you’re, you’re looking at, erm, I think it’s a bit like er, a driving test in some ways, you know, you, you learn in one way to pass the test and then obviously you, you learn where you can take shortcuts and erm, speed things up a little bit, you know, those rules of thumb and things that, not always completely reliable but, erm, quite accurate most of the time (Psychiatrist 9)

Echoing the use of intuitive prototypes of diagnostic criteria, GPs described much less reliance on specific diagnostic criteria, and some acknowledged being unfamiliar with current versions of diagnostic classification: “I don't know the, the ICD classifications, but I do know they are, you know, quite finicky, and I don't, I don't think there's a, there's a great value in that, at the level I'm working, you know...because I'm, a generalist, and, and that's, that's my speciality” (GP 2). Other GPs stated, “...I'm not, it's not something that I, I you know I've heard of them [ICD diagnostic criteria] but I don't use them, erm, I'm not, not using them, I'm using good old fashioned ears and eyes” (GP 3) and “I haven't even looked at DSM-5, I haven't looked at diagnostic things for years, I just know there are certain symptom patterns that seem to link to certain things, and certain management approaches” (GP 5).

GPs tended to value this intuitive method of recognition, whilst some acknowledged that it is “not clinically based evidence or anything” (GP 6), and “probably isn't very scientific” (GP 9). Clinicians' recognition of patterns of distress is therefore assisted by, but not reliant upon, diagnostic criteria; instead these skills are developed through clinical experience.

4.5.1.2 *Limitations of a prototypical approach*

4.5.1.2.1 Variability across clinicians

Prototypes by definition reduce data, smoothing away complexities and individual differences. However, an issue was raised regarding the variability of prototypes between clinicians. Psychiatrist 2, for example, spoke about the category of ‘schizoaffective disorder’, introduced to manage the overlapping boundary between the diagnoses of schizophrenia and affective disorder categories. He described how clinicians, depending on their standpoint, might come to have differing representations of this diagnosis, and the implications for reliability across clinicians. Psychiatrist 7 spoke about how differing prototypes might be developed across clinicians dependent on the experience they had had:

...in the large part it's probably not problematic, but it would perhaps depend a bit on the experience you'd had. If you'd seen atypical clusters of patients the prototype you build might be – so provided you've had a kind of broad range of kind of, and experience and also standard, you know worked in standard psychiatric settings as well then probably that's, that's helpful, but if you've only ever worked with patients within a very narrow range say, and done most of your training within a forensic setting or a learning disabilities setting or something you might find that assessment in other situations, it wasn't good to rely on those kind of prototypes (Psychiatrist 7)

Psychiatrist 10 and one of the GPs supported this idea of a non-representative prototype as a result of a particular kind of experience:

I think probably as forensic psychiatrists our view's a little bit skewed perhaps, and we'd probably want to diagnose more schizophrenia than anything else, erm, and it's probably because we are able to treat it as well, erm, so, not saying that it's right, but, it's probably one of the things that we tend to do (Psychiatrist 10)

One GP acknowledged a link between social deprivation and mental distress, and how their patient population may therefore influence diagnoses:

...it depends on your patient population, you know, I work in a very deprived area, and every other person I see has depression you know, so maybe I'm getting to the point where I may be under-diagnosing the mild ones because there are just so many moderate ones to follow up, moderate to severe (GP 8)

Some of the psychologists interviewed noted the differences in the ways that some psychiatrists used diagnosis, with two wondering whether the diagnosis given depended on the clinician's "personal choice" (Psychologist 3), and how "there's kind of certain people who diagnose certain things all the time, erm, kind of have their favourites" (Psychologist 9).

4.5.1.2.2 Difficulty applying diagnostic criteria

Clinicians cited examples of people's difficulties not fitting neatly within diagnostic criteria or typical patterns. For GPs, these examples were not necessarily of more complex difficulties, but were difficult because they existed on the threshold of diagnostic criteria. In these examples, clients would discuss feeling "low from time to time", with some anxiety and "fleeting" thoughts of suicide, but "it's not...ticking all the criteria for depression or anxiety, so then in that situation, it's, it's a bit more er, difficult to come to a proper...you're kind of uncertain about what's going on" (GP 7). Psychiatrists, by contrast, cited presentations where there were multiple difficulties across diagnostic categories; "just kind of chaoticness initially...it could be fitting a number of different things" (Psychiatrist 10). Clinicians discussed uncertain or grey areas between diagnoses that made the categories at times difficult to apply in clinical practice, such as where blurred boundaries occur between two diagnostic categories:

...people don't fit neatly into sort of categorical things, we're trying to make categories of things that are often dimensional, I think, and if people don't, you have to kind of do something with that, that dissonance or that uncertainty (Psychiatrist 7)

People's experiences might meet the criteria for several diagnoses, and there may be disagreement between clinicians' regarding a diagnosis, despite the person's needs being clear:

...sometimes you think that the diagnosis doesn't matter, because you understand the person, so you know what the person needs, and if you just look at the needs, erm, there's not going to be much difference [in clinicians' opinions] about assessments because people will broadly agree that this person needs interventions for erm, their vulnerability, or their lack of assertive skills, but if you look at the diagnosis then we might have different ideas, so diagnosis can be sometimes unhelpful (Psychiatrist 13)

4.5.2 Intervention and treatment planning

Much of the analysis of clinicians' uses of diagnosis related to intervention and treatment planning, which is discussed in this theme. Diagnosis was used as a heuristic or 'rule of thumb', as an initial guide to care planning, however clinicians described how individualised information was also needed in order to plan and make such decisions. Subthemes relating to these ideas will be discussed.

4.5.2.1 *A 'road map' for intervention planning*

Clinicians described using diagnoses to inform the next steps for intervention, as a "rough guide" (Psychiatrist 2), "road map" (Psychiatrist 5) or a "starting point" (Psychiatrist 3) for intervention planning. As one GP remarked, "we're so used to the structure we have, like if you've got this lot of symptoms, you do this, which I do use to an extent" (GP 1). The formalised nature of diagnostic categories was seen as providing a 'structured' link between assessment and management (Psychiatrist 11). Without this "scaffolding" (Psychiatrist 5), some clinicians felt that assessments would be "woolly" (Psychiatrists 6, 8, and 11), and could result in "hesitant" treatment planning (Psychiatrist 8). Clinicians used diagnosis as an indication of the prediction of the course of a person's difficulties, with implications for longer-term interventions, "I suppose also sometimes prognosis of things as well, kind of what pattern might come up in the future, as well, so I suppose it's a useful broad brush" (Psychiatrist 5).

4.5.2.2 *Diagnosis as a rule of thumb for severity*

Clinicians described using broader categories of diagnoses, sometimes groups of difficulties that would incorporate several different diagnostic categories. Such groups of diagnoses were used in broad ways to give an indication of severity of difficulties, and therefore

management; “if we do know that somebody's got a severe mental illness, as by definition, any psychotic illness really, we do know that they need on-going follow-up in the community” (Psychiatrist 3). The GPs described referring to secondary care all new presentations that met a particular threshold of risk and/or a group of diagnoses seen as more complex and needing confirmation and further input from specialist services. These difficulties included presentations of psychosis and suspected bipolar disorder: “...the only diagnosis I would be completely erm, definitive about would be depression, but mainly we would leave definitive diagnoses to psychiatrists” (GP 1). Others stated:

We would look after most of erm, our patients who've got mental health problems in the community, we would only refer on those that we cannot manage, or we're unsure of diagnosis, erm, you know or obviously risk, of self-harm (GP 9).

...my diagnosis is more mainly related to anxiety, depression, personality, stress and things like that, but if I'm worried about this person who's having thought disorder, hallucination, erm, might have got some psychotic symptoms, erm, then definitely there needs to be, referred to the secondary care (GP 10)

...most of them are...like you know, depression or anxiety ones, we do that...as well like well post traumatic stress disorder, so these kind of conditions, I can confidently diagnose, I don't have to refer them to a psychiatrist for that (GP 6)

Reflecting the use of broad groups of difficulties that may encompass several diagnoses, GPs talked about the overlapping nature of mild to moderate problems such as depression and anxiety; “I don't distinguish between depression and anxiety because they usually just come together” (GP 1). Frequently GPs managed social difficulties alongside these problems (these are explored further in Section 4.5.2.4.3, below, Social factors and trauma); one GP described being comfortable to hold that ‘mishmash’ (GP 4), which reflected the general approach of GPs in managing a wide range of more common or lower severity difficulties in the community, alongside social problems.

4.5.2.3 *Diagnosis as a rule of thumb for cause*

Although diagnoses are deliberately atheoretical and do not contain information about the cause of problems, except in specific cases such as PTSD, clinicians described using broad groups of diagnoses as a heuristic for identifying the cause of a problem, and therefore guiding its management. One example was of understanding some diagnostic categories to be biologically caused compared with others that were seen as more related to life experiences, “I do believe that there are a series of mental health problems that probably are biologically driven” (Psychiatrist 12):

I think we have some very clear cut, I think, biological illnesses, and then and then there are others that are much more likely to be psychological, and then there's a whole range of, that are kind of in between. So for example if I looked at the, what we now describe as the psychotic illnesses, schizophrenia and bipolar, particularly bipolar type I, which presents with a more severe manic type of episodes, er, in my view these are biological illnesses... the treatment emphasis would be very much biological in my mind because we think the origin is very biological, and similarly if you looked at the other end of the spectrum for example, the personality disorders where we think the aetiology is likely to be largely psychological or psychosocial in origin, then the emphasis of treatment with biological treatments is less so really... there are exceptions always... but as a rule of thumb that's kind of, that's my guiding principle (Psychiatrist 2)

4.5.2.4 *Incorporating causes of distress*

Causal information, in addition to that which may be assumed within diagnostic criteria as above, was valued in building and recognising a pattern of distress and planning a subsequent intervention. Clinicians identified being able to establish a clear intervention plan as making a case straightforward to assess and manage. Seeing an obvious cause for the difficulties was an important factor; clinicians described discrete, specific difficulties with a clear cause and "without the complexity of social issues around them" (Psychologist 3). For example, GPs described cases of stress, low mood or anxiety, and there being a focus for intervention owing to a clear triggering factor, for example personal problems such as a failing business (GP 3) or termination of pregnancy (GP 10).

4.5.2.4.1 Understandability versus 'proper' mental health difficulties

Reflecting a rule of thumb or heuristic approach to treatment options, some GPs discussed using causal information outside of diagnostic criteria to untangle the 'understandable' from the 'un-understandable'. This information was used to direct the next steps for intervention. Where there were clear indicators of the cause of distress, for example, family difficulties, bereavement, or otherwise understandable triggers as the cause of low mood, counselling or other support might be offered. However, these cases were compared with difficulties seen as not understandable, not externally caused or triggered, which were characterised as "actual depression" (GP 9) or other mental illnesses, and therefore biologically caused. These difficulties were seen as requiring medication and/or further psychiatric support:

...when we see the patients we have to sort of like erm, filter it out, which are a general mental health problem, or which could be just a reaction to certain things

which happen, you know for example, erm, some people will have problems at their work or they have changed their job, so it's more like adjustment problem rather than the actual mental health problem, OK, we don't start them on er, medication which we, which we do for our patients who suffer from proper depression or anxiety, but yes they do need some help in terms of like, you know, counselling and some time off work, you know, things like that, so, so, so that's the filtering out, so once we have sorted out well, that's just a reaction, reactional situation condition (GP 6)

These taken-for-granted understandings, however, were not consistent across GPs. One GP, for example, discussing low mood in the context of social deprivation and environmental factors, said they would still diagnose understandable difficulties: "...no I would definitely diagnose it as depression, erm, it's just that the management of it, or how I follow it up may be different... I'd still diagnose it, erm, just access different services" (GP 8).

4.5.2.4.2 Individual presentations as indicators for cause and intervention

Diagnoses offer a recognised pattern against which to match a person's difficulties, and heuristic information about prognosis and the cause of distress which signposts towards interventions. However, care plans were often predicated on the particular 'symptom profiles' and experiences of the individual. Clinicians described the individual factors that give nuance to their assessments and steer them towards particular individualised care plans, "medication is tailored according to the individual", "you have to treat...the person" (Psychiatrist 8), "it's more a needs-based assessment and you know, what's right for the patient really when they come in" (Psychiatrist 3) and "at the end of the day, you're dealing with whoever's sitting there in front of you" (GP 9).

For example, clinicians acknowledged heterogeneity within diagnostic categories, whereby people with the same diagnosis may have very different experiences or patterns of difficulties, prominent features, or specifiers. Some clinicians described recognising different 'groups' of clients within the same diagnostic category that had different trajectories or presentations; "you're going to have sub-types...in everything...we want to kind of group people together because it's easier to manage" (Psychiatrist 10):

...if I think of the people on my caseload with depression...I might just say they've all got depression, some of them erm, have got severe depression, some of them have got psychotic depression, some of them have got predominant sort of, you know, neurotic type presentations, some of them have clearly got personality issues, erm, so there's, there's quite a range within that group of depressed people, erm, that when I...input their diagnosis onto the computer, that doesn't go on there, but I

suppose when I'm thinking about them, I know I've got certain sort of groups, even within the depression group. (Psychiatrist 6)

Identifying different causes within a diagnostic category was most frequently described within the context of a diagnosis of depression. This diagnosis is perhaps a more mixed or heterogeneous diagnosis in terms of its taken-for-granted understandings about cause, with more scope for incorporating other, contextual, factors: "...so I'm kind of teasing out and understanding the bit about are there some other things that might be explaining this presentation that isn't an illness thing?" (Psychiatrist 12). Psychiatrists and GPs discussed what were described as biological symptoms of depression (e.g. Psychiatrists 2, 6, GPs 1, 9). These inferences often related back to using intuitive prototypes (Section 4.5.1.1, above) developed through clinical experience:

...it's hard to describe, but you get a kind of feeling from someone, where there's just such heaviness erm, and, and, and complete lack of er, kind of, expressed emotion, you know, there's just a heaviness and a deadness about someone who seems organic, but that's just, I mean there's er, that's just my own kind of feeling... (GP 1, describing what they called 'organic' depression, compared with depression related to social circumstances)

Clinicians described prescribing medication for these sorts of more 'biological' presentations, and seeing a good outcome from this type of intervention, "I got quite used to being good at predicting who would respond to antidepressants...and you could literally put money on it" (Psychiatrist 11). The same psychiatrist, however struggled to see what that presentation ["later middle aged men...with a very biological depression"] had in common with mood problems "secondary to something else, either a life event, or say an eating disorder", despite both meeting the criteria for depression.

4.5.2.4.3 Social factors and trauma

Using their clinical experience, clinicians described developing patterns of difficulties that incorporated individual information that is not contained within diagnostic criteria. Such factors were often important in differentiating between straightforward and complex assessments. Psychiatrist 11 described recognising such patterns, "I sometimes say with my teams, I, I've seen one of these before", such as eating distress within the context of a turbulent relationship between separated or divorced parents, school absence or bullying. Some clinicians remarked that despite having useful functions, individuals' diagnostic labels did not represent "the uniqueness of their difficulties" (Psychiatrist 5).

In the context of multiple social difficulties, including traumatic and adverse experiences, the diagnostic label was seen by some as becoming somewhat meaningless; “I could construct a diagnosis of depression in the middle of that, but I don't think that would be terribly helpful, erm, because it would be ignoring...just a million other things that were going on in his life” (GP 4). Clinicians described how contextualising a person's distress could offer a greater understanding of what was going on, and the ways that this context could inform patterns of the course of a person's difficulties:

I don't think a diagnostic label, as often as not, it'll, it labels them with something that is not helpful because they're called schizoaffective or this, or that, or bipolar, when actually if you find out what their life was like, that's much more revealing than the label they've been given... (GP 5)

...so if somebody was erm, hallucinating, then, then I would kind of have in my mind that that's more likely to be erm, a biological problem...that might lead me to a diagnosis but it wouldn't be the thing that I would think would have the greatest impact on outcome for the patient, so I would be more interested in, have you got a job, who's at home, are they giving you hassle, erm, you know, are you likely to act on this voice that er, rather than, well that symptom means you've got this disorder, and therefore this is the outcome... (Psychiatrist 12)

Layers of complexity included multiple difficulties that might fall within more than one diagnostic category, as well as further complicating non-diagnostic factors such as additional drug or alcohol abuse, and social, environmental, or other difficult experiences, including poverty and trauma:

I do have patients who, who, who have got an education, have got a job, erm, and, and have a period of depression, erm, where, where you know, it's, it's er, it comes out of the text book, and, and, and er, I can diagnose depression, I can prescribe an antidepressant, I can encourage them to take part in an exercise programme, I can encourage them to take part in counselling, and then they get better, er, but that's not, I think in, in, in deprivation, where often there's the greatest concentration of people who have got a much more substantial, complex erm, problems, the diagnostic criteria erm, are, are too restricting... and the patients' responses are not erm, er, just don't match the, the expectation of...diagnostic classification (GP 2)

...all of the social issues that people might be experiencing, that might be contributing to their difficulties, and poverty, or being cold, not having enough money to put the heating on, or, not having a job, or your family's not talking to you, or you're using drugs, none of that's captured in the psychiatric label (Psychologist 1)

Clinicians described three broad categories of these difficulties - social problems, experiences of trauma, and drug and alcohol use - however they were typically reported together. Social problems that complicated assessment were often described as long-term consequences of people having “not great lives” (GP 8), “bad upbringings” (GP 2), or spending time in care as a child (Psychiatrist 1). Financial problems and being unemployed were frequently described, as well as unstable living situations, including seeking asylum. Trauma, frequently repeated experiences of which, was discussed often. Long histories of trauma (Psychologist 10), witnessing domestic violence (GP 2), and physical attacks (Psychologist 3) were described, and childhood abuse mentioned and alluded to often. Clinicians tended to associate traumatic and difficult histories with multiple psychiatric problems. In reporting these types of additional difficulties together, clinicians frequently made links between these experiences in terms of their causal impact. For example, associations between experiencing early and long histories of difficult lives with drug and alcohol use in order to cope with these experiences and the toll they took on individuals’ mental health and social situation, “...this was a person who just had year after year of...appalling experiences...and surprise, surprise, he got drug and alcohol problems er, he had difficulty with relationships, erm, you know, couldn't cope with holding down a job” (GP 2). Clinicians described difficulty identifying the cause of problems and consequently, on establishing a treatment plan, because the picture was often longstanding, multi-layered, and difficult to untangle:

I suppose that when you've kind of got layers of complexity erm, as opposed to a more discreet sort of recent onset of problems, so I suppose yeah, I guess if there's been difficulties for a long time, often you kind of need to go into a lot more depth and detail to try and understand kind of the hows and whys of why the person's experiencing the problem at this point in time... (Psychiatrist 5)

There was less of a focus on diagnosis as people's difficulties were described as so complex that it was not generally possible to assign only one diagnosis. Other factors play a much more significant role:

...in many ways I've moved away from worrying too much about a single diagnosis...often, people here, like I say, they, they will have a psychotic disorder but that's often not the particular problem, you know, that's often the easy part to treat, erm, you know, and it's everything else, the, the sort of the individual underneath who's often had a very difficult life and quite damaged by that, erm, personality problems, substance misuse problems, and a lack of understanding of those sorts of difficulties, it's often those that are keeping people here (Psychiatrist 9)

4.5.2.5 *Diagnostic attempts to manage complexity*

Clinicians from each group observed the ways that diagnosis is used to contain people's difficulties, and the limitations of this use were acknowledged. As GP 4 described, "that is my worry...we use diagnoses to, to cover up our, yes, er, to ignore the complexities and cover up the shortcomings of the things that we're, we're doing"; by applying a 'generic' diagnostic category, the individual differences, and therefore complexities, are contained within a familiar, recognised diagnosis. One psychiatrist explained their expertise in diagnosis being used by others in the multidisciplinary team as a means of consolidating unclear presentations that may have aspects of various different difficulties, "so I kind of get drafted into being the containing thing" (Psychiatrist 12). Whilst this simplification of difficulties may appear to offer clinical utility, others described the limited implications for intervention:

...it felt a bit like this kind of almost like a wish to contain some of the anxiety around complexity, so I think the reason we weren't sure it was going to be terribly helpful is that it was a bit like, you know if they, if we'd done an IPDE [International Personality Disorder Assessment] and there was a label somehow it would take all the difficulty away, and I think that does happen quite a lot with diagnosis, you know that people have multiple assessments and multiple reports that say oh no it's not this it's this, but it doesn't really get you much further in terms of your intervention...
(Psychologist 4, describing a request for an IPDE to be carried out)

...the tribunal wanted to know whether it was personality disorder or mental illness, they wanted a definitive diagnosis. So, we spend a long time trying to write this report, saying it doesn't actually matter what the diagnosis is, it's more about the risk and it would be very hard to come down one way or the other... (Psychologist 3)

Clinicians described diagnostic categories as at times prohibiting further efforts to understand the individual or explore their experiences. Where a diagnostic category is used to contain a person's complex difficulties, it was suggested that this might limit further attempts to understand the person; "...we could just call this dementia, but I almost feel if we do that, it will stop me trying to get to the bottom of what's going on for her" (Psychiatrist 6). As well as overlooking additional experiences such as systemic or environmental factors, as reported above, clinicians described the potential for diagnostic overshadowing (Section 1.3.2.2.1), overlooking experiences or 'symptoms' that do not fit within the given diagnostic category. This can even affect clinicians who do not generally make diagnoses but still encounter them, for example in referral letters:

I think sometimes when people are diagnosed, you miss other stuff that's going on, erm, so if you've got in mind, oh this person's psychotic, and you're looking to give them that diagnosis, you might miss other stuff that's going on for them like they might be dissociating, for example... (Psychologist 10)

Alternatively extraneous experiences that do not seem to fit the category might be minimised in order to create certainty or separation into a label or category. For example, experiences of hallucinations additional to a diagnosis of personality disorder might be minimised as 'pseudo-hallucinations':

There's a lot of talk about kind of pseudo-hallucinations versus hallucinations, and sometimes erm, it can feel like erm, clinicians are trying to erm, fit people into diagnostic categories and sort of play down the symptoms that don't fit neatly into a particular diagnosis, so if you had somebody with quite a clear say emotionally unstable personality disorder, if they had psychotic symptoms that didn't fit the kind of pattern you might expect from that condition they might sometimes be sort of downplayed or dismissed because it doesn't, doesn't fit neatly... (Psychiatrist 7)

One psychologist gave an example of the way that diagnostic categories can dominate interpretations of a person's behaviour to such an extent that simpler, alternative explanations are not considered. Most of the clients with whom Psychologist 4 worked would meet the criteria for borderline and antisocial personality disorder, and one person's non-attendance at the program was put down to their diagnoses, risk, and lack of engagement, whereas further exploration revealed that they simply struggled to get to the appointments:

...I think the other problem with diagnosis actually is people you know people might also be highly anxious, like that example I got of someone might not be coming because they're really terrified of getting on a bus, you know that actually you can then forget all the other challenges, you know social and psychological difficulties that are around, 'cause you kind of go 'oh right ok it's [the diagnosis]' and actually it might be that and multiple other things... (Psychologist 4)

4.5.2.5.1 Using formulation to explain distress and account for non-diagnostic difficulties

When clinicians gave examples of complex difficulties, frequent mention was made of the inter-relatedness of multiple factors. Formulation was at times used to represent the links between difficulties, for example, to compensate for where the structure of diagnostic classification does not allow for difficulties across multiple diagnostic categories to be associated, in terms of either having a causal impact on each other, or by having a common cause or mechanism. Diagnostic formulation was at times referred to by psychiatrists.

Diagnostic formulation is part of the Royal College of Psychiatrists' curriculum (Royal College of Psychiatrists, 2010) and is predicated on a psychiatric diagnosis. It contains further information such as differential diagnoses, causes of distress and prognosis (Royal College of Psychiatrists, 2010). This approach is not necessarily used during each assessment conducted by psychiatrists:

...the good practice from the Royal College, and internationally, suggests that we ought to be looking at those kind of formulations for every case we see, so I think, I don't know I think there's a, there's an element of time constraints I think, and bit of laziness perhaps, and er just a lack of the appreciation of the importance of it I think. (Psychiatrist 2)

...you will find that...there's no standardisation to that multi-disciplinary you know, biopsychosocial formulation, erm, I'm quite fond of it, so I work hard at it, there are some really biological psychiatrists I've worked with, who just do their bit, do the medicines, they don't believe in psychological nonsense... (Psychiatrist 3)

There was a common idea of seeing formulation as a way of exploring and understanding a person's difficulties and their causes. The evidence from interviews with psychiatrists demonstrates that diagnostic formulation is a method of incorporating into assessment the factors that diagnosis omits. It was used strategically as a way of supplementing diagnostic assessment, in particular the integration of problems or factors not incorporated within a diagnostic label, such as risk, additional drug or alcohol abuse, and trauma. Views on formulation differed between psychiatrists, with some seeing diagnosis and formulation as quite different frameworks for assessment (Psychiatrists 3 & 5). Formulation was described by some as a way of acknowledging psychosocial factors that were seen as separate from symptoms (e.g. Psychiatrist 3), whereas others saw formulation as bringing together different perspectives of a multi-disciplinary team assessment (Psychiatrist 13). Difficulties, traits, and symptoms were seen by others as inter-related, and formulation was a way of integrating these (Psychiatrist 12). One psychiatrist described their use of diagnostic formulation as being a useful strategy for some select clients:

...often they're people who've maybe had quite a lot of adverse life experiences, or I feel that there's other factors in their life that's impacting on the, on the diagnosis...the other group where I'd maybe think about more of a narrative or formulation is people who are just very complex, and maybe I, I can't come to a conclusion... (Psychiatrist 6)

Although not all psychiatrists who worked in complex care mentioned the use of formulation, there was a clear indication from the interview data that by virtue of people's problems being

more complex, and therefore less contained or easily explained within one or more diagnostic category, diagnostic formulation was more relied upon in these services:

I think if I was running an acute clinic it would be different, I think if somebody comes in with acute problems, it's probably more useful to have a more precise label, erm, I think coming up with a more detailed formulation to the level we do is quite a luxury and it takes a lot of time, but that's necessary because you need all that information to decide what's gonna work (Psychiatrist 1)

Psychiatrist 5 described the difference between diagnosis and formulation as diagnosis being a "static thing", a broad-brush used to label and link in with NICE guidelines, versus capturing individual uniqueness and problems specific to the individual within a formulation. Psychiatrist 11 described taking the diagnosis as "read" at the start of an assessment, followed by using a formulation approach:

...in terms of understanding the case and the specifics of its management, the formulation erm, and the individualised elements I, I think are more significant, so, we have a framework for working in our treatment model [using the diagnosis], but erm, the individual aspects...the understanding of the condition, what has led to, what maintains it, what might be the obstacles to treatment and I think are probably much more important than the diagnosis itself... (Psychiatrist 11)

One psychologist drew on her experience from working in children's services to advocate a more detailed assessment that explored in depth the different factors involved in such complex patterns of difficulties:

I've come across erm, people where they've, you know, they've been through services multiple times, and then eventually get to a service where they're asking...in much more depth about their relationship style and their relationship experiences, and actually thinking mmm, this is much more complex than maybe we thought...if you've got their history...certainly when I've worked in...looked after children's services, we would have assessments that would include foster carers, social workers, teachers...and we'd have an initial consultation with all those people, before we'd decided what we were going to do for the child, and actually that was, er, and, it's, it's not always easy, but actually that was the way we worked, and that really helped because you had a whole picture of the, the person before they came to your door really, erm, and I guess I do really like that approach, for, for much more complex populations. (Psychologist 6)

4.5.3 Communication between professionals

Despite the need for individualised information to make specific care plans for clients, diagnosis was valued as the central way of communicating with others beyond the individual clinical assessment. Record keeping and referrals are likewise connected by communication between professionals. Making client referrals to other services was seen as a particularly important use of diagnosis, and this is explored below as a sub-theme of communication.

The brevity of a diagnostic category was seen as a useful communication short hand between clinicians by relaying a shared understanding of a pattern: “it kind of encapsulates all of that sort of cluster, just into a, you know, sort of single phrase” (Psychiatrist 6), and “...diagnosis gives an understanding so that you can share it with other professionals, so that they have a baseline” (Psychiatrist 13). A psychologist described:

Although I probably do use [diagnoses] when talking with staff, well I mean I tr, I don't think I use the word schizophrenia any more but I'd be talking about psychotic symptoms and that sort of thing, as a way of communicating, I guess. So I don't think I do use the, the diagnosis, well...if we're going to see, assess someone to see whether they'd come in [the service], I might write something like 'has a diagnosis of schizophrenia' but then I'd always describe how they got that diagnosis, and what that diagnosis meant... (Psychologist 3)

GPs noted the limited time available in appointments and the importance of the electronic clinical record when service users frequently see different GPs; “I have to be able to rapidly check the symptom list and see what else has been said, so I think it's a cop-out if I don't communicate with colleagues by putting somebody into a category” (GP 5). Another stated, “it's important that we all know what's going on...and if they come in and there's just a ream of symptoms then we can't quickly pick out the important bits, that will affect patient care” (GP 9).

4.5.3.1 Referrals

Clinicians routinely used diagnoses, or a queried diagnosis, for making referrals to mental health services: “of course I need to have some kind of working diagnosis, erm, otherwise my referral letter will sound [like] gibberish” (GP 6). Another GP remarked, “I'd say these are the symptoms, and this is what I think it is, but I want your confirmation, and discussion... confirmation of diagnosis and/or management plan, those are the reasons for referring” (GP 8).

Those who focused less on diagnosis in their clinical work described feeling pressured to reframe clients' difficulties diagnostically in order for referrals to be accepted, "I guess the benefit of a diagnosis is it can open doors to services" (Psychologist 7):

...there have been occasions when I've er, when, when the men who are here have required services from adult mental health services...and in, well I feel in order to help them access services, I have put a label to their difficulties... (Psychologist 6)

...there's almost a need to kind of communicate in diagnostic terms, so that people actually get the service that they need...maybe they don't take it as seriously as if it says 'schizophrenia', so...sometimes it has sort of power for actually ensuring people have a service as well... (Psychiatrist 5)

...we've had a letter back [from the CMHT] saying...please could you ask the consultant in your team to write a [referral] letter including the diagnosis, it wasn't clear from your letter on the patient's diagnosis, erm so there are instances where people are specifically requesting that piece of information erm, when they've had you know very good formulation-based letters written to them. Sometimes people still want that, you know that sort of diagnostic label applied. (Psychiatrist 7)

or for funding to be accessed:

...it felt like if the psychiatrist said 'he has OCD', that would help us sort of acquire another level of funding, another level of kind of concern, so that's quite interesting really 'cause it kind of went against all my beliefs and ideas, and it reflects, mostly the state of play around funding and service design, and the lack of services for people with quite complex presentations, as much as actually my beliefs around diagnosis... (Psychologist 11)

Conversely, concern was raised regarding the potentially limiting implications of organising service entry by diagnosis:

...mental health services are set up in such a way that we have to put people in boxes erm, I find that difficult because of the overriding framework that goes alongside that...it's really difficult to meet young people when they don't meet our criteria but you know that they're still really struggling, and, you have to go, they're not for us, erm, when you kind of think, we could probably offer them something and just because you don't meet our criteria, we've got to now send you to a service that perhaps isn't as psychological as ours... (Psychologist 1).

4.6 Discussion

This chapter addressed the first and second theoretical questions outlined in Chapter 2 (Section 2.4.2): 1) what are the conceptual underpinnings of diagnostic categories, and are these consistent across contexts and practices? And 2) how are psychiatric diagnostic categories used in practice?

The findings have demonstrated that clinicians' explicit uses of diagnosis include pattern recognition, intervention and treatment planning, and communication between professionals, including documentation and referrals. Diagnoses offer a prototypical approach to pattern recognition, and a heuristic for intervention planning, severity, and cause of distress, despite diagnostic categories being atheoretical and without including information about cause. However, clinicians reported limitations of this short hand approach, including a need to incorporate individualised information within assessments. Diagnoses struggle to contain complexity, and clinicians use formulation to develop an understanding of distress and psychosocial difficulties, and the inter-relatedness between them.

The following section is structured around the following discussion points:

- Differences between diagnostic classification as protocol and its use in clinical practice
- Conceptual underpinnings of diagnostic categories
- Clinical implications
 - Reliability
 - Standardising intervention planning: NICE guidelines
 - Constructing certainty
 - Managing complexity
- Implications for research and data capture

4.6.1 Differences between diagnostic classification as protocol and its use in clinical practice

Reflecting Bowker and Star's (1999) analysis concerning the rift between protocol and practice, these findings demonstrate that diagnostic criteria are not applied in the precise manner that is intended by the DSM model of diagnosis. Instead, diagnosis is a tool that is used flexibly by clinicians. The findings are supported by Brown (1987, p. 40), who highlights, "[d]espite the attention which professional leaders give to formal diagnosis, practitioners have very personal styles which transcend formal systems". Highlighting the loose application of diagnostic criteria, and the varying uses of diagnosis across services, some GPs, as generalists by profession, were comfortable with holding in mind and acting upon an uncertain 'mishmash' of difficulties. These findings are supported by previous

qualitative research concerning the ways in which GPs manage risk, and can be comfortable within “this glorious twilight zone of uncertainty” (Dew, Dowell, McLeod, Collings, & Bushnell, 2005, p. 1189).

The use of idiosyncratically developed prototypes of diagnoses also represents an internal conflict between the technological and clinical uses of diagnosis; a tension between general pattern recognition and the rules-based approach of the DSM and other diagnostic manuals. The finding that clinicians tend to use heuristics developed through experience is supported by literature showing that rather than using a criteria-matching approach to diagnosis (Maj, 2011) as the DSM and ICD intend, clinicians tend to use a prototype approach to assessing clients (e.g. Blashfield et al., 2014; Hacking, 2013). Although perhaps more intuitive (Ortigo et al., 2010), prototype-matching tends to obscure individual differences, including specific experiences and personal meaning. The rules of thumb and prototypical approach used by clinicians are reflective of a heuristic reasoning style commonly used to navigate uncertainty, and is typically illogical fallible (Tversky & Kahneman, 1974). Likewise, both diagnostic labels and corresponding prototypes give little information about the experiences of the diagnosed individuals, such that their clinical utility can be questioned. Psychiatric literature associates diagnostic expertise with pattern recognition and cognitive shortcuts (Loveday, Wiggins, Festa, Schell, & Twigg, 2013), however this differs from the criterion-based protocol of the DSM-5 and the ICD-10. Clinicians described narrowing from broad diagnostic categories that signpost and offer heuristic reasoning, to using more detailed, symptom-level focus on a person’s difficulties. These findings suggest that diagnosis represents a middle ground of detail that may have less utility for clinicians than broader categories or a more granular assessment of individualised experiences.

4.6.2 Conceptual underpinnings of diagnostic categories

The conceptual underpinnings of diagnostic categories reflect the taken-for-granted understandings (Bowker & Star, 1999) that are embedded within classification systems. The findings presented in this chapter illustrated two potentially opposing conceptualisations of diagnostic categories. Clinicians might describe diagnoses as a neutral tool with pragmatic functions, however there was evidence of implicit aetiological influence in the way that diagnoses are discussed. The use of diagnostic categories of explanations for difficulties, tied up with ideas about disorder and biological and psychosocial causation is associated with their reification as categories. There is a tension, therefore, between diagnostic categories as a flexible assessment tool or as a system reflecting natural categories.

A distinction might be drawn between implicit and explicit notions of causality. Explicitly, diagnostic classification systems are atheoretical and typically do not refer to cause, however, implicitly they support an illness model. Diagnostic categories are seen as a way of

implicitly explaining distress, rather than a more neutral conceptualisation that might see diagnoses as a useful way of describing a person's difficulties. Beyond this explanation, diagnoses are also informally assigned causes that are predominantly biological or psychosocial, dependent on where on that spectrum a diagnosis lies.

Likewise, more heterogeneous diagnostic categories such as depression, or broader categories of difficulties, perhaps including 'mild to moderate mental health difficulties', are viewed as understandable responses to life circumstances if social causes are clear, or biological in nature if not. These findings suggest that clinicians may default to biological notions of cause where psychosocial explanations are not obvious. GPs, for example, reported a practice of differentiating between understandable and non-understandable distress. The former was contextualised as a response to an external stressor or adversity, and the latter seeming to have no such triggers and therefore being seen as biological in nature. These different ways of categorising mental distress are supported by the research of Clarke and colleagues (2008), who found that despite the terms no longer being used by specialists, GPs in Australia differentiated between endogenous and reactive depression according to whether or not a situational cause could be identified. Demonstrating further variability in the uses of diagnostic categories between clinicians, some of the GPs interviewed saw this distinction between understandable and non-understandable as a distinction between usual/'normal' distress and a "proper" mental illness. Others, however, as with those clinicians interviewed in Clarke and colleagues' research, labelled both of these informal categories as depression and thus as a clinical disorder. These variations in the conceptualisation of mental distress have implications not only for treatment but also for labelling of individuals.

These findings suggests that diagnoses might therefore have been seen by some as categories reflecting clusters of difficulties represented in nature, rather than developed through sociocultural means as a way of conceptualising difficulties. These ideas about the diagnosis or 'disorder' as causing a person's difficulties might therefore contribute to the reification of psychiatric diagnoses. As outlined in Section 1.3.1.4, it has been argued that reification of psychiatric diagnoses as biological categories of illness has led to increased medicalization of the problems that are represented by these categories (Bracken et al., 2012). These understandings may also have implications for the ways that clinicians assess people's difficulties; if psychosocial causes such as trauma are not anticipated due to taken-for-granted understandings about a diagnosis such as schizophrenia being biologically caused, the limitations of the prototype approach suggest that any such causes may be overlooked or minimised.

4.6.3 Clinical implications

4.6.3.1 *Reliability and communication*

The purpose of the specific diagnostic criteria incorporated into psychiatric classification since the DSM-III was to improve diagnostic reliability between clinicians (Blashfield et al., 2014; and see Sections 1.3.1.1 and 1.4.1.1 of the Literature Review). However, the use of intuitive pattern recognition and internal prototypical representations demonstrates a looser, less stringent way of using diagnoses than is directed by the DSM or ICD. These findings show that the reliability of diagnostic categories, as they are used in clinical practice, may be called into question.

As a consequence, the utility of diagnostic categories as a short hand aid to communication has important limitations. Psychologists, for example, remarked that clinicians appeared to have their “favourites” as to which diagnoses were used. In view of the evidence around the prototypical approach to diagnosis, perhaps these “favourites” might be an implication of particular clinicians having a prototype or internally held representation about a diagnosis that looks quite different to others’, or perhaps a broader representation such that greater numbers of clients fit into it leading to more being given that diagnosis by that clinician. Alternatively, clinicians’ uses of familiar labels may meet a need to frame difficulties in a way that enables access to a particular type of intervention. Nevertheless, the psychologists’ perceptions raise a limitation of the use of heuristic diagnoses for communication where other professionals may view the labels as unreliable or meaningless.

4.6.3.2 *Standardising intervention planning: NICE guidelines*

NICE treatment guidelines are broadly organised by diagnostic category, with an aim of standardising interventions available to service users. These guidelines may result in a construction of ‘safety’ in clinical practice that perhaps enables or justifies more ‘robust’ drug treatment (Psychiatrist 8). However, the NICE guidelines can only standardise treatment to the extent that there is high reliability and consistency in the application of diagnostic categories against which the guidelines are used. As discussed above, these findings call the reliability of diagnosis, and therefore of the standardisation of interventions, into question. Furthermore, the findings demonstrate that clinicians utilise extensive individualised information in care planning, contributing to idiosyncratic application of the guidelines according to individual need.

4.6.3.3 *Constructing certainty*

Where a pattern appears to be very clear, for example where a person's difficulties clearly match diagnostic criteria, or there is an obvious pathway between a triggering event, a person's mood, and a plan for intervention, diagnosis appears to offer clinicians a desirable level of certainty or assurance about their clinical work. Highlighting the use of diagnosis as providing a sense of certainty, clinicians spoke about diagnosis at times offering order from chaos. However, given the limitations of diagnosis that clinicians acknowledged (such as needing additional information like specifiers within diagnostic categories, or additional information surrounding the diagnostic label), the extent to which diagnosis reduces ambiguity must be questioned. The provision of certainty was highlighted as useful particularly for straightforward cases that reflected a familiar discrete pattern of difficulties that fitted tightly into a diagnosis. However, these cases are typically already characterised by a seemingly direct cause, a clear focus for interventions, and a good response to treatment. It is therefore important to reflect on the question of what further information to reduce uncertainty a diagnosis really offers in these cases. It is suggested that the diagnostic category simply confirms a certainty or confidence that is already present. The assertion is that the certainty described by clinicians in these cases is derived not from the diagnostic categories, but from the clinicians' own experience and confidence. Furthermore, where diagnosis is thought to offer certainty, clinicians frame it positively. However, given that humanity and human information processing are characterised by uncertainty, perhaps it is this search for fixedness, for discrete categories, in an analogue world (Pilgrim, 2014) that is problematic. As can be seen in the data, problematic implications arise when diagnostic categories overshadow additional difficulties or more everyday circumstances that possibly shed light on the nature of people's difficulties. The 'draw' of certainty may be a mirage.

4.6.3.4 *Managing complexity*

Clinicians' descriptions of more complex presentations demonstrated a failure of diagnostic categories to provide clinical utility. In cases such as these, the diagnostic framework may not only fail to provide clinical utility but actively hinder clinicians' work. The characterisation of complex case examples and the difficulty clinicians reported in applying diagnostic categories in such cases shows that the separation of difficulties into discrete diagnostic categories is problematic. Clinicians employ diagnostic formulation in order to understand not only the causal context of difficulties but also the complex reverberations that exist between distinct difficulties. In these cases, formulation was viewed as a useful supplement to diagnosis because it is better able to represent the inter-relatedness of difficulties. Indeed, Mohtashemi and colleagues (2016) found that risk or complexity triggered the use of formulation by psychiatrists. Time was also found to be a notable barrier to the use of

formulation in psychiatric practice (Mohtashemi et al., 2016). Therefore, the increased use of formulation within forensic and other complex care services may also reflect greater time and space available for its implementation.

Whilst acknowledging the obvious limitations on the time available in GP appointments, as GPs described managing overlapping experiences of distress and additional psychosocial difficulties, it may be appropriate to introduce training in psychological formulation for GPs to develop clinical skills where diagnoses have limited utility.

4.6.4 Implications for data capture

This chapter has shown that diagnoses are used as prototypical heuristics to guide clinicians thinking about distress, its severity, causes, and the interventions they may use to support their clients. However, these prototypical guides vary across clinicians, and are therefore not reflective of standardised categories applied rigorously wherever clients' experiences of distress closely match the criteria given in the ICD-10 or DSM-5. Routine data capture from, for example, electronic health records, is used for outcomes measurement, commissioning, and soon payments by results in mental health. However, where diagnosis is the central measure of distress, there are clearly limitations in the utility of generalising across categories that are heuristically and flexibly applied by clinicians.

4.7 Conclusions

This chapter has used data from interviews with psychiatrists, GPs, and clinical psychologists to explore the clinical functions and practices of diagnosis and their conceptual underpinnings. The findings demonstrate that clinicians use psychiatric diagnosis for pattern recognition, intervention and treatment planning, and communication between professionals. Diagnoses provide a heuristic for severity, cause, and intervention planning, through prototypical representations developed through clinical experience. This prototypical approach has limitations, however, and represents a departure from the criteria-matching protocol set out by systems of diagnostic classification, and the reliability of diagnosis and its clinical utility is therefore called into question. The variation in use of diagnoses between clinicians also has important implications for routine data capture. Diagnostic categories carry implicit conceptual understandings of cause and disorder, which are not consistent across clinicians. There is a tension between diagnostic categories as a flexible assessment tool or as a system reflecting natural categories. There is, similarly, a tension between the expectation that expert clinicians will be able to follow the rules and protocols for 'accurate' diagnosis, and the demands on clinicians to use tools flexibly in the best interests of their clients. Diagnoses offer a sense of certainty, however the categories may represent a certainty already possessed by clinicians in straightforward cases. Within less

straightforward cases, diagnoses struggle to contain complexity, and clinicians use formulation to develop an understanding of distress and psychosocial difficulties, and the inter-relatedness between them.

5 Chapter 5: Assessing how diagnosis is used in mental health service entry criteria

5.1 Abstract

The purpose of this chapter was to explore how psychiatric diagnosis is used in the service entry and eligibility criteria of NHS adult mental health services, and to identify additional non-diagnostic factors upon which criteria are organised. A Freedom of Information request was made to each of the 17 NHS adult mental health trusts in the north of England asking for this information. Thematic content analysis was used to analyse the textual data. Four service types were identified: broadly diagnostic specialist services, non-diagnostic services supporting specific problems, services supporting specific life circumstances, and needs-led services providing specialist services. The findings demonstrate that diagnosis is used to some extent, however, there are also many non-diagnostic factors, including severity and impact on functioning, that are central to service entry and eligibility criteria. Diagnosis is neither sufficient nor necessary in establishing service entry criteria. Broad clusters of difficulties (such as 'severe and enduring mental illness') were used over specific diagnostic categories, and these clusters appeared to differentiate services on the basis of the specialist skills needed to support these difficulties, such that services tend to be competency-driven. The findings are discussed in the context of the Mental Health Act (1983, 2007), and clinical and research implications raised, including the ways in which innovative pathways are developed, and the need for an empirical method to explore where and when non-diagnostic versus diagnostic models would best meet clients' needs.

5.2 Introduction

The interview data analysed in the previous chapter demonstrated that clinicians use diagnostic categories as broad heuristics or rules of thumb to guide pattern recognition and the management of service users' distress. However, there are limitations to this approach, including the need for more individualised information about clients.

The findings of the previous chapter showed that clinicians valued the use of psychiatric diagnoses in order to make referrals and gain access to other mental health services for their clients. Queried diagnoses were used by GPs if they were not certain, and clinical psychologists and other clinicians who focused less on diagnosis in their clinical work described feeling pressured to reframe clients' difficulties diagnostically in order for referrals to be accepted. Supporting these findings, proponents of diagnosis have argued in the psychiatric literature that it facilitates communication between individuals and professionals about support and service needs (Craddock & Mynors-Wallis, 2014), and provides boundaries about who can be identified as having difficulties, and who receives services for

those difficulties (Callard et al., 2013). Even those who are critical of psychiatric diagnosis see it as central to the planning and organisation of mental health services (Harper, 2013). Kendell and Jablensky (2003) discuss the poor validity of current diagnostic categories, but nevertheless argue that many diagnoses remain invaluable due to their utility for clinicians. However, they emphasise that, “statements about utility must always be related to context, including who is using the diagnosis, in what circumstances, and for what purposes” (p.11). This chapter considers the utility of psychiatric diagnoses from a service perspective, within the context of the gatekeeping role performed by service entry criteria.

5.2.1 Rationale: Analysis of NHS adult mental health services eligibility and entry criteria

Given the value clinicians place on the use of psychiatric diagnoses in referrals, identified in the previous chapter, the service eligibility and entry criteria of adult mental health services were used as a source of data in order to examine the ways in which diagnosis is used in these policies. Service entry criteria across the NHS are closely tied with the interventions particular services are commissioned to provide. Clinical Commissioning Groups (CCGs) were introduced in 2012 consequent to the Health and Social Care Act (2012) (NHS Clinical Commissioners, 2017). CCGs are NHS bodies that plan and commission services in response to local need. CCGs and local authorities use a Joint Strategic Needs Assessment to identify which services are required locally (Department of Health, 2013). Services are obliged to follow Department of Health (DoH) implementation frameworks (DoH, 2012) and guidelines from the National Institute for Health and Care Excellence (NICE), which for mental health are largely organised around psychiatric diagnostic categories.

However, owing to their relatively recent establishment, CCGs use large, overarching contracts that give the flexibility for already existing services to be commissioned. Because trust commissioning and service planning, and therefore service entry criteria, are negotiated on a local level, in response to local needs, there is considerable heterogeneity across trusts in the way that services are commissioned. This heterogeneity may be a strength of the process as it allows for local innovation in service provision. Indeed, innovation is a goal of overarching commissioning bodies (NHS Commissioning Board, 2017), and many CCGs have specific innovation strategies and funds used to commission pilots. Consequently, both traditional diagnostic and innovative non-diagnostic approaches are commissioned, which may be directed by CCGs themselves, or bottom-up by trusts. Ultimately, therefore, how commissioning contracts are delivered at a local level is a matter of negotiation between the trust and the CCG, and this relationship allows for innovation at a trust level. Owing to the local flexibility with which services are commissioned, multiple NHS mental health trusts were approached in order to understand the different ways in which psychiatric diagnosis is used in mental health service entry and eligibility criteria.

5.3 Aims

This chapter addresses the second theoretical question outlined in Chapter 2 (Section 2.4.2); how are psychiatric diagnostic categories used in practice?

The purpose of the chapter was to analyse NHS mental health service entry criteria to compare and contrast the ways in which diagnoses are used in gatekeeping decisions. In addition, the analysis sought to identify the non-diagnostic factors and methods upon which service entry criteria were organised.

5.4 Methodology

5.4.1 Freedom of Information requests

Services' entry and eligibility criteria is not held centrally within the NHS (Freedom of Information, NHS England, personal communication, 17 December, 2015), therefore Freedom of Information (FOI) requests were submitted to each of the 17 NHS mental health trusts in the north of England. The mental health trusts were identified using the NHS England website, north of England region (NHS England, n.d.). This region covers Yorkshire and The Humber, the North-West and the North-East of England. The submitted requests each asked the same question, using the exact wording as follows:

What are the service entry criteria for each of the adult mental health services (community & specialist) within the trust? I.e. on what information is a decision based when accepting an individual to each service (e.g. the service entry criteria for CMHTs, early intervention, eating disorders services and so forth).

5.4.2 Trust responses

Each of the seventeen north of England NHS mental health trusts responded to the requests. An overview of these responses is given in Table 5-1 below, and a detailed analysis of these responses is presented in the findings that follow (Section 5.5):

Table 5-1

Outline of responses received from north of England NHS mental health trusts

Number of Trusts	Response Type
11	Breakdown of service entry criteria for different services within the trust
2	Signposted to trust website where some or all of the above information was publicly available
2	Brief response giving an overview of the referral and service access process
2	Declined to respond

Of the eleven trusts that gave criteria for various services, seven gave detailed responses that represented all of the services within the trust, as requested, and four trusts gave only information for a limited selection of six or fewer services. The services described in these incomplete responses are analysed as part of the overall presentation of findings below. The majority of the trust responses included descriptive information about the purpose of the services, as well as lists of their entry and eligibility criteria. This information was analysed as part of the criteria lists.

Two trusts offered only a brief response giving an overview of the process of referrals to services; these responses will be discussed in Section 5.5.6.

Two trusts declined to respond (Trust C and Trust L). Within the NHS FOI handling procedure (Wanless, 2014), in accordance with the government's FOI request fees regulations, trusts may refuse to respond if they deem the time taken to gather the information to exceed 19 hours, or the equivalent to one person working for three and a half days.

5.4.3 Method of analysis

5.4.3.1 *Deductive thematic analysis*

Deductive thematic analysis (Braun & Clarke, 2006) was used to analyse the data, in order to identify and analyse patterns or themes in the data, and to give a map or outline of these themes across the interview dataset. Deductive analysis is used when the structure of analysis is derived from previous knowledge (Elo & Kyngäs, 2008). The analysis of service entry and eligibility criteria for NHS mental health services, as described above, was carried out in order to further elaborate upon the finding from Chapter 4 (Section 4.5.3.1) that

clinicians used diagnostic labels for making referrals to mental health services, even if making diagnoses was not a central part of their clinical assessment practices.

5.4.3.2 Data preparation and organisation

The data received from each of the trusts were prepared and organised in order to ensure comparison across services where appropriate. The entry criteria data for individual services were identified and extracted for those trusts that returned breakdowns of service entry criteria. To assess the spread of services across trusts, the number of trusts that had returned information about each service type was noted in a frequency table. The 'outliers', or idiosyncratic services that were not replicated across trusts were then explored further. Details of each outlying service were identified from the information given by trusts. This was particularly important where the names were ambiguous as to what service was being provided (e.g. 'access team', 'clinical treatment team'). In several cases, once these details were identified, it was possible to collapse these services within other already identified services. For example, the 'clinical treatment team' (Trust G) was an electroconvulsive therapy (ECT) service, and so categorised accordingly. Likewise, the 'access team' (Trust F) performed the same role as Single Point of Access (SPOA) teams.

Detailed data for each of the services were organised using nVivo software, and the specific service entry criteria (including exclusion criteria) were coded under service types (such as 'CMHT'), so that data for each service type could be compared across trusts.

5.4.3.3 Data coding

The central question of the use of psychiatric diagnosis within service entry and eligibility criteria directed the initial phase of data coding and within each service type, data were coded into 'diagnostic' and 'non-diagnostic' categories of information. For example, the only non-diagnostic information coded to attention deficit hyperactivity disorder (ADHD) services was "...an open referral system for people over the age of 18 years. The person being referred must consent to this" (Trust P). Examples of diagnostic information coded for ADHD services included "The Adult ADHD service will accept both new referrals (for suspected ADHD in adulthood) and the transfer of care for individuals open to CAMHS or Paediatrics with an established diagnosis of ADHD" (Trust G) and "To provide assessment and/or follow up for people with symptoms of ADHD graduating from CAMHs, those adults with a previous diagnosis of ADHD not in Service and those adults with a suspected diagnosis of ADHD" (Trust A).

Some data extracts were coded into both categories. For example, "Services users with severe and persistent mental illness, such as schizophrenia, severe depression or bipolar

disorder” (CMHT, Trust I) contains information about the diagnoses accepted, but also about the severity of those difficulties.

Following the initial coding of the categorisation matrix of service types against diagnostic and non-diagnostic categories, the data extracts coded from each service to the ‘diagnostic’ and ‘non-diagnostic’ codes were read and re-read to identify themes against which the data could then be coded. For example, the service types were considered, such as whether these contained information about the diagnostic or non-diagnostic nature of the service (e.g. ADHD services compared with a homeless and traveller service in Trust K). The proportion of information coded to diagnostic compared with non-diagnostic codes was taken into account, such as the difference noted above in ADHD criteria whereby minimal information was coded to the non-diagnostic code and the majority of information was diagnostic. This process produced a coding framework of four service types; 1) broadly diagnostic specialist services; 2) problem-specific but non-diagnostic services; 3) services supporting specific life circumstances; and 4) needs led services providing specialist/particular services. All the data were then coded according to this framework. A further theme derived from the data was used to explore a finding that emerged during coding whereby diagnostic categories were frequently used in exclusion criteria across services. This theme is presented below as part of the findings and the analysis sought to explain why diagnostic labels were used within exclusion criteria.

The data from the two trusts that offered only a brief response (noted above) giving an overview of the process of referrals could not be coded in the same way as described above, as they did not include data for separate trusts, and nor did the data have clear delineations between diagnostic and non-diagnostic information. These data, therefore, were coded to a separate theme, ‘Central access and referrals’, so that these responses could nevertheless be included as part of the findings.

The development of the coding framework and the data assigned to it were discussed with the research supervisors in order to reach agreement and to ensure that the coding was grounded within the data rather than the positioning of the researcher.

5.5 Findings

The following findings section will demonstrate that with regards to use of diagnosis, there are five types of service within NHS mental health trusts in the north of England. These service types are outlined in Table 5-2 below, alongside an additional theme concerning the use of diagnosis within exclusion criteria. Each of these themes and subthemes will be discussed in detail below.

Table 5-2

Outline of themes and subthemes

Broadly diagnostic specialist services
Problem-specific but non-diagnostic services
Services supporting specific life circumstances
Needs led services providing specialist/particular services

Central access and referrals**Exclusion criteria**

Exclusion on the basis of a person's needs being too low

Exclusion on the basis of a person's needs being too high

Inappropriate service

5.5.1 Broadly diagnostic specialist services

A breakdown of diagnostic services is given in Table 5-3 below. Additional criteria were reported by some trusts for older adults-specific services; these are noted in the table.

Table 5-3

Number of trusts reporting service entry criteria for broadly diagnostic services

Number of Trusts	Service
8	Early intervention in psychosis (EIP)
6	Improving access to psychological therapies (IAPT)
5+2	Memory / cognitive assessment + dementia service for younger people
3	Learning disabilities (LD)
3	Attention deficit hyperactivity disorder (ADHD)
3	Eating disorders
3	Personality disorders
1	Gender identity difficulties
1	Psychological medicine

Note: '+' denotes number of trusts reporting criteria for older-adults specific services of that type

The services within the broadly diagnostic theme were for the most part specialist services. The services categorised to this theme are described as 'broadly diagnostic' because

diagnostic labels were used predominantly as a signpost to what types of difficulties would be supported within the services, however, other measures and non-diagnostic information were also used in the service entry criteria, as will be discussed below. Services that typified this description were, for example, those for adults with diagnoses of ADHD, or learning disabilities (LD). Three service types were for the specific assessment and intervention of a particular diagnosis (ADHD, dementia, gender identity difficulties). These services were described as being for individuals seeking assessment for the diagnoses concerned, where the diagnosis had been potentially indicated, or already formally given. For example, “To provide assessment and/or follow up for people with symptoms of ADHD graduating from CAMHS, those adults with a previous diagnosis of ADHD not in Service and those adults with a suspected diagnosis of ADHD” (Trust A).

EIP services all relied upon identification or suspected presence of psychosis as part of their entry criteria, and so have been organised under the ‘broadly diagnostic’ category. EIP services, however, are also a special case. Interventions are provided for a specific band of experiences across psychosis, which is not a formal diagnosis in itself, often with less of a focus on formal ICD or DSM diagnoses, such as schizophrenia. More than one team specified an emphasis on symptoms, “Acceptance will be based on symptom presentation rather than diagnostic criteria” (Trust D), and another defined psychosis as “distressing hallucinations or delusional beliefs of sufficient intensity and frequency” (Trust N), which is a much looser definition than the diagnostic criteria for any psychosis-related diagnoses in classification manuals. Two highlighted working with “diagnostic uncertainty” (Trust F and Trust N), whereby the teams assess and work with people’s experiences even where a diagnosis appears unclear. Trust N went on to state, “acceptance is irrespective of potential diagnosis”. Furthermore, six of the eight trusts reporting criteria for EIP services made specific mention of pathways for those presenting with an “At Risk Mental State” (ARMS), which is explicitly for people not currently meeting criteria for psychosis but who report what are seen as attenuated psychotic symptoms or other experiences considered to be prodromal symptoms of psychosis (Broome et al., 2005). Thus, although EIP services are broadly diagnostic, these services vary according to how much value is placed on specific diagnostic categories.

Some services within the broadly diagnostic theme were specific, not only to a range of difficulties or diagnoses, but also to a particular level of severity. IAPT falls within this group, being largely centred around depression and anxiety diagnoses and associated difficulties contained within several other diagnoses, such as phobias and body dysmorphic disorder. In many ways IAPT services are very diagnostic, commissioned on the basis of particular diagnoses (Clark, 2011) and audited on whether the therapies provided are in line with the diagnosis according to NICE guidelines (Royal College of Psychiatrists, 2011, 2013). The entry criteria for IAPT services reflected this; with some trusts identifying a few diagnoses,

“Individuals suffering depression and/or anxiety and/or stress or an anxiety disorder, or living with a long term physical health condition that has a psychological impact” (Trust K), to others giving lists of a dozen different diagnoses with a statement that treatment “is primarily provided for the following psychological problems only” (e.g. Trust F and Trust J). However, these diagnoses are used as a proxy for indicating a particular need, at a specific severity of difficulties, for people who “experience mild or moderate social and /or functional impairment” (Trust F). Services in two trusts (Trust F and Trust J) used a formal rating scale to assess level of functioning. Exclusions for IAPT included some diagnostic criteria, including psychosis, bipolar disorder or personality disorder, however these diagnoses are again used as an indication of “severe and enduring mental health problems”, and tied in with other exclusion criteria such as “medium to high levels of risk” and “difficulties which prevent [service users] from engaging effectively in short term therapy”. Other services were those working with people with diagnoses of personality disorders and eating disorders. Similarly, personality disorder services represented services that see people with potentially broad bands of difficulties, which were largely diagnostic but criteria also explicitly required potential service users have complex needs and significant risk associated with the diagnosis that necessitated such a specialist service. Specialist eating disorders services’ criteria had a minor remit focussed on diagnoses, however within these were also requirements that service users should have ‘moderate to severe Anorexia Nervosa...severe Bulimia Nervosa’ (Trust M). These criteria indicate a particular level of severity, with an expectation that mild to moderate eating difficulties would be seen in primary care, or other non-specialist services. It is therefore evident that despite the existence of specialist services commissioned around particular diagnoses, clients with those diagnoses are not seen exclusively within that service.

5.5.2 Problem-specific but non-diagnostic services

A breakdown of problem-specific but non-diagnostic services is given in Table 5-4 below.

Table 5-4

Number of trusts reporting service entry criteria for problem-specific but non-diagnostic services

Number of Trusts	Service
2	Psychosexual
1	Traumatic stress
1	Alcohol
1	Substance misuse

These services relied on descriptions of problems without referring to diagnosis in their entry criteria. These services provided interventions for collections of similar difficulties, to organise and access specialist care, but without diagnostic indicators. Examples from this theme are services that provide interventions for traumatic stress, psychosexual, and alcohol and substance misuse problems. Although for each of these problem descriptions there is more than one DSM or ICD diagnosis that could be associated with it (for instance, DSM or ICD diagnoses of substance misuse disorders), the criteria for these services used broad descriptions that did not make reference to diagnostic categories. For example, the psychosexual services used age and descriptions such as “All adults (individuals and couples) who are experiencing relationship difficulties or sexual dysfunction with likely psychosexual components” (Trust K). The traumatic stress service (Trust G) used a checklist tool to determine the severity of presenting difficulties, stating it is, “a specialist service and is provided for patients who are assessed as experiencing severe or extreme symptoms. It is assumed that local teams will have the skills and capacity to provide assessment and treatment for patients who present with mild to moderate symptoms of trauma” (Trust G). These services offer an example of specialist teams working together with specialist skills, but also indicative of how NHS trusts can design, commission and manage services without necessarily relying on diagnoses.

5.5.3 Services supporting specific life circumstances

A breakdown of the services supporting specific life circumstances is given in Table 5-5 below.

Table 5-5

Number of trusts reporting service entry criteria for services that support specific life circumstances

Number of Trusts	Service
2	Military veterans
1	Homeless and traveller
1	Perinatal mental health

Some of the less common services for which criteria were given had seemingly been established pragmatically in response to local need. These services did not work with specific diagnoses but instead worked with individuals experiencing particular life circumstances. The veterans’ services, for example, described a clear need for flexible, open provisions for a group that may not always be best served by traditional mental health

services; “The whole ethos of the service is to be more responsive and accessible to this hard to reach cohort” (Trust P):

The individual must be suitable for psychological therapy but unable or unwilling to access local mainstream services. The [service] does accept referrals for veterans whose mental health problems are co-morbid with alcohol/substance misuse, and those with significant forensic histories... (Trust F)

The homeless and traveller service (Trust K) offers support to groups of people who may represent diverse demographics and difficulties but are similar in their accommodation status; “Homeless families in temporary accommodation and refuges; Young people (16-19 years), pregnant women and adults in temporary accommodation and hostels; Gypsies and Travellers.” It is therefore implied that this service makes provisions for the adaptations required to meet the needs of an itinerant or insecurely housed population.

5.5.4 Needs led services providing specialist/particular services

The largest group of services has been categorised as needs led. A breakdown of these services is given in table 5-6. Rather than being ordered by frequency as with Tables 5-2 to 5-5, Table 5-6 is ordered to give a sense of the level of need or severity required to access the service, beginning with the highest need. Additional criteria were reported by some trusts for older adults-specific services; as in Table 5-3, these are noted in the table.

Table 5-6

Number of trusts reporting service entry criteria for needs-led services

Number of Trusts	Service
3	Secure services
4	Psychiatric intensive care units (PICU)
5+1	Inpatients
4	Rehabilitation
5	Crisis services
5+2	Home treatment team (HTT)
4+1	Assertive outreach
1	Acute day service
5+1	Liaison psychiatry
1	Complex needs
4+2	Psychological therapies

11+5	Community mental health team (CMHT)
2	Community services (psychosis)
2	Community services (non-psychosis)
2	Electroconvulsive therapy (ECT)
3	Recovery services
5	Single point of access & other access teams
1	Primary care (not IAPT)
1	Respite care
1	Liaison and diversion (offence-related)
1	Community mental health nursing service

Note: '+' denotes number of trusts reporting criteria for older-adults specific services of that type

Whilst criteria for these services often require a diagnosis of a mental health problem, they are non-specific, such as “patients who present with significant disability due to mental illness” (assertive outreach service, Trust D). Examples of needs led services include psychiatric intensive care units (PICU), crisis services, including home treatment teams (HTTs), and CMHTs.

CMHTs dominated the responses received, being the most common service to be reported across all of the trusts. Some CMHTs gave examples of diagnoses, but as with the specialist services these also indicate a particular level of severity and need, “Individuals accessing secondary care services are most likely to be: Services users with severe and persistent mental illness, such as schizophrenia, severe depression or bipolar disorder” (Trust I). The level of support required is also used to override diagnostic inclusion criteria, for example, although typically accepted diagnoses might be schizophrenia or bipolar disorder, two CMHTs stated that they would also accept “Any disorder where there is significant risk of self harm or harm to others (e.g. acute depression, anorexia, high levels of anxiety) where the level of support exceeds that which the primary care team can offer” (Trust I and Trust M). Where lists of accepted diagnoses were offered, additional qualifiers were given that indicated the relevant level of need required to access the service, such as “Psychotic disorders that cannot be managed within primary care services due to severity or because of complex and enduring need...Severe types of obsessive/compulsive disorder, phobia, anxiety disorders that significantly impair social functioning” (Trust P). Non-diagnostic factors made up most of the criteria for CMHTs; other than geographical criteria these focused on the level of input that services could provide, such as “People who have substantial and complex mental health needs which cannot be met by primary care, the IAPT Service or other community services” (Trust A and Trust K), and that require a “skilled or intensive treatment, multi agency approach” (Trust F). Frequently named non-diagnostic factors or difficulties were significant levels of risk (“Complex presentations with a significant risk of self-harm, harm to others, risk of harm from others or serious self-neglect”, Trust A),

impaired functioning and other disability, “Suffer substantial disability as a result of their illness, such as an inability to care for themselves independently, sustain relationships or employment” (Trust D). Two trusts (Trust N and Trust P) had divided their CMHTs into two pathways, identifying broad categories of ‘psychosis’ and ‘non-psychosis’, akin to the wide-ranging diagnostic, or quasi-diagnostic, use of ‘common mental disorder’ in IAPT. This distinction between the two intervention pathways appeared to reflect the different needs that these two groups have. For example, the psychosis pathway for Trust P emphasised “proactive interventions” to help with “poor treatment adherence”.

Other examples of needs led services included Psychiatric Intensive Care Units (PICUs), which similarly required that difficulties be “only in the context of a serious mental disorder” (Trust A), but the overarching emphasis across PICU entry criteria was of the level of care needed by individuals. For example, “...assessment will always be based on clinical need. Patients will only be admitted if they display a level of risk aggression [*sic*] that presents as risk to self, others and property” (Trust H). HTTs’ criteria specified mental health problems, such as “Acute onset of a suspected psychiatric illness”, but given the pragmatic nature of HTTs, designed to be a last port of call of intensive intervention to attempt to avoid inpatient admission, the focus was on individuals’ needing such a high level of care:

- Crisis likely to necessitate psychiatric inpatient admission
- Imminent risk of harm to self or others by a service user experiencing mental health problems.
- Early intervention is required to prevent relapse... (Trust J).

One trust noted, “Decisions on whether someone should be accepted for services are based on their health and social care needs as a whole and not on Diagnosis alone” (Trust I), and this balance between assessing the experiences of an individual alongside their needs and what could be provided within a given service was a common thread that ran throughout the needs led service criteria.

5.5.5 Central access and referrals

Two trusts gave a brief overview of the process of accessing services without giving a breakdown of their individual adult mental health services.

Trust B offered information for a Single Point of Access team for primary care referrals as other trusts had done, but no further details regarding individual services. Referrals may be directly triaged to secondary care services “if the referral indicates longer term support of potential severe and enduring mental illness.” This approach outlines the nature of stepped care, separating between differing levels of support needs. The broad diagnostic category of

'severe and enduring mental illness' is used, as within inclusion criteria for CMHTs and exclusion criteria for IAPT, as an indication of level of complexity and therefore need.

Trust E outlined their referral service, which is an innovative first point of access service, developed following a pilot with the local CCG. The information provided under the FOI response outlines the service as carrying out initial screening and forwarding of referrals onto relevant services "based on the clinical and risk information contained in the referral documentation." Where the service refers an individual to secondary care, a mental health practitioner undertakes a developmental biopsychosocial approach to assess vulnerability, precipitating and maintaining factors in clients' mental health problems, with a focus on external factors where necessary (Social Care Institute for Excellence, 2006). The eligibility criteria for secondary care services included the same broad stipulation of a 'severe and enduring mental health problem' but also an 'and/or' requirement of 'social care needs', which included an extended outline of need, including difficulties related to activities of daily living, such as "being able to make use of one's home safely...developing and maintaining family or other personal relationships", and the requirement that these difficulties had "a substantial impact on the person's wellbeing" (Trust E). Each of the overall access criteria for both Trust B and Trust E demonstrate a system with greater scope for flexibility within the assessment process, with an emphasis on triage and service response on the basis of differing level of support need.

5.5.6 Exclusion criteria

Diagnoses were frequently used in exclusion criteria across services, irrespective of whether these services were diagnostic or needs led, and so forth, therefore these criteria were compared and analysed. The most commonly cited diagnoses in exclusion criteria were drug or alcohol misuse and dependency, organic or degenerative conditions such as dementia, and LD or autistic spectrum diagnoses, followed by 'severe and enduring mental illness', with examples given of personality disorder, schizophrenia, and bipolar disorder diagnoses.

In considering for what these diagnoses may be a proxy, the use of diagnoses in exclusion criteria can be divided into three categories:

- Exclusion on the basis of a person's needs being too low
- Exclusion on the basis of a person's needs being too high
- Inappropriate service

5.5.6.1 *Exclusion on the basis of a person's needs being too low*

Exclusion on the basis of low need was sometimes described by higher support services, for example mild to moderate difficulties would not usually be seen in a CMHT. However, as

mentioned earlier within the context of CMHTs, these decisions might be overruled by clinical need, for example, within the exclusion criteria for a specialist psychological therapies service, “People who have mild to moderate mental health needs unless other interventions and treatments have failed...People whose assessed needs are classed as moderate to low unless specialist intervention is necessary to prevent an imminent risk of deterioration” (Trust I).

5.5.6.2 *Exclusion on the basis of a person’s needs being too high*

Exclusion on the basis of high need was frequently noted in lower level services, particularly within primary care. For example, “Severe and enduring mental illness or in need of complex care package” (Trust N, Primary care), which is listed within the context of other exclusion criteria such as high risk.

5.5.6.3 *Inappropriate service*

Where excluded diagnoses indicate that a service is inappropriate for particular difficulties, these diagnoses tended to be alcohol or substance misuse or dependency, organic problems or learning disabilities. These diagnoses indicate a need for particular intervention or skills that are available in specialist services.

Some trusts’ responses were more explicit about why particular diagnoses were excluded from their service entry and eligibility criteria. These descriptions give an indication of what these diagnoses represent, and therefore the roles these diagnostic labels have in such criteria. For example: “When clear evidence of diagnosable antisocial personality disorder which infers significant risk.” (Trust N, EIP) and “...repeat suicide attempts, deliberate self-harm, other impulsive self-injurious behaviours likely to indicate personality problems requiring interventions around emotion regulation” (Trust H, IAPT). The same service stated:

Individuals with a current diagnosis of a personality disorder or PD traits which prevents them from engaging effectively in short term therapy e.g. patients for whom low mood or anxiety is a co-morbid feature of a personality disorder which require intervention in themselves. (Trust H, IAPT)

These represent clearer indications of why particular diagnostic categories might be excluded, describing specific difficulties or levels of need that cannot be appropriately managed within these particular services. This issue is discussed further in the following discussion section.

Non-diagnostic exclusion criteria included descriptive information to the same effect; for example, exclusion criteria for one psychosexual service were based on difficulties outside of the remit of the support offered:

We are not able to offer the service to patients whose sexual difficulties or behaviour have brought, or are at risk of bringing, them into conflict with the law; patients with advanced sexual or other addictions; patients who pose high risk of harm to self or others... (Trust A).

5.6 Discussion

This chapter addressed the second theoretical question outlined in Chapter 2 (Section 2.4.2); how are psychiatric diagnostic categories used in practice? The analysis of data derived from the FOI requests made to NHS mental health trusts in the north of England demonstrated that diagnosis was neither necessary nor sufficient in establishing service entry criteria. Even where service entry criteria were mostly diagnostic in character, these diagnoses denote the presence of specific problems at a specific level of need, which could arguably be established in other ways, as evidenced by the other less diagnostic-focused service types that identify and work with specific difficulties (such as traumatic stress) or at particular levels of service need (such as community mental health and home treatment teams). As was expected given the process of local commissioning that is negotiated between CCGs and individual NHS trusts, service provision was heterogeneous across the north of England NHS mental health trusts. This heterogeneity of services represents a system that is responsive to local need, where different practical solutions are established to best meet the needs of the local population. The service entry criteria data may not be able to identify whether or not more diagnostic services better meet clients' needs, but it is evident that diagnosis does not play an essential role in differentiating between services.

This discussion will explore the following matters:

- How 'diagnostic' are diagnostic services?
- The use of broad, quasi-diagnostic, categories
- The use of diagnoses in exclusion criteria
- Wider uses of diagnosis
- Clinical implications
- Future research

5.6.1 How diagnostic are diagnostic services?

Diagnostic categories are used to narrow the focus of a service, however a range of additional information is necessary to ascertain which service is appropriate for clients, such

as the severity of difficulties and their impact upon a person's functioning. Three services of this type worked with specific diagnostic categories; ADHD, gender identity difficulties, and dementia. However the majority identified broad bands of diagnoses, such as LD, personality disorders, and mild to moderate mental health difficulties (IAPT). One such service type was early intervention in psychosis (EIP), which was the most commonly given service criteria of the broadly diagnostic service types. EIP services represent a broad range of experiences and diagnoses under 'psychosis', not a DSM or ICD diagnostic category in itself. Some EIP services made explicit mention of a focus on symptoms, and others of using a 'diagnostic uncertainty' approach. Most EIP services also had an ARMS pathway for those considered to be at risk of, but not currently experiencing, a psychotic episode. With less of a focus on diagnosis, EIP services, therefore, appear to represent an exception to what would typically be seen as diagnostic specific services, such as eating disorders. However, EIP services work with a more specific range of difficulties than some of the broad ranges of diagnostic services; difficulties for EIP are limited to 'psychosis', compared with the wide range of diagnoses named in the criteria for IAPT services. They work with a particular client group and ethos, with the focus being on early intervention and when people's difficulties may not be as clear, but they nevertheless represent a service type that has a particular range of skills for a particular set of people, that does not rely on diagnosis. Rather than diagnostic divisions being essential, it could alternatively be argued that the 'broadly diagnostic' services are about competency-based teams working together because they have a specialist skillset necessary to work with particular difficulties, and perhaps a particular ethos, in the case of some EIP teams.

5.6.2 Use of broad, quasi-diagnostic, categories

Labels such as "severe and enduring mental illness" are referred to here as broad or quasi-diagnostic categories, however, they are not diagnostic categories in the sense of current classification systems, and bear very little resemblance to DSM or ICD categories. Such terms may have clinical or financial utility in organising services, such as identifying "common mental health problems" for IAPT services, or separating between "psychosis" and "non-psychosis"/"affective disorders" for those trusts that divided their CMHT streams into two intervention pathways. These broad categories of diagnosis reflect the heuristic uses of diagnostic categories seen in Chapter 4. However, such categories are very different to the "rational, careful, respectful, diagnosis" (Callard et al., 2013, p. 2) that is advocated by diagnostic classification.

5.6.3 Use of diagnoses in exclusion criteria

The analysis of the use of diagnoses in service exclusion criteria suggested that diagnoses are being used as a proxy for other information. The data showed that typical diagnoses of

exclusion were categories such as LD, personality disorders, attention deficit hyperactivity disorder, and psychosis; each associated with typically higher levels of care input or other specialist skills. Where diagnoses are used within exclusion criteria, such as “The service is not normally open to service users with a primary diagnosis of schizophrenia (or other psychotic disorders), bipolar disorder, dementia, clients with moderate LD and clients who have a history of sexual offences” (Trust F, personality disorders service), those diagnoses are often used as a way of indicating the types of difficulties that might interfere with an individual’s ability to engage with the therapeutic interventions on offer, such as group work. Alternatively, they might indicate that other teams may have specific skills to better support that person, for example, in the case of LD. However, even where diagnostic categories are used to indicate that a person’s needs would be more appropriately met by services that are commissioned elsewhere and for different difficulties, such as drug and alcohol abuse, and organic causes, these terms, although suggestive of diagnoses, are so broad as to be descriptive. Diagnoses are inefficient proxies for individuals’ needs, as evidenced by the fact that caveats and exceptions must be made on the basis of individual clinical assessment.

Whilst it is appropriate and good practice to signpost individuals to alternative services if their needs can be better met elsewhere, diagnostic categories may not be the most effective way of doing this. Not all services use diagnostic proxies, using more detailed factors such as risk, and where some trusts use diagnoses, criteria are used where services are more explicit about what difficulties a particular diagnosis might convey that make a service inappropriate for someone, such as “When clear evidence of diagnosable antisocial personality disorder which infers significant risk” (Trust N, EIP). Such descriptions represent a more nuanced clinical rationale, which can be applied to both inclusion and exclusion criteria, rather than a black and white inclusion or exclusion based on a given diagnosis. These descriptions are also more appropriate given the now well-established NHS policy that personality disorder is no longer a diagnosis of exclusion (NIMHE, 2003), despite its frequent occurrence in trust exclusion criteria. Common across each of the four categories of service types derived from the data was the indication that differences across service provision are driven more by professional competencies in specific teams than by diagnosis. Given the medical history of mental health services, diagnosis may be less a necessity for service entry criteria so much as a historical artefact.

5.6.4 Wider uses of diagnosis

The Mental Health Act (MHA) facilitates compulsory admission to hospital and guardianship orders within the context of an individual experiencing mental health problems. The 1983 version of the MHA identified broad categories of ‘mental disorder’, including ‘mental illness’, ‘severe mental impairment’, and ‘psychopathic disorder’. However, the 2007 amendments further reduced these categories, defining ‘mental disorder’ as “any disorder or disability of

the mind; and “mentally disordered” shall be construed accordingly...” (MHA, 2007, ch. 12, p. 1). Neither version of the MHA, therefore, includes a necessity that a specific DSM or ICD psychiatric diagnosis is assigned to an individual’s difficulties prior to admission. These references to ‘mental disorder’ hint towards but do not require the use of diagnoses, and are far from the rigorously applied criteria of diagnostic classification.

The two most commonly used sections of the MHA, Sections 2 and 3, require simply that the individual “is suffering from mental disorder of a nature or degree which warrants the detention of the patient in a hospital for assessment...” and “he is suffering from mental disorder of a nature or degree which makes it appropriate for him to receive medical treatment in a hospital” (Mental Health Act, 1983a, 1983b), and that both the assessment (Section 2) and treatment (Section 3) are in the interests of the health and safety of the individual concerned and the protection of others. Therefore, neither the wording of the MHA nor the data obtained from the FOI requests suggest that diagnosis is required for gatekeeping as was identified by clinicians in the previous chapter. The MHA and the Equality Act (2010) can be utilised to aid the clinician in achieving what is in the best interest of their clients, without using specific psychiatric diagnostic labels.

5.6.5 Clinical implications

Heterogeneity across services can encourage innovation, and this variation can offer trusts ways of learning from each other. Alternatives to diagnostic approaches are already embedded within NHS mental health services. The mental health system is evolving and may travel in either a more or less diagnostic direction. Local flexibility means that innovative pathways are developed, which can offer an understanding of the ways that services are evolving. For example, some trusts initiated demographic-specific services, such as those offering flexibility for military veterans, or the homeless and travellers, who each have individual needs that require specific approaches and competencies. Likewise, two trusts divided their CMHTs into psychosis and non-psychosis streams. These broad bands of difficulties may be a more useful or economical way to manage services to take account of these specific needs and competencies. Nevertheless, even needs led services are defined narrowly. These services acknowledge different levels of support, however they do not formally recognise other needs that are highlighted by the literature (discussed in Chapter 1, Section 1.3.2.1.2, Contextualising distress), such financial and income needs, home, family and social support, and specific interventions such as trauma therapy.

However, to adopt such innovative practices, including non-diagnostic approaches to service delivery, it is necessary to dispel myths; including the myth that diagnoses such as those in ICD and DSM are necessary for service planning and delivery. The use of broad pseudo-diagnostic categories for important gatekeeping functions of both service entry criteria and

the MHA are significant. These ways of taking up diagnosis are at odds with the DSM and ICD models, new versions of which seek to increasingly define diagnoses in more precise ways (Kupfer et al., 2002). The model of diagnostic classification places an emphasis on specificity and detail, and of tightening the diagnostic system (Frances, 2014). However, in practice, mental health services and legal systems use much broader, more flexible definitions.

5.6.6 Future research

Future research exploring these implications could usefully subject the alternatives, including diagnosis-led approaches, to empirical tests, in order to compare whether individuals would have better access to services and receive better care if services use diagnostic versus non-diagnostic entry criteria. Research should aim to establish in which context, for which type of problems, non-diagnostic versus diagnostic models would be best, as well as further exploring whether the use of broad, quasi-diagnostic categories are more effective, flexible ways of signposting appropriate services than specific diagnoses.

From an early intervention perspective, empirical research should be used to identify whether assessment and intervention provided on the basis of need rather than meeting diagnostic criteria would allow earlier, and therefore more effective, intervention in order to reduce the progression of difficulties. A recent study (Cross, Hermens, Scott, Salvador-Carulla, & Hickie, 2016) of youth mental health care found that individuals with more clear cut cross-sectional profiles of difficulties that met diagnostic criteria received more care input than did those with less clear presentations, irrespective of the potential trajectory of their difficulties or impairment in functioning. Lack of a current DSM diagnosis was associated with receiving less care than was indicated by their level of functional impairment. The authors suggested that clinicians might have biases towards offering more care towards those with clearer diagnoses. Research should establish whether these findings apply more widely across mental health care, and if a more descriptive approach based not on diagnosis but on severity, level of impairment, and support needs could better support service users.

Regarding the frequent use of specific diagnoses in exclusion criteria, and common occurrence of 'comorbidity' or multiple difficulties, research could usefully establish whether having a particular diagnostic label precludes individuals from accessing a service that would otherwise be the most appropriate to meet their needs. Closer links and inter-team working between services might be used to advise on better managing individuals' needs where multiple difficulties are experienced that with very diagnostic-led services may lead to an individual being shoehorned into a particular service due to a 'primary diagnosis' but have other needs left unmet.

5.7 Conclusions

This chapter has used data acquired through FOI requests to NHS mental health trusts in the north of England to explore how psychiatric diagnosis is used in service entry and eligibility criteria. The findings demonstrate that psychiatric diagnosis is neither necessary nor sufficient in planning service entry. Some services used diagnostic labels and these represented specific difficulties but also a particular level of severity or need. As with the clinicians in the previous chapter, broad, quasi-diagnostic categories are used by services, which give an indication of the type and severity of distress experienced. However, it can be argued that these broad categories act as a proxy for the team competencies required to work with particular expressions of distress. The largest group of services was more explicitly oriented towards individual needs and team competencies, and innovative services worked with specific life circumstances. However, services could go further to incorporate more generally applicable life factors and needs, such as social, financial, and trauma-related interventions and support.

6 Chapter 6: Ways in which psychiatric diagnosis travels beyond the clinic: The practices of recording diagnoses

6.1 Abstract

Beyond the clinical settings described in Chapters 4 and 5, diagnosis is used in a variety of different functions and contexts. This chapter explores the travel of psychiatric diagnoses beyond the clinic through its formal record on health records and other paperwork. Interview data from clinicians and services users is contextualised using information about the uses of diagnosis in other spheres, such as NHS outcomes and incentives frameworks policies. This data is used to analyse the ways in which different social spheres, including business, legal, and social worlds, take up psychiatric diagnoses and use them for differing purposes that move the categories beyond the clinical setting. The findings demonstrate that diagnoses are used to facilitate cooperation between the clinical context and these other contexts. Clinicians use diagnoses pragmatically to achieve their clinical aims and to meet service users' needs, however, beyond the individual clinical context, diagnoses are used as inflexible categories and without the nuances of clinical use. What begins as a flexibly used category in the clinic is stabilised by its documentation on health records, legal forms, and other formal paperwork. The changing conceptualisation of psychiatric diagnoses beyond the clinic demonstrates their 'progressive reification'. The implications for clinical work, recipients of diagnosis, research and data capture are explored.

6.2 Introduction

6.2.1 Moving from flexible local uses of diagnosis beyond the immediate clinical relationship

The previous chapters outline clinicians' and services' flexible and pragmatic uses of diagnosis as an individual clinical tool and within service entry criteria. Clinicians, even those who do not use diagnosis predominantly in their individual clinical work, described a need to use diagnosis at administrative and bureaucratic levels. Beyond the individual clinic setting, diagnosis is used in a variety of different ways and contexts, which this chapter explores. Clinicians are encouraged by services to record a diagnosis on the individual's electronic health record. This information is then used for a variety of purposes by health systems, including audit, quality targets, funding and commissioning, which will be discussed throughout this chapter (e.g. Mazars LLP, 2013). Often, different forms of support or intervention must be accessed beyond the relationship between the assessing health professional and their client. In such cases, clinicians need a way of communicating

information about a person's mental health difficulties to other health professionals, mental health services, and on clinical legal paperwork to enforce treatment.

6.2.2 Use of diagnoses in organisations outside of the NHS

Outside of health services, the clinician and the recipient of the diagnosis may need to convey this information to non-clinical bodies; governmental departments such as the Department for Work and Pensions (DWP) or the Criminal Justice System, and regulatory agencies such as the Driver and Vehicle Licensing Agency. Less formally, information may need to be passed on to an individual's place of work or study. Diagnosis is typically used as a means of conveying this information (e.g. Burton, 2011). As has been discussed in earlier chapters diagnosis has multiple functions. Records of psychiatric diagnosis take on different roles according to their context. For a lawyer in a Mental Health Act (MHA, 1983) tribunal, a diagnosis on a legal report is an indication of a particular level of risk and need. For the DWP, a diagnosis on a benefits application is an indication of functional impairment, a justification for receiving welfare payments.

6.2.3 Rationale: Analysis of the travel of diagnostic records

Critical sociological study argues that psychiatric records should be read not simply as descriptions of a patient's behaviour, but instead viewed as "procedures and consequences of clinical activities as a medico-legal enterprise" (Garfinkel & Bittner, 1967, p. 168). These records, therefore, and the practices associated with them, can reveal important information about the functions of diagnosis, how they are used, and their consequences.

6.3 Aims

This chapter addresses the second and third theoretical questions outlined in Chapter 2 (Section 2.4.2); 2) how are psychiatric diagnostic categories used in practice? And 3) what do diagnostic categories produce; what are their implications?

The purpose of this chapter was to explore the practices of recording psychiatric diagnosis on health records and other formal paperwork, and to analyse the ways in which different social spheres, including business, legal, and social worlds, take up psychiatric diagnoses and use them for differing purposes that move diagnostic categories beyond the clinical setting, and evaluated the consequences of these practices.

6.4 Methodology

Data for this chapter are predominantly from the interviews carried out with clinicians, who reported routinely recording psychiatric diagnoses for administrative and clinical purposes. One quote is used from an interview conducted with a service user; this quote is used at the start of the findings section to frame the analysis.

The methodology for clinicians' interview data collection is described in the main in Chapter 4, Section 4.4. The methodology for service users' interview data collection is described in Chapter 7, Section 7.4. Data were organised, coded, and analysed according to the methods described in Chapter 4, Section 4.4.5.

6.4.1 Presentation of findings

The three domains derived from analysis of the full dataset of interviews with clinicians and service users are described in Chapter 4, Section 4.4.5.7. Figure 6-1, on the following page, is presented to remind the reader of these domains, their themes and subthemes. This chapter presents findings from the second area: The travel of psychiatric diagnosis beyond the clinic through formal records.

The interview data is presented alongside information about the policies and processes of the adjoining social worlds across which diagnosis is used to communicate, for example, NHS outcomes and incentives frameworks. This information is presented so as to contextualise the interview data, giving a richer understanding of the purposes and practices of the formal recording of psychiatric diagnoses.

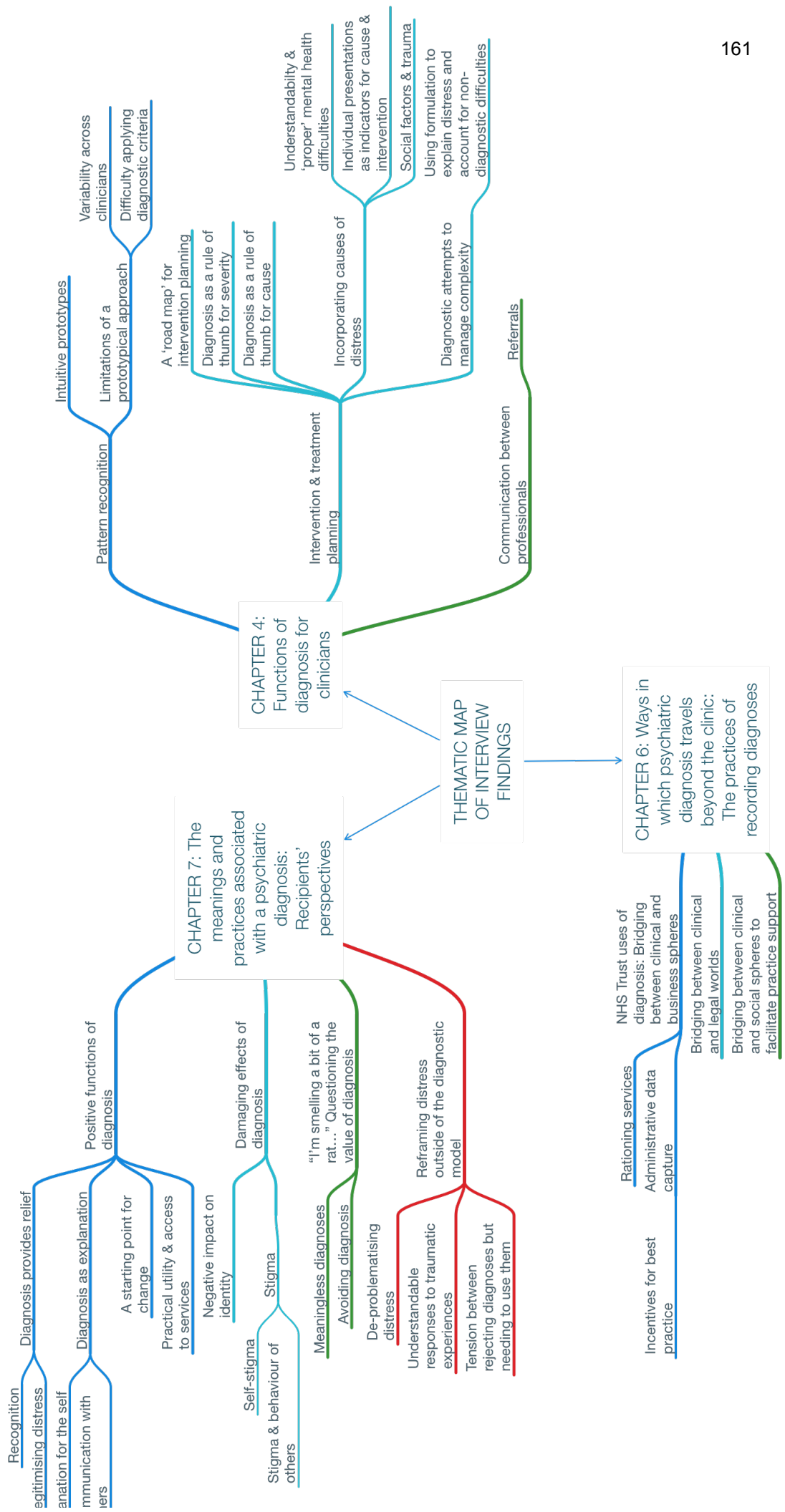


Figure 6-1: Thematic map showing themes and subthemes from the three domains of findings of the interview data analysis

6.5 Findings

The following findings will demonstrate that the recording of diagnosis is ubiquitous in communicating information beyond the clinical assessment. Clinicians, particularly psychiatrists and GPs, are encouraged by services to record psychiatric diagnoses for their clients. However, clinicians described their practices of recording diagnoses as oriented towards achieving particular aims, such that the categories represent pragmatic ways of navigating bureaucratic systems. Clinicians described potential for diagnostic labels to ‘stick’ once recorded, both personally for recipients of diagnoses, and administratively being difficult to remove. Conceptualisations of diagnoses change from the flexible clinical uses described here and in Chapter 4, to fixed inflexible categories once recorded. Clinicians’ practices demonstrated this awareness, judiciously applying diagnoses to reflect a balance between meeting clinical needs and reluctance to record an uncertain diagnosis, not least as a result of the potentially stigmatising impact for service users of recording a psychiatric diagnosis on official documentations. Table 6-1, below, outlines the themes presented in the findings; each of these is explored in detail in the following section.

Table 6-1

Outline of themes and subthemes

NHS uses of diagnosis: Bridging between clinical and business spheres

Rationing services

Administrative data capture

Diagnoses and incentives for best practice

Bridging between clinical and legal worlds

Bridging between clinical and social spheres to facilitate practice support

The following quote from a service user illustrates the potential for inconsistencies between types of records and their different uses as a result of the flexible ways in which diagnoses are used for different purposes. The impact of psychiatric diagnoses for service users is explored in Chapter 7; however, this quote is used to frame the following findings section. In her appointments with health professionals (her GP, and two different psychiatrists), Service User 22 was variously told that she had borderline personality disorder, bipolar disorder and depression, and she had been referred to a treatment programme for people with personality disorder diagnoses:

I’ve had problems in work recently, and I told, they knew about my diagnosis of BPD [borderline personality disorder], and I told them when they said bipolar as well,

which my work thought was like the right diagnosis, because they were saying we can see your ups and downs and that, and I had an incident in work, and they'd requested a psychiatrists' report, and I've seen the report, and it says depression, so it makes me look like I've lied to work, saying that I've got BPD, when they haven't diagnosed me with it, but yeah they wrote on the letter that they're treating me for depression. (Service User 22)

Potential problematic implications for the client are highlighted not only when different categories are used to perform different functions, as with Service User 22, but also when the diagnosis is used in a social setting (such as work) and conceptualised differently to flexible clinical uses, as a fixed label rather than a loose category, pragmatically applied.

6.5.1 NHS uses of diagnosis: Bridging between clinical and business spheres

The recording of psychiatric diagnoses on a person's health records has both clinical and business-related functions. Once a diagnosis has been recorded, this information is used to inform both individualised care plans and generalised data capture that is used at a trust level. Clinicians reported the recording of diagnostic categories as an important part of clinical practice; as one psychiatrist remarked, "virtually any document we write will, will have a sort of diagnosis written on it I guess" (Psychiatrist 9). Although diagnostic categories were critiqued in their utility for individual clinical use, as discussed in Chapter 4, they were nevertheless strongly valued for other, often administrative uses. Referring to the brevity of a diagnostic label, one psychiatrist remarked:

I think you might as well just have one word really...I think the current system is probably ok for that, because it's, there's so much diversity that you're just not going to cover it all in a different system, for information gathering... (Psychiatrist 1)

6.5.1.1 *Rationing services*

Diagnosis was used as a way of giving reason to why a person cannot be seen in a particular service, and forwarding them on elsewhere, as was described in the theme of 'exclusion criteria' in Chapter 5. Clinicians described this type of gatekeeping in political terms over clinical utility; for example, the limitations imposed by commissioning on the basis of divisions made between diagnoses. Forensic or secure mental health services, for example, commonly do not accept someone with a primary or only diagnosis of a personality disorder, because these services should be commissioned elsewhere. Where more general services, such as community mental health teams (CMHTs), are struggling to manage large caseloads or limited resources, diagnoses are used in effect to move clients to a more specific service that might be able to accept them. This appeared to be a way of at once

accessing the timeliest and most appropriate care for clients, and of reducing the burden on the original service:

I think often it can be, feels like it can be kind of used a bit politically, kind of between services, so if erm, somebody, if, if kind of, I don't know, services are stretched and kind of somebody thinks that actually we'd be the best kind of service for them, and then you can often see kind of diagnosis being kind of bandied around as a, as a kind of way in... (Psychologist 7)

Clinicians who worked particularly within forensic and secure units noted how the gatekeeping role of the distinction made between diagnoses of personality disorder versus 'mental illness' could be a useful differentiation. This translation of difficulties into two broad categories that are used to differentiate between services creates a temporary sense of certainty for gatekeeping purposes. However, clinicians also described the confusion and problematic consequences that such distinctions can also create:

...the thing that comes up usually is whether or not erm, people wonder whether someone has a personality disorder, or whether they're having psychosis, so that's the question that I'm asked, which has so many assumptions in the question, it's, you, you kind of feel like you need to unpack the question before you can answer it... (Psychologist 8)

Personality disorder was described as being used as a diagnosis of exclusion, despite policy against this practice (NIMHE, 2003); "there is quite a lot of stigma and erm, exclusion on the basis of diagnoses, erm, even when there, there's a kind of, 'we don't do it', it's like well, you kind of do..." (Psychologist 9); "I still think there probably is, an exclusion criteria, although it's not supposed to be, of a personality disorder" (Psychologist 3). Psychologists described trying to circumvent these requirements by focusing on other factors that would impact upon their decision whether or not to accept a person into the service, for example writing a tribunal report to argue that the level of risk is more important than whether the diagnosis should be of personality disorder or mental illness (Psychologist 3).

6.5.1.2 *Administrative data capture*

Of those clinicians interviewed, psychiatrists and GPs, but not psychologists, were expected by trusts to use diagnoses administratively, including having a responsibility for recording a diagnosis, and/or a care cluster for Payments by Results (PbR) systems, for example needing an ICD-10 code on online records and discharge summaries. As such, psychiatrists and GPs are positioned within services as seeing diagnosis as having a separate administrative purpose as well as clinical, including communication to other health

professionals via the client record system. Similarly in contrast with psychologists, psychiatrists spoke about being subject to “political, internal sort of monetary pressures I guess to make a diagnosis” (Psychiatrist 6) due to commissioning targets, and trust investments ahead of the introduction of PbR systems and other mechanisms for service planning:

...all consultants are required to erm, make a note of the diagnosis of the patient...I've got about 750 patients, so I'm supposed to go on this portal we have, online portal, to record the diagnosis, so we can map out, Dr__ has how many dementia patients, how many functional patients, which'll then have an impact on the number of nurses that deploy...so in terms of service delivery that's certainly one use... (Psychiatrist 8)

6.5.1.2.1 Diagnoses and incentives for best practice

The Quality Outcomes Framework (QOF) is a voluntary participation NHS reward programme for general practice, incentivising data recording and target outcomes. Statistical data derived from the programme includes the prevalence of various common diagnoses of particular public health concern, and achievement based on meeting targets, such as the “percentage of patients with schizophrenia, bipolar affective disorder and other psychoses who have a record of blood pressure in the preceding 12 months” (NHS England, 2016a, p. 21). Although voluntary, participation is high, with 96% of GP practices participating in the reporting year 2015-2016 (NHS Digital, 2016a). Practices are rewarded using a points system of payment, with one QOF point in 2016/17 worth £165.18, up to a maximum of 559 available points (NHS England, 2016a). Points are scored according to achievement against various indicators. Four points are available, for example, for keeping a register of patients, which largely relies on diagnosis (schizophrenia, bipolar affective disorder and other psychoses and other patients on lithium therapy) (NHS England, 2016a). Ten points are available for achieving the appropriate percentage “of patients aged 18 or over with a new diagnosis of depression in the preceding 1 April to 31 March, who have been reviewed not earlier than 10 days after and not later than 56 days after the date of diagnosis” (NHS England, 2016a, p. 20). Because achievement, and therefore payment, is measured against indicators directly related to diagnoses, practices are incentivised to record a diagnosis in service users' health records. However, incentivised recording practices are nevertheless subject to work-arounds by clinicians, as one GP highlighted:

...don't use depression much, but that, but that is for the terrible reason that, with this, it's dreadful, erm, no, if you, if you put down certain depressions, then they get coded in the system and, with requirements of GPs, if you di.., it was, er, it's not the case anymore, but at one stage, if you were given a diagnosis of depression, then it

was a requirement that you had to have done a silly assessment form...and you had to have that repeated in 6 weeks' time...so we tended not to use it just to avoid that... (GP 1)

Similar to the QOF, secondary care services are subject to the Commissioning for Quality and Innovation (CQUIN) scheme. The CQUIN reward scheme is another way of incentivising clinical improvements, which incorporates national indicators, such as 'improving physical health for patients with severe mental illness', and local indicators which are negotiated by Clinical Commissioning Groups (CCGs) according to local need (NHS England, 2016b). The CQUIN scheme is worth up to 2.5% to providers in addition to the actual annual value of the contract (NHS England, 2016b). National indicators for mental health identify 23 ICD-10 diagnostic codes for inclusion under the 'severe mental illness' audit. Specific indicators require the use of these diagnostic categories, such as informing the service user's GP of their care plan or discharge summary, of which diagnosis is specifically identified as an essential component (NHS England, 2016c). Several local CQUIN templates centre on the use of diagnoses, such as screening and assessment of depression in older people (NHS England, 2016d).

Following some assessments, a pattern that is 'abundantly clear' (Psychiatrist 7) and matched diagnostic criteria might be seen, and so a diagnosis would be used in record keeping and the client would also be informed. Here, the purposes of the translation of a person's difficulties into a diagnosis go hand in hand; the process is consistently linked. However, the data demonstrated a tension between administrative and clinical uses of diagnosis, of which service users fall at the intersection. For example, clinicians discussed the practice of using the diagnosis where required by the trust, but not informing the client. Various reasons were offered for this practice, for example, using an alternative clinical approach with clients, such as a formulation-based explanation of difficulties (e.g. Psychiatrist 7), to avoid uncomfortable conversations with clients (discussed by Psychiatrist 3), or because the diagnosis does not accurately represent a client's difficulties. A diagnostic category may at once be seen as vital for formal recording processes, yet therapeutically unhelpful for the person diagnosed:

...sometimes we, we're required to code on a, the erm, on our IT system, and I might code without necessarily saying to the patient I've put you with this label, 'cause I see the two as separate, you know, that's, that's a statistical task and, and, and that's different than actually making a, I might put something on the system that I don't necessarily fit, think fits entirely 'cause I have to put something on the system... (Psychiatrist 12)

Conversely, it may be seen as important to inform the service user whenever a diagnosis is recorded, regardless of the purpose of that record, “this is what the diagnosis is, as far as I’m concerned” (Psychiatrist 3). This stance was described within the context of ethics, and not hiding information from the service user.

6.5.2 Bridging between clinical and legal worlds

Legal translations of diagnosis move from clinical to legal spheres and back, in the case of MHA assessments and tribunals in which decisions are made regarding whether a person can be detained in hospital. Documents include MHA papers, and clinical reports. Diagnoses are traditionally seen as required for defending detention under the MHA, or for court reports. As mentioned in the discussion of Chapter 5, the wording of the MHA itself defines mental disorder as “any disorder or disability of the mind”, which the MHA code of practice (Department of Health, 2015) states should be used in accordance with good clinical practice and “accepted standards of what constitutes such a disorder or disability” (p. 26). Diagnostic categories that may be recognised under the definition are listed, however specific diagnoses are not explicitly required in order to fulfil the definition according to the MHA. The standard joint medical recommendation for admission for treatment under Section 3 of the MHA (Form A7, Regulation 4(1)(d)(i) of The Mental Health (Hospital Guardianship and Treatment) (England) (Amendment) Regulations, 2008), for example, states, “this patient is suffering from mental disorder of a nature or degree which makes it appropriate for the patient to receive medical treatment in hospital” (p. 29). Indeed, in both of the above quotations from the MHA, neither states a requirement for ‘a’ mental disorder, but rather the more broadly defined presence of ‘disorder’ (without the indefinite article, which was removed in the 2007 revision of the Act). The clinician is required to support their declaration, to “describe the patient’s symptoms and behaviour and explain how those symptoms and behaviour lead [the clinician] to [their] opinion”. Because, as the code of practice states, “[t]he fact that someone has a mental disorder is never sufficient grounds for any compulsory measure to be taken under the Act” (p. 27), the focus of the paperwork advocating detention is on the supporting information evidencing the necessity for hospitalisation, rather than on a given diagnostic category. Nevertheless, the use of diagnosis for these purposes was generally accepted as a necessity by clinicians interviewed. Both psychologists and psychiatrists described the lack of room for critical discussion of the use of diagnoses in such circumstances. Clinicians may not place strong emphasis on diagnostic labels clinically, but would use them if it were seen as necessary for other purposes, such as for court reports or for use within the criminal justice system. For example, Psychiatrist 9 stated:

I wouldn’t tend to worry too much about diagnosis, except that you know, in many ways the medical system relies on diagnosis, you know, when I’m detaining

somebody under the Mental Health Act, you know, certain sections I've got to have a diagnosis and I would be questioned on that diagnosis by tribunals and by solicitors... (Psychiatrist 9)

In other words, paperwork such as that of the MHA “forces your hand” to record a diagnosis (Psychiatrist 5), even where treatment and intervention planning does not rely on a conclusion about a diagnosis being made (Psychiatrist 9). The difficulty in applying diagnostic categories in clinical practice, particularly for complex presentations, described in Chapter 4, is particularly highlighted when a recorded diagnosis is required for MHA paperwork that will keep a person detained in hospital:

...it's really hard if you've had someone in for a month, and then you don't have a diagnosis for them, which is really possible, for God's sake, not everyone can be diagnosed, erm, I just really struggle erm, to, to keep them detained further because there's an expectation that the arbitrary 28 days you have, is enough time to diagnose someone with something...so you just kind of, a lot of times end up, giving people some diagnosis that I don't really know whether it's going to be the right thing or not, and realise then afterwards, but I have to put something on paper sometimes... (Psychiatrist 3)

In her account of a case in which she had to defend what she believed was an incorrect diagnosis (but could not identify one more appropriate), Psychiatrist 3 described feeling almost compromised by the need for a diagnosis in its use as a way of sharing information across the knowledge boundary between clinical and legal arenas, in that she had to defend a label of which she did not feel certain. Yet at the same time she felt there was a clear need for the person to be in hospital, as a result of being extremely vulnerable as well as a risk to others. Irrespective of a diagnosis, she felt that there should be sufficient evidence supporting her clinical judgement. A psychologist noted a similar issue:

...what I'm noticing is that parole boards are seen to be very wedded to the medical model, so they're now making demands...that this person, we need to check whether he's got a diagnosis of this, or we need to check whether he's got a diagnosis of that, and that's very frustrating because, you know, you sort of think well, even if he's got this label, how is that going to inform risk necessarily and, and manage it, and is it going to help this person, or not... (Psychologist 5)

These examples emphasise the tension present for clinicians in these circumstances. Clinicians are faced with recording a potentially inappropriate diagnosis, one that they do not necessarily believe in, or would use clinically, but which would gain access to care or risk

management seen as necessary for their client's welfare. One psychiatrist described part-time medico-legal work she does for asylum cases and victims of torture:

...they have to have a proper diagnosis if it's going to make a difference to their, their, their erm, so, so I'm usually looking to make a diagnosis under that circumstance, and there's always one you can find, you know, I'm not lying, that, they have, they have got, but probably I wouldn't of used that in, in a clinical sense, but, but, but they have always got something and you can always describe it in beautiful detail what symptoms they've got that mean that they've got that disorder, 'cause they're so wide really that...if somebody said to me make a diagnosis on this person, I could always do that in a beautiful wordy way that purely you've matched across two criteria and, but, but I'm not sure that's always that helpful for the person, and sometimes people want it and sometimes they don't, so I'll just frame what I see in front of me according to what it would seem most helpful for them... (Psychiatrist 12)

Legal translations can also bridge between the clinical and the criminal justice system, for example in assessing the role played by a person's mental health difficulties in their committing a crime. Documents include court reports, hospital reports and so on. Contrary to the flexible use of diagnoses seen at a one-to-one clinical level, once recorded on legal paperwork a diagnosis must be defended by the clinician as a fixed, certain idea. Clinicians may be content with this concept, for example:

I've done some, quite a bit of medical legal work, as an aside, and I quite like that rigour, because one has to argue the case for a particular diagnosis or understanding and you know, maybe defend it, in a court or something, so I, I quite like erm, that clarity. (Psychiatrist 11)

However, concern was also expressed regarding the potentially negative implications of recording a diagnosis in order to achieve a certain outcome (such as keeping someone detained in hospital) which then has other consequences of fixing the diagnostic category and its association with the person diagnosed. Psychologist 6 spoke of her concern that clients would "carry that diagnosis for life" when it is used for bureaucratic systems outside of the service:

...it's not really helpful to have a diagnosis at this point, because then the label sticks, and then you might introduce you know, a variable that then impacts upon how that person's life, you know it becomes a risk factor, having, carrying that label... (Psychiatrist 4)

Administratively, clinicians described the difficulty of removing the category from records once it is assigned: “I wouldn’t try and shoehorn them into something that they’re not, because once you’ve made that diagnosis, or you’ve added that label, it’s very difficult to actually take it away” (Psychiatrist 10).

Psychiatrist 3, below, was discussing diagnoses given for MHA tribunals, and an example of what she believed to be a mistaken diagnosis of schizophrenia:

Respondent: ...it takes a...long time to actually write someone’s diagnosis off, do you know what I mean? ...

Interviewer: and how do you even go about that, trying, trying to get rid of that?

Respondent: oh God, it’s hard, it’s hard, oh my God, it’s absolutely, I mean you can only say what you want to say, but nothing more we can do about it... really hard...I had a couple of dangerous, difficult people, that I think God, Lord knows how they got diagnosed with schizophrenia, but they did, you know, er, and it’s one of those things isn’t it, because the whole damn thing is subjective... (Psychiatrist 3)

Once recorded, particularly in the context of legal frameworks, diagnoses are difficult to remove and ‘detach’ from an individual and their health records.

6.5.3 Bridging between clinical and social spheres to facilitate practical support

By using diagnostic labels to represent a particular level of need, severity, or disability, GPs, and at times other clinicians, can use a record of the diagnosis to perform particular functions in accessing support. The most frequent uses of this type of recorded diagnosis were statements of fitness for work (fit notes, previously sick notes) to justify time off work, and forms to apply for disability and sickness benefits. These uses of diagnosis represent its bridging function between clinical and social spheres.

The form that comprises a statement of fitness for work contains information about the ‘condition’ a person is experiencing. The guidance for GPs completing the form (DWP, 2015a) is to give as accurate information as possible about the diagnosis assigned to a person, “unless you think a precise diagnosis will damage your patient’s wellbeing or position with their employer” (p. 11). Despite the use of diagnosis, the form is largely pragmatic, identifying the functional impact of a person’s difficulties, “[y]our advice should focus on what your patient can do at work rather than their diagnosis and symptoms” (p. 12). Statements of fitness for work and associated medical reports are also used to support applications for welfare benefits, such as employment and support allowance (ESA). The ESA application form (Department for Work & Pensions, 2017) asks the individual for details of their illness, disability or health condition rather than asking explicitly for a diagnosis.

Likewise, the Equality Act (2010) defines disability in terms of physical or mental impairment, where “the impairment has a substantial and long-term adverse effect on his or her ability to carry out normal day-to-day activities” (Section 6(1) Guidance on the Equality Act, Office for Disability Issues, 2011) elaborates that the adverse effects of the impairment must be substantial, long-term, and affect day-to-day functioning. It is these details, therefore, that are the most significant in defining disability, over and above a psychiatric diagnosis, none of which are considered *de facto* disabilities (in comparison with some physical diagnoses, such as HIV). In practice, however, clinicians interviewed agreed that, “diagnosis is unavoidable when it’s, when it comes to...benefits” (Psychologist 2), “when you have write reports for people, which is almost always for benefits, then I would probably use depression because they also want a, a diagnosis” (GP 1).

As seen in this chapter and Chapter 4, diagnostic labels were used judiciously and to perform specific functions rather than uniformly across clients meeting diagnostic criteria. GPs described using the label if it would help their clients, for example to “stave off...pressure from elsewhere” (GP 4):

I have to label it as depression to the University, so they can get, so sometimes people want a diagnosis because they want to be labelled as disabled because it gets them more support, or it gets them more time, erm, gets them a different type of accommodation, so sometimes we play that game, but it's just about how people cope with their adverse circumstances and their, their adversity and their, their problems coping day to day, for whatever reason... (GP 5)

Alternatively, a diagnostic label might be used simply to access benefits if it would be useful for the person, but a diagnosis would not always be formally recorded if it would not open up additional practical support; “there are lots of people who kind of, they meet the criteria but you don’t want to go down that line” (GP 8). GPs described using diagnostic categories but, in accordance with the fit note guidance, were also aware of the potential stigma associated with formal diagnostic categories, and the consequences their use may have for the individual. Therefore, GPs also used idiosyncratic labels or informal labels that would justify their request, but at the same time this represented an attempt to shield their clients from the negative impact of the diagnosis in wider social spheres, such as ‘low mood’ or ‘stress-related illness’ (GP 2). Some GPs described this as a negotiation with the service user: “so I could give you a sick note for a couple of weeks and I’ll write whatever you want, anxiety, exhaustion, depression on it” (GP 4). In a manner similar to the legal use of diagnosis to achieve a particular outcome, some GPs described using diagnosis flexibly on fit notes dependent on what would be most useful, and least stigmatising, for the client:

...it sort of depends what job people do, I'm mindful, I will use 'low mood' a lot because employers don't like 'depression'...well if there's an advantage to them from having their illness then I will make it sound a lot worse by using terms like 'manic depression', right, as I say I wouldn't put that on their sick note for their employer, but if I felt this patient genuinely couldn't work I would bang 'manic depression' on it because obviously you see that and 'ooh'... (GP 3)

Where clinicians use diagnosis to convey a sense of severity about a person's difficulties, a tension was noted between using a diagnostic label to get a client access to something and not believing it to be helpful for clients personally. This finding was in part about the 'power' that diagnosis holds in communicating with other professionals; Psychologist 11, for example, spoke of her discomfort with the power that resides in detailing the severity of a person's difficulties, rather than their strengths. The data also showed that clinicians might struggle with the idea that a diagnostic label locates problems within the person themselves rather than environmental or other systemic contributing or causal factors: "...if you say that they've got depression or they've got a depressive illness, then that's, that, they may have some utility in terms of work, but in terms of themselves, you're actually telling them that there's something profoundly wrong with them" (GP 4).

6.6 Discussion

This chapter addressed the second and third theoretical questions outlined in Chapter 2 (Section 2.4.2); 2) how are psychiatric diagnostic categories used in practice? And 3) what do diagnostic categories produce; what are their implications? Using interview data with predominantly clinicians, contextualised by documents and policies relating to the recording of diagnoses, the findings presented in this chapter show that diagnoses are used to facilitate cooperation between the clinical context and other spheres, including business, legal, and social contexts. As this discussion will elaborate upon, clinicians use diagnoses pragmatically to achieve their clinical aims and to meet service users' needs. However, beyond the individual clinical context, diagnoses are used as inflexible categories and without the nuances of clinical use.

This discussion section will be organised by the following points:

- Pragmatically applied diagnoses
- Records of diagnosis as boundary objects
- Reification of diagnostic categories
- Implications for research and data capture
- Clinical implications: Practical utility vs. therapeutic utility

6.6.1 Pragmatically applied diagnoses

The findings presented in this chapter demonstrate that clinicians often record diagnoses with a view to reaching an intended outcome for what they believe their clients need. Chapter 4 demonstrated that clinicians use diagnoses pragmatically, for example only giving a diagnosis if they feel it would benefit the person in some way, such as giving access to a particular intervention that would not otherwise be available to them. Where flexibility is not offered within the context of legal and administrative form filling, clinicians create flexibility themselves by adapting these processes to meet the needs of the client. These findings reflect Bowker and Star's (1999) concept of work-arounds, in which it is argued that people negotiate the formal restrictions imposed by a standard by introducing their own local flexibility. The findings to an extent support research carried out by Brown (1987), in which it was found that ambiguity and avoidance of diagnostic clarity was created by the clinician's need to serve non-clinical outside agencies. Clinicians in Brown's study at times used "creative diagnoses" because they felt an administrative pressure to "put some DSM thing on paper" (p. 39). Although most GPs and psychiatrists in this thesis research did not describe reluctance to put down a diagnosis where administratively necessary, several acknowledged that the recording of diagnosis was oriented towards administrative goals rather than for patient care. Although not equivalent, the findings are also reminiscent of the psychiatrists Whooley (2010) interviewed who chose what they believed to be acceptable diagnoses to record on medical insurance forms to meet the bureaucratic requirement for a diagnosis before treatment could be reimbursed. The findings from Chapter 4 showed that clinicians emphasised the flexibility and nuances within their assessments, and this chapter shows that diagnoses are used judiciously to meet client needs. However, this nuanced information is not captured within the administrative use of a diagnostic label. As Moncrieff (2010, p. 373) argues, the record of the diagnostic label "gloss[es] over the complex subjective judgements involved in the process of applying the label".

6.6.2 Records of diagnosis as 'boundary objects'

The findings from this chapter show that psychiatric diagnosis is used to represent mental distress across social worlds, from clinical uses to business, legal, and social spheres. The application of knowledge across different functions has been referred to as "knowledge boundaries" (Carlile, 2002). Carlile argues that knowledge becomes localised and embedded within practice, and that this specificity can become problematic when working across boundaries of function. Knowledge boundaries are evident in mental health, particularly when diagnosis moves beyond immediate clinical uses within services. Where diagnoses are used, for example, to support a person to access welfare benefits, the information must at some point be conveyed from clinicians to non-clinicians, representing a boundary across which information must effectively understood across disciplines and purposes.

Scientific objects that are used across and within different social worlds, but at the same time satisfy the needs of each, have been described as “boundary objects” (Star & Griesemer, 1989). Boundary objects are tools that facilitate the transfer of knowledge across these knowledge boundaries. Reflecting the flexible, pragmatic use of diagnosis described by the findings of this chapter and in Chapter 4, Star and Griesemer (1989) describe boundary objects as “plastic enough to adapt to local needs...yet robust enough to maintain a common identity across sites” (p. 393), that is, they are subject to local flexibility and site-specific use, yet they are universally recognised. The local meanings associated with boundary objects may therefore vary, but they maintain common understanding across social worlds. The formal records of psychiatric diagnoses that are described in this chapter can be conceptualised as boundary objects. In assessing people’s mental distress, it is necessary to communicate complex clinical information, and to find a way of convey this information to non-clinical settings as well as other clinicians. Diagnoses are used in flexible, pragmatic ways to contain information about people’s mental health difficulties, and by having broadly shared understandings of what the categories represent they act as a bridge into worlds outside of the immediate clinical setting. As seen from this chapter, this communication is generally carried out indirectly through various types of records of a given diagnosis, from electronic health records, to legal documentation and formal forms, to referral letters. These records act as tools, standardised across services and broader spheres, to allow the information to be understood in each, enabling cooperation. The findings from this chapter demonstrate that cooperation is necessary across social worlds including business interests, legal, and social spheres, and that diagnostic labels facilitate this cooperation.

6.6.3 Reification of diagnostic categories

Fujimura (1992) has further developed the idea of boundary objects to explain not only cooperation across social worlds, but also “fact stabilization” (p. 169), which incorporates Latour and Woolgar’s (1986) concept of the hardening of claims or ideas into scientific facts. Concepts can be drawn from Fujimura (1992) and applied to the uses of psychiatric diagnosis described in this thesis. Fujimura describes the combined influence of flexible or “ambiguous” theory and specific, standardised methods in the development of fact stabilisation. Flexible or ambiguous theory might be applied to general conceptualisations of mental health and illness; the broad diagnostic concepts such as ‘psychosis’ and ‘mild to moderate mental health problems’ seen used in Chapters 4 and 5, and inconsistent representations of diagnoses as discrete illnesses or disorders, described by clinicians in Chapter 4. Given their flexible application and individual interpretations, this term might also be applied to diagnostic categories themselves. The standardised tools in this case are

represented by the subsequent recording of diagnoses on paperwork to meet various requirements for the individual.

Records of diagnosis on formal documentation, such as Mental Health Act papers, health records, or journal articles, are akin to Latour and Woolgar's (1986) "transformation of statement types" (p. 81), whereby by accepting and using a particular assertion, such as a diagnostic category recorded on such documentation, the category is transformed into "an established matter of fact" (Latour & Woolgar, 1986, p. 81). Star describes Latour and Woolgar's argument as the transformation of "everyday uncertainties" into facts (Star, 1989, p. 64). In recording a diagnosis on formal paperwork, the critical discussion of diagnosis and its flexible use and uncertainties is made invisible. What begins as a pragmatically used category is crystallised; formalised by being documented on health records and legal forms, potentially moving the category to systems outside of health services via administrative means such as claiming benefits. Diagnosis is transformed from a flexible tool to a fixed certainty or 'reality'. As is seen from the findings of this chapter, the clinician no longer has a hold on the diagnosis; it is no longer under their ownership, and can be difficult to 'take back'. Documentation of the diagnosis therefore performs a role of what Star (1989) describes as "progressive reification" (p. 64).

6.6.4 Implications for research and data capture

The progressively reified or crystallised use of diagnoses as fixed categories in non-clinical contexts has been identified previously within the DSM-5 Research Agenda: "...criteria listed in the DSMs have been uncritically used by legal professionals and health care administrators as representing lapidary, received wisdom about the nature of mental disorders." (Rounsaville et al., 2002, p. 1). However, the recognition of this problem fails to acknowledge that it is the way that diagnoses are recorded on formal paperwork that leads to these reified ways of using psychiatric diagnosis.

6.6.4.1 *Research*

Less drawn upon by participants within these interviews is the use of diagnostic categories by the pharmaceutical industry, and within research. By virtue of being between clinical and social spaces, these uses of diagnostic categories contribute to the crystallisation of diagnoses and their use from tools that perform particular purposes to categories that people 'have'. These uses then move into more social worlds, for example, where the media report on research or individual cases using diagnostic categories. Future research could be used to represent individuals' difficulties more descriptively, in ways that reflect the nuances that are present within clinicians' assessments.

6.6.4.2 *Data capture*

Much of the contextualising information and policies reviewed in this chapter regarding NHS outcomes and incentive frameworks concerns data capture. However, the findings presented within this chapter demonstrate that clinicians use diagnostic labels with flexibility to meet their clinical needs, and/or to protect service users from stigmatising labels, but this information is then used for higher level data gathering purposes. For example, whether or not a clinician uses a formal diagnostic label on a statement of fitness to work, for example, plans for anonymous data collection from fit notes seek to aggregate data using ICD-10 diagnostic classification (Department for Work & Pensions, 2015b), so this data is likely to be transformed into a fixed diagnostic category irrespective of how the information was originally framed. This demonstrates that the diagnostic data retrieved from NHS patient records cannot be an accurate representation of experiences of mental distress within the population. Rather, the data gathered from the formal recording of psychiatric diagnoses will represent these political and individual aims.

6.6.5 Clinical implications: Practical utility vs. therapeutic utility

The findings from this chapter represent a tension between the practical versus therapeutic utility of psychiatric diagnoses. This tension is discussed below from the perspectives of clinicians and of service users.

6.6.5.1 *Tension for clinicians*

For clinicians, summing up a person's difficulties in a diagnostic label for administrative purposes might make little difference to the immediate clinical situation in which detail and nuances can be described in other ways, but the practices beyond the individual health record to the outside world demonstrate the different ways in which diagnostic categories are used. Clinicians' concerns about stigma suggested that they were aware of the reified conceptualisations of diagnosis outside of the clinical context. Clinicians often weighing up the benefits of assigning a diagnosis against the potential stigma and negative impact it may have on a person, particularly for diagnoses generally seen as longer lasting, such as schizophrenia or personality disorders. Alternatively, idiosyncratic, non-diagnostic labels such as 'low mood', 'stress' or 'exhaustion' were used to avoid stigmatised labels. Brown (1987) describes this process as the "minimization or normalization" (p. 40) of a person's difficulties, in order to protect clients. Nevertheless, diagnoses are made every day in the clinic, and in their position as expert or professional, the clinician is central to the translation of mental health difficulties into diagnoses, and onto formal paperwork. The utility of this translatory work may often prioritised over the personal impact that it has on the individual

whose difficulties are being transformed in this way. The impact upon those who are diagnosed is explored further in the next chapter.

6.6.5.2 *Consequences for the person given the diagnosis*

As is exemplified by the quote from Service User 22 at the start of the chapter, the negative implications may be most significant for the person being diagnosed; not least because of their personal impact, but also because the individual is at the intersection of many of these worlds, by virtue of needing to access them. Linking pragmatic use of diagnosis to Service User 22's experiences, the confusion around which diagnosis was put on the participant's letter for her workplace (depression) compared with one for which she had been referred for therapy (borderline personality disorder) was perhaps the result of a well-meaning clinician using arguably a less controversial label than personality disorder, yet the potential here can be seen for the negative consequences of amending a diagnosis according to its recorded context for the intended benefit of the client.

For example, service users may receive a diagnosis due to recording requirements that would not otherwise have been given at that time. The pressures on clinicians to assign diagnoses for non-clinical trust or legal purposes might accelerate the process of diagnosing and 'fix' a diagnosis at an earlier stage on a client's health records than would otherwise be made clinically. As highlighted in this chapter, some clinicians view the different purposes of diagnosis as quite separate from each other, and therefore assign a diagnosis without informing person who has been diagnosed. This practice allows the possibility of the service user discovering their diagnosis by accident, and the distress that this may cause. This way of working also directly contravenes the government white paper 'Liberating the NHS: No decision about me without me' (Department of Health, 2012a), which sought to increase patient involvement and choice. The uses and implications of psychiatric diagnoses for the individuals who receive them are explored further in Chapter 7.

6.7 Conclusions

This chapter has used interview data with clinicians, contextualised by guidance documents and policies such as NHS outcomes and incentives frameworks, to explore the ways in which diagnostic categories are formally recorded and used across social worlds and contexts beyond the clinic. The findings demonstrated that the recording of diagnosis is ubiquitous in communicating information beyond the clinical assessment. Clinicians pragmatically apply diagnoses to achieve particular aims, and as such diagnoses can be framed as boundary objects that facilitate cooperation across contexts. Clinicians acknowledged the changing conceptualisation of diagnostic categories beyond the clinic; data capture and bureaucratic documents likewise represent categories as fixed, inflexible,

and even reified. The implications for research and data capture are important; diagnostic data may be collected as representing certain, stable categories, yet this is at odds with their nuanced and pragmatic application by clinicians. Clinicians are caught within a tension between the practical utility of diagnostic categories facilitating numerous clinical outcomes, and the therapeutic impact of giving diagnoses, which clinicians acknowledge may be long-term and stigmatising for those diagnosed.

7 Chapter 7: The meanings and practices associated with a psychiatric diagnosis: Recipients' perspectives

7.1 Abstract

Previous chapters have explored the uses and practices of diagnosis from the perspectives of clinicians and services, and the ways that diagnosis travels and its conceptualisations change beyond the clinic. At the intersection of these different worlds is the person diagnosed. The literature describes psychiatric diagnosis as having both positive and negative impact for the individuals who are diagnosed. This chapter uses data from interviews with service users, and is supplemented by data from interviews with clinical psychologists, to explore the practices in which service users take up and use, or avoid, their diagnostic categories, what enables or facilitates these processes and the impact and implications of these receiving diagnostic labels. The findings demonstrate four themes that illustrate the practices and implications of diagnoses:

- The positive functions of diagnosis for service users
- The damaging impact of diagnosis for individuals and their identity and via stigma
- The ways in which individuals come to question the value of diagnosis
- Ways of reframing distress outside of the diagnostic model

The findings are discussed with regard to the conceptualisation of diagnosis and the removal of its social context, and the process of negative experiences of diagnosis, which makes visible the diagnostic infrastructure and allows individuals to explore different ways of framing their experiences. There is a tension, however, between service users (and psychologists) avoiding diagnostic labels, and the clinicians, systems, and services that demand their use, such that avoidance of diagnoses can only be achieved to an extent.

7.2 Introduction

This chapter explores the practices in which service users take up and use, or discard, their diagnostic categories, and what enables or facilitates these processes.

7.2.1 The impact of psychiatric diagnoses

Scientific literature on the personal impact of psychiatric diagnoses is somewhat limited. A feature that findings have in common is that whatever the valence of the response to receiving a diagnosis, the meaning that is conveyed by the diagnosis for the individual takes on important personal significance and can impact upon a person's identity (Hayne, 2003; Probst, 2015b). These findings suggest a stark contrast between the pragmatic application

of diagnosis as a clinical or bureaucratic tool and the subsequent impact on the individual. Studies show that receiving a diagnosis can be both a positive and a negative experience. Positive responses to diagnosis include feelings of relief and validation from having a name for one's difficulties (Pitt et al., 2009; Probst, 2015). Diagnoses are used to facilitate access to treatment, support, and understanding (Pitt et al., 2009). Where diagnosis has a negative personal impact, however, it can be experienced as harmful and stigmatising (Thomas et al., 2013) and disempowering (Pitt et al., 2009). A diagnosis can de-legitimise the self (Hayne, 2003), reducing one's experiences to a simplified category (Probst, 2015b). As discussed in Chapter 1, psychiatric diagnoses can become essentialised as biomedically caused disorders, and the public may associate individuals with psychiatric diagnoses with violence, dangerousness, and as being fundamentally different from 'normal' (Dietrich et al., 2006; Haslam, 2000; Read et al., 2006). This stigma may lead to social exclusion for the person diagnosed (Pitt et al., 2009). Through this essentialised thinking about psychiatric diagnoses, Chapter 1 also highlighted the ways in which diagnostic categories may be represented by recipients as categorising the person themselves, rather than simply describing their distress, such as Pat Deegan, who wrote: "I was told I had a disease... I was beginning to undergo that radically dehumanising and devaluing transformation ... from being Pat Deegan to being 'a schizophrenic'" (Deegan, 1993).

7.2.2 Avoiding diagnosis and the 'mentally ill' identity

As introduced in Section 1.3.3.2 of the literature review in Chapter 1, there is a significant body of literature that describes the resistance of service users to diagnosis, the psychiatric model, or to mental health services in general. Crossley (2006), for example, describes this resistance to psychiatry as formed of rights-based social movements. Campbell (1999) suggests that the service user/survivor movement represents a challenge to the perceived social status of those who have been diagnosed 'mentally ill', and that this movement is borne out of the problematic experiences that can result from being labelled in this way, such as the impact on people's identity described above.

Lewis (1995) has described how some participants rejected their diagnoses of depression because the diagnosis did not relate to their own understandings of their distress. Compared with Pitt and colleagues' (2009) and Probst's (2015) research, the diagnosis was seen by some in Lewis' study as pathologising their experiences, rather than validating them. Karlsson and Malmqvist (2013) describe Malmqvist's experiences of conveying an alternative narrative to that of social inadequacy and mental illness that she first embodied when diagnosed with schizophrenia. The language used to introduce her in the paper echoes the non-psychiatric language described by Burstow (2013) in Section 1.3.3.2.1.1, "Annika Malmqvist (AM), one of the authors of this article, was diagnosed as schizophrenic in her early 20s and considers herself a voice hearer and an ex-mental patient" (Karlsson &

Malmqvist, 2013, p. 732). Malmqvist is described as using embroidery as a form of resistance, a means of uncensored expression outside of the identity of the 'mental patient'. Coleman has described the shedding of the identity of a 'schizophrenic': "In the early 1980s I was diagnosed as schizophrenic. By 1990 that was changed to chronic schizophrenic and in 1993 I gave up being a schizophrenic and decided to be Ron Coleman" (Coleman, 1999, p. 160).

For Coleman, his 'diagnosed' identity was one of being a victim, of being different and disordered. He describes his recovery as being about owning his voice hearing, as giving up being the victim and losing the 'status' of being a victim (Coleman, 1999). These first-hand accounts contribute to literature exploring how individuals come to reject their psychiatric diagnoses and the identities associated with them, and frame their distress in other ways, however this body of literature is limited compared with research describing the social movements as a whole.

7.2.3 Rationale: The use of psychiatric diagnoses by those who receive them

Where the existing literature takes a single perspective approach to diagnosis (as discussed in Section 1.6.1), the different functions and implications of diagnosis across individuals are not considered. The psychiatric literature frequently discusses diagnosis as one of several tools available to the clinician, however much of the service user/survivor literature discusses the imposition of a diagnosis and the labelled identity and power imbalances that can result. These discourses are very different from the perception of diagnosis as providing day-to-day utility in an individual's work. The reason for service users' inclusion in the study, therefore, was to understand how these clinical categories are transformed into social and explanatory categories for non-clinicians, and how individuals who are given diagnoses make sense of and assign meanings to them.

7.3 Aims

This chapter addresses each of theoretical questions outlined in Chapter 2 (Section 2.4.2); 1) what are the conceptual underpinnings of diagnostic categories, and are these consistent across contexts and practices? 2) how are psychiatric diagnostic categories used in practice? And 3) what do diagnostic categories produce; what are their implications?

The purpose of this chapter is to explore the practices of participants in the context of their distress and the diagnostic categories assigned to their experiences, and the impact and implications of these received diagnostic labels.

7.4 Methodology

Data were gathered from semi-structured interviews with service users who had been given a psychiatric diagnosis by a clinician (e.g. a GP or mental health professional). The methodology for the data collection with service users, including ethics, procedure, and methods of analysis, reflect the methodology for the interviews with clinicians, which is described in the Methodology section of Chapter 4 (Section 4.4). Differences in the participants and procedure for this chapter are outlined in the following sections below:

- Participants
 - Sampling
 - Inclusion criteria
 - Recruitment
 - Demographic information
- Procedure
 - Consideration of ethical issues
 - The interview
 - Debrief
 - Risk

7.4.1 Participants

7.4.1.1 Sampling

As with the interviews carried out with clinicians (the methodology for which is described in the Methodology of Chapter 4) purposive, or criterion based, sampling (LeCompte, Preissle, & Tesch, 1993; Mason, 2002; Patton, 1988) was used in the recruitment of participants for this research (see Section 4.4.3 for further details).

Service users were recruited in order to purposively sample participants with a range of views and practices with regards to their diagnoses. A range of diagnosis types was sought in order to recognise the potential differences in impact of different diagnostic labels, for example, research shows that the experience of self-stigma for people diagnosed with bipolar disorder and schizophrenia differs in its intensity and impact on functioning (Karidi et al., 2015). In addition, participants with differing experiences of receiving diagnoses were invited, for example, those who had received a single diagnosis versus being given multiple diagnoses.

7.4.1.2 *Inclusion criteria*

The inclusion criteria for NHS service user participants were that they were over 18 years of age, and had been given one or more psychiatric diagnoses by a clinician. NHS service users were invited to take part specifically rather than anyone who considers themselves to have experienced mental health difficulties or considers themselves to have a psychiatric diagnosis. The reasons for this were twofold. The first was to ensure that participants had been formally given their diagnosis by a clinician. The second was to ensure that participants had experienced mental health care via the NHS, in order that they had experience of the ways that the health system works with mental distress.

Individuals who had been given a diagnosis by a clinician at any time in their life were invited to take part; by not imposing a limit on the time since being diagnosed, it was possible to gain an understanding of how different individuals had responded to and used (or not used) their diagnosis in the time since diagnosis. Individuals must have received NHS support for mental distress either currently or in the past. This support could either be from primary care or GPs, or from secondary (or tertiary/specialist) mental health services.

7.4.1.3 *Recruitment*

Clinicians who were interviewed were asked to give the study information to clients on their caseload who would meet the inclusion criteria. Local community mental health teams were approached and asked to pass on the study information to clients. An advertisement for the study was also included within the research newsletter for Trust 1, and within the newsletter for Trust 1's service user group. Recruitment was extended to include non-NHS organisations, such as those that run local groups and support hubs. Three local charity-run support centres were contacted and advertisement flyers made available across three active local sites. The research was also advertised via the mailing list for two local mental health interest groups.

Through all means of recruitment, potential participants were invited to contact me directly if there were interested in taking part. Usually this contact was via phone or email, and this medium was used to have an initial discussion about the study, its purposes, and what it would involve, as well as to ensure that participants met the inclusion criteria. At this stage a participant information sheet (Appendix 6) was emailed or mailed to potential participants to give them further information about the study. Potential participants were invited to contact me again to arrange the interview if they were still interested in taking part. If they did not respond, a week was allowed for potential participants to consider the information given, and then up to two attempts at contact (email or telephone call) were made to discuss whether

the individuals would like to take part. If potential participants agreed to set up the interview, a time and mutually convenient meeting place was then arranged.

7.4.1.4 Demographic information

All participants were in current receipt of support for their mental health to some extent, for example, some individuals were in contact with their GP only, whilst others were engaged with secondary care services. All participants were outpatients although many had had past experience of being admitted to an inpatient ward.

In order to preserve participant anonymity, the service users' demographic information is divided into separate tables. Table 7-1, below, gives the participants' age, gender, and ethnicity. Ethnicity was self-identified.

Table 7-1

Service user demographic information

Participant ID	Age	Gender	Ethnicity
Service User 1	73	M	White British
Service User 2	24	F	White British
Service User 3	56	M	White Other
Service User 4	58	F	White British
Service User 5	65	F	White Irish
Service User 6	57	M	White British
Service User 7	59	M	White British
Service User 8	66	F	Jewish
Service User 9	53	F	White British
Service User 10	53	M	Irish British
Service User 11	53	F	White British
Service User 12	42	M	African British
Service User 13	55	F	Black British
Service User 14	45	F	White British
Service User 15	60	M	Arabic
Service User 16	54	F	White British
Service User 17	54	F	White British
Service User 18	43	F	White British
Service User 19	42	F	White British
Service User 20	46	M	White British
Service User 21	35	M	White British

Service User 22	24	F	White British
Service User 23	37	M	White British

Table 7-2, below, gives the diagnoses that had been received by service user participants, and the numbers of participants reporting those diagnoses. The frequency total numbers more than the total number of service users due to many participants having received multiple diagnoses, either across their lifetime or given at one time. The specific combinations of given diagnoses are not reported in order to protect participant anonymity. 'Borderline personality disorder' and 'emotionally unstable personality disorder' are collapsed into one category, as these are the different labels given to a roughly equivalent diagnostic category in DSM-5 and ICD-10, respectively. Identifying participants' diagnoses in a thesis that explores diagnosis from a critical perspective might potentially be questioned. However, it should be acknowledged that psychiatric diagnoses do convey some information, although somewhat limited. The diagnoses are given below in order to give the reader some information about the spread of diagnoses that participants had received. The diagnoses also provide some information about the ways that diagnostic categories are applied in practice; for example, just 7 participants had received a single diagnosis. Another reason for asking participants about the diagnoses they had received was to enable analysis (if appropriate, and if such a finding occurred in the data) regarding the potentially differing impact of different diagnoses, as has been found in previous research (e.g. Karidi et al., 2015).

Table 7-2

Psychiatric diagnoses received by participants, ordered by descending frequency

Diagnosis	Frequency
Depression (including post-natal depression & depression with voices)	12
Borderline personality disorder / emotionally unstable personality disorder	5
Schizophrenia	5
Anxiety (including panic attacks)	4
Obsessive compulsive disorder (OCD)	3
Bipolar disorder (including one queried diagnosis)	3
Tourette's syndrome	2
Post traumatic stress disorder (PTSD)	2
Psychosis	1
Cyclothymia	1
Body dysmorphic disorder (BDD)	1

Dementia	1
Agoraphobia	1

7.4.2 Procedure

7.4.2.1 *Consideration of ethical issues*

Consent to participate was obtained through the procedure described in Chapter 4 (Section 4.4.4.1). Participants were given the participant information sheet (Appendix 6) and consent form (Appendix 8) to read prior to the start of the interview. If there was any doubt as to the service users' ability to understand the information given on these two sheets, I read through the information step by step with participants. Participants were told that details of the interview would not be disclosed to their care teams unless I believed them to be at risk of harm, either to themselves or to others. Further details on the management of risk are given below in Section 7.4.3.2.1, Risk. Capacity to consent was judged on an individual basis once all the study information had been given. No potential participants were deemed to lack capacity to consent.

7.4.2.2 *The interview*

The procedure for the interviews with service users was the same for that of clinicians, described in Chapter 4 (Section 4.4.4.2). Within the interviews with services users, occasionally the personal experiences being discussed were upsetting for participants. When this happened, participants were offered the opportunity to take a break and pause the recording or stop the interview altogether. In these circumstances, as throughout the interviews, I tried to offer an understanding and empathic response to the person's distress, and give them time to talk or to compose themselves as they needed. None of the participants took up my offer to stop the interview in these circumstances, so when they were ready, the interview continued.

The majority of interviews took place in a meeting room at the University of Liverpool. There were several other venues where the remainder of the interviews took place, according to the preference of the participants, including the non-NHS support centres in which a quiet room was used for some interviews, and a local library. Two participants preferred not to travel, and so interviews were carried out in their homes (see the following section - Risk).

The mean interview length for service users was 57 minutes (ranging from 25 to 102 minutes).

7.4.2.3 *Debrief*

Participants were thanked for their time following the interview. A verbal 'debrief' was given to each participant, explaining again the purposes of the study of understanding the functions of diagnosis and the ways that different individuals use it, in order to inform the development of different ways of conceptualising and assessing mental health.

Participants were asked how they had felt answering the questions and how they were feeling now that the interview had finished. The potential for feeling distressed following the interview having discussed personal experiences was explored. Participants were encouraged to contact me again if they felt they would like to discuss this, or alternatively the principal investigator for the study and my supervisor, Professor Kinderman. Service users were given a debrief pack (Appendix 9) that included a letter detailing what to do if they felt distressed by their participation in the study, and a list of useful contact numbers, including the primary care 24 hour urgent care service in Merseyside, and the contact details for various mental health charities, including the Samaritans and the Hearing Voices Network.

7.4.2.4 *Risk*

7.4.2.4.1 Psychological risk

Participants were reassured that their responses in the interview would be confidential, and that no information would be given to their mental health care teams, except in situations where I believed them to be at risk of harm, either to themselves or to others. Participants were reassured that if I were to share this information with their clinician I would inform them of this first where possible, and that only the information pertaining to risk would be disclosed. This disclosure of information was not required for any of the study participants.

7.4.2.4.2 Risk to the interviewer

Most of the interviews were carried out in public places such as the university or in local support centres. Two interviews were carried out at participants' homes, however, and so the University of Liverpool's lone worker policy, using a buddy system, was implemented. A designated colleague was informed about the estimated time of the visit and a specific time was agreed for a 'safe and welfare' call. In the emergency event that all attempts to contact me failed, the designated colleague was instructed to open a sealed envelope containing the participant's address and telephone number and contact local police for a 'safe and welfare' check. No such emergencies arose in the course of the study.

7.4.3 Methods of analysis

7.4.3.1 *Achieving data saturation or theoretical sufficiency*

For the service user participants, a slightly larger sample was sought than the groups of clinical disciplines recruited (described in Chapter 4, Section 4.4.3.3.1). This was decided in order to reflect the possibility that there may be greater variation in the views and experiences of service users, as unlike the clinicians, there may be less cohesion as regards to the frameworks and explanations that participants used to make sense of their mental distress. As with the clinicians' interviews, data collection was ceased when no new theoretical insights were gained from the interviews, and in light of the concept of theoretical sufficiency, when thoroughness of data had been achieved (see Section 4.4.5.1, Achieving data saturation or theoretical sufficiency).

The interviews with each of the clinician groups (described in Chapter 4) and service users were analysed as one dataset. The interview data were prepared, organised, coded, and analysed according to the methods described in Chapter 4, Section 4.4.5.

7.4.4 Presentation of findings

The three domains derived from analysis of the full dataset of interviews with clinicians and service users are described in Chapter 4, Section 4.4.5.7. Figure 7-1, on the following page, is presented to remind the reader of these domains, their themes and subthemes. This chapter presents findings from the third area of interview findings: The ways in which service users take up and use (or do not use) their diagnoses.

In addition to data from interviews with service users, latter findings are supplemented by data from interviews with clinical psychologists. These data did not contribute to the theme development within this chapter, but are presented to demonstrate some of the similarities between service users' ways of reframing their experiences outside of the diagnostic model and the practices described by clinical psychologists. The method for interviewing clinical psychologists can be found in Chapter 4 (Section 4.4, Methodology).

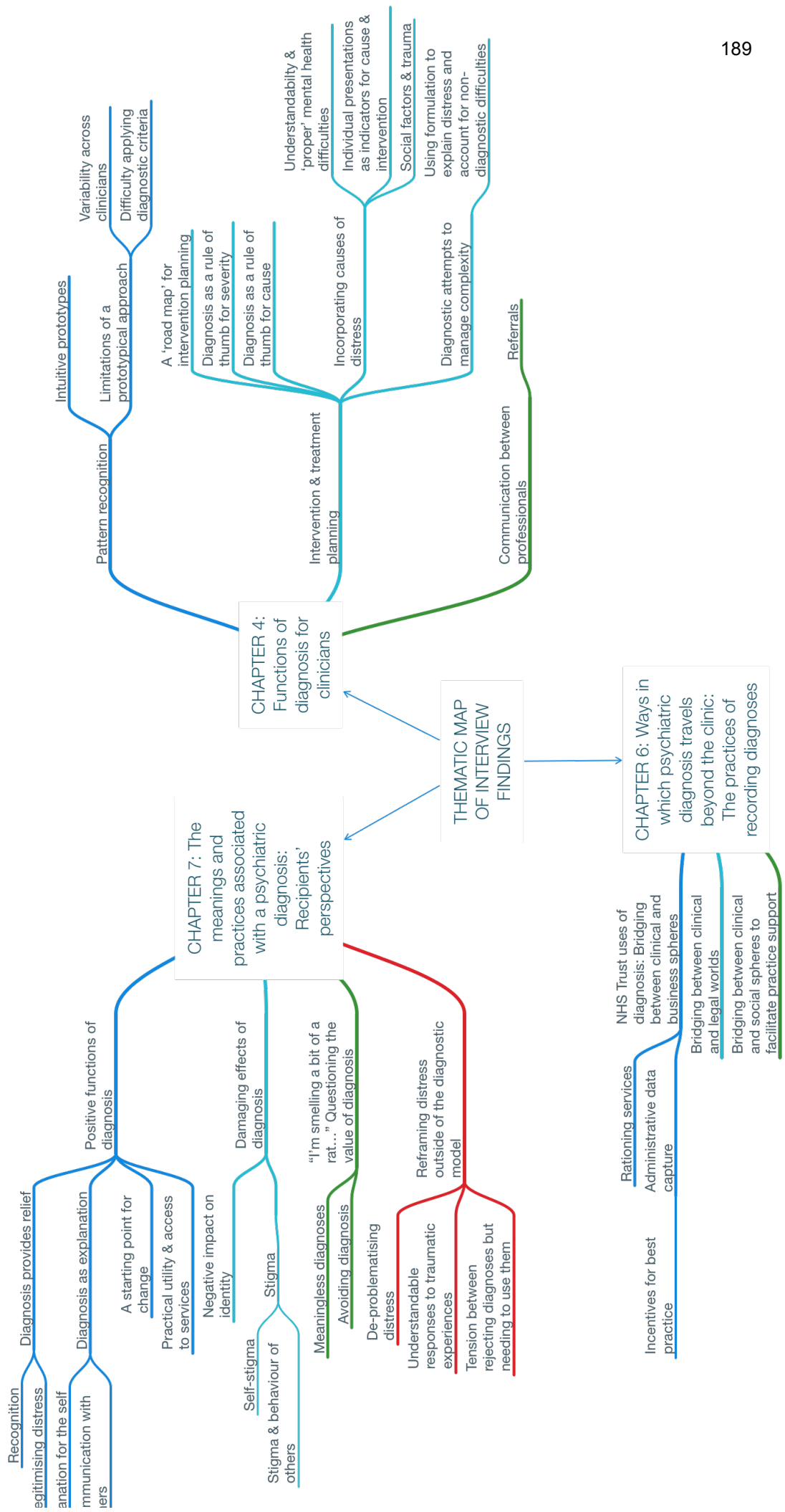


Figure 7-1: Thematic map showing themes and subthemes from the three domains of findings of the interview data analysis

7.5 Findings

The following findings will demonstrate that psychiatric diagnoses are used by service users for several positive functions, including offering a sense of relief through recognition of distress and reassurance that others have experienced similar kinds of difficulties.

Diagnoses legitimise a person's distress, and the labels are used by individuals both as an explanation for their own distress, and in explaining and gaining understanding from others. As recognised in previous chapters, diagnoses are used to access practical support as well as treatment and mental health services. However, a conflicting theme described the damaging effects of being diagnosed; through stigma and the impact on a person's identity. Participants who had had these negative experiences came to question the value of the diagnostic label, and to what extent it could provide meaning to their distress. The final theme explored the ways in which individuals may come to avoid or reject their diagnosis. The data highlighted two ways in which people come to reframe their distress using non-diagnostic ideas; de-problematising their experiences, seeing them as simply part of their life, and understanding their distress within the context of difficult life experiences.

This findings section is organised by four themes and associated subthemes, which are outlined in Table 7-3, below. Each of these is explored in detail in the following section.

Table 7-3

Outline of themes and subthemes

Positive functions of diagnosis

- Diagnosis provides relief
 - Recognition
 - Legitimising distress
- Diagnosis as explanation
 - Explanation for the self
 - Communication with others
- A starting point for change
- Practical utility and access to services

Damaging effects of diagnosis

- Negative impact on identity
- Stigma
 - Self-stigma
 - Stigma and the behaviour of others

“I’m smelling a bit of a rat...” Questioning the value of diagnosis

- Meaningless diagnoses

Avoiding diagnosis

Reframing distress outside of the diagnostic model

De-problematising distress

Understandable responses to traumatic experiences

A tension between rejecting diagnoses but needing to use them

7.5.1 Positive functions of diagnosis

The data demonstrated several positive functions of diagnosis for those who had received them; the subthemes illustrated the ways in which receiving diagnosis can be a relief, an explanation of a person's distress, a starting point for change, and a way of accessing practical support and mental health services.

7.5.1.1 Diagnosis provides relief

Participants often reported experiencing relief on receiving a diagnosis. Feelings of relief were divided into two subthemes; recognition, and legitimisation of distress.

7.5.1.1.1 Recognition

The data demonstrated that diagnosis offered confirmation that a person's difficulties were recognised. Participants explained this as recognition that difficulties like theirs have been seen before, that other people experience similar distress. Part of this finding was about having a name for their experiences; "I suppose it puts a name on lots of unknown things like, why am I reacting this way?" (Service User 2). Service User 23 described the relief of having a name for his experiences, as well as around being able to attribute his upsetting intrusive thoughts to the diagnosis, although these thoughts did not allow the relief of the diagnosis to last:

...the relief was just...it was just enormous when he said you, it was like it was an illness... There was a label for it...I'd never heard of OCD before, and there was a label. Yeah it was all to do with that, and, I mean, like I said the relief didn't last, it lasted seconds, and a minute, 2 minutes at most... (Service User 23)

The data showed that a diagnostic label can provide a known quantity that a person can attribute experiences to:

...family and friends would be like 'really?', so that kind of alienates you and makes you feel really different and weird because you're saying these things which, you know, so that was, it was such a huge relief, erm, for somebody to say well that's actually part of this diagnosis, and they're some of the symptoms that you will experience because of your experiences, I can handle that, what I couldn't handle was not knowing. And what I was imagining things to be was far worse than what it actually was. (Service User 14)

Participants also described a feeling of relief from other things that are tied in with the assessment and receiving a diagnosis, for example, talking to someone for the first time about one's experiences, and being reassured that treatment could now be planned:

...the relief was having somebody to open up to, and talk, er, and the diagnosis, well, I didn't feel, er, well I didn't mind, you know the description. I thought well you know what, that sounds about right. Post-traumatic stress disorder. You experience trauma in your life, and you're left with this, er, stress... (Service User 10)

I knew something was wrong 'cause I wasn't well, erm, but being able to tell me what it was...once they knew what it was they could maybe start thinking about treatment for it, erm, and just having some certainty, that was a relief. (Service User 9).

7.5.1.1.2 Legitimising distress

There was a relief in a person being told by a clinician that their problems are genuine, legitimising difficulties by making them real; "it is actually a condition, not a flaw" (Service User 6). In this manner, diagnoses were used in order to facilitate communication and explanation to others. Participants described diagnoses as a legitimised acknowledgement and explanation of difficulties that enabled their families to recognise their difficulties; to understand and be more understanding. In turn, the data suggested that this may be as a result of people being able to demonstrate that they were "not swinging the lead" (Service Users 4, 5 & 15), shirking work or faking:

I found when I got the diagnosis [my parents] sort of understood more like they didn't really see it as my fault any more, whereas before it was like 'oh she's attention-seeking' and all that, whereas when I got the diagnosis, they actually saw it like an illness and that, so it meant that they were more understanding... (Service User 22)

I think how I felt, and a lot of people do when they're diagnosed first, they feel relief, because it's got a name, this awful something that happens to you, this very very

distressed state, you're not pretending, you're not swinging the lead, because people say you know 'pull yourself together', all that sort of stuff, so when you're told there's a name for this, you think oh! (Service User 5)

7.5.1.2 *Diagnosis as explanation*

As is suggested by some of the quotes above, the data showed that receiving a diagnosis can give an explanation for a person's experiences of distress. This explanation extends both to the person themselves and in explaining to others.

7.5.1.2.1 Explanation for the self

Participants reported using diagnostic categories as an explanation for the life impacting difficulties they experienced. Diagnoses such as post-traumatic stress disorder (PTSD) offer more obviously descriptive labels, however diagnoses such as schizophrenia, which have embedded within them arguably less tangible explanation for difficulties, were also used to identify a known and recognised cause for difficulties. One participant, on receiving a schizophrenia diagnosis, explained, "I could put it down to, I wasn't going doodle lally, I wasn't going mad, there was reasons for why I was behaving the way I was behaving" (Service User 11). Another participant described:

...it was useful to put a handle on what I'd been experiencing...it helped me to make sense and, and even to have someone mention me and bipolar in the same sentence, was erm, a revelation, that I just never considered it before... the psychiatric services actually helped enormously, in spite of my resistance, to have a label, which I'm very reluctant to have, but at the same time it helps me to understand what might be going on... (Service User 3)

Distressing experiences are described as caused by the diagnosis, and as the above quote shows, this may be reassuring for service users as an explanation in itself even without information about the cause of the disorder itself. Knowing that the problems are 'caused' by schizophrenia or another diagnosis offers a sense of understandability, of recognition by mental health professionals, rather than being in the midst of the "unknown" (Service User 2), despite the person not having explicit information about what is causing the diagnosis or condition seen as represented by the diagnosis. The data within this theme suggested that diagnoses could be helpful in separating a person's difficulties from themselves, "it just put things in boxes, like, an OCD box and a bipolar box" (Service User 23). In part this process was around removing blame or responsibility for uncomfortable behaviours or thoughts:

...when I have thoughts that I don't like, or thoughts that, erm, I find offensive or anything like that, I kind of tell myself... 'cause I tend to beat myself up if I have bad thoughts, and I need to sort of tell myself... it's my OCD... and sort of attribute it to that label rather than attributing it to me as a person. (Service User 9)

7.5.1.2.2 Communication with others

As well as explaining their own difficulties, participants described diagnoses as facilitating communication with others, which relates to the themes of recognition and legitimization of distress, above. Diagnostic labels were described as communicating information about distress in way that has broadly shared understanding. The data suggested that this shared understanding allows communication whilst at the same time sharing minimal personal details about how it impacts upon one's life or from what personal experiences it may have stemmed; "...as soon as you say...schizophrenia, they automatically just know what, what it is... without going into detail and what, you know, what happens in your life and all that" (Service User 11). Another participant shared:

...it's easier to just say, oh I've got bipolar, than to start saying oh well I went through this and I went through that, and that's why I'm like this, like 'cause then they'd just be like 'oh that's a bit deep', like it's easier to just like give a label...but when you give like say bipolar, no one thinks 'oh why's she got that?' You just think, they just assume 'oh you're ill', like you wouldn't really think 'well what's caused that?' Like people just accept it at face value, whereas if you start going into it more, people then want to know, well what's caused that, and all this. (Service User 22)

In contrast, more descriptive diagnoses such as PTSD were described as inviting intrusive questions about the trauma experienced that resulted in such a diagnosis; "...because you then have to say, if you say you've got PTSD, 'well why have you got PTSD, what happened?' so it's how much do you share?" (Service User 14):

...depending on how well I knew them... I would tell them that I suffer, I suffer, use that word, you know er, I wouldn't say mental illness, I would say you know I suffer depression and anxiety and I take meds for it, but... I wouldn't tell them immediately I've been diagnosed having posttraumatic stress disorder, again because it leads people into thinking 'alright what happened?' (Service User 10)

7.5.1.3 A starting point for change

Just as clinicians in Chapter 4 were seen to use diagnosis as a point of departure for their assessments, so did service users report using diagnosis as place to start, for the person to

make changes for themselves, “it was a starting point...big starting point...to start picking up the pieces. I think, it was just knowing where to fight the fires...” (Service User 23):

Before I had the diagnosis I'd never looked at myself before, I was just me, and I just done everything for everybody else, nothing for me. I wasn't important, I was a nothing, really. But today, I do things for me... (Service User 16)

7.5.1.4 *Practical utility and access to services*

Chapter 6 described the ways that the formal recording of diagnosis is used to gain access to various means of support, including time off work and early retirement, welfare benefits, and within health services, medication and interventions such as therapy. The data from interviews with service users demonstrated similar uses of diagnosis, including welfare benefits, “I must admit I am on disability, but that's all, nothing else, and I wouldn't be on that disability if I didn't have the bipolar” (Service User 16).

...the diagnosis is just the way the system sort of reacts isn't it...it's helped me in some ways, and not in others...because along the line I've had like benefits I've qualified for, which have helped me when I haven't been able to work, erm, which I've needed, for some form of income (Service User 21)

...if you're applying for benefits and stuff, it helps to have the diagnosis, like they wouldn't give you nothing if you wasn't diagnosed with anything, and in terms of accessing treatment as well, like I'm on, they've referred me to [NHS service], which is really hard to get onto, and I don't think I'd have got onto it if they hadn't diagnosed me... (Service User 22)

Another participant described being able to access support services owing to their diagnostic label: “I think if, if you've got a label or a diagnosis or a name, there's help somewhere along the line, because if I didn't have that diagnosis I wouldn't be into the groups I'm into now” (Service User 17).

Some participants did not separate the diagnostic label from the support or intervention they received, suggesting that the association between receiving a diagnosis and accessing support was so important that the two could become synonymous; “it was helpful, 'cause I wasn't well...at that time I was in a state, and I needed help, I needed something to calm me down, and I was getting all the help I could get, from the hospital.” (Service User 13).

As one participant replied when asked about what was helpful about receiving his diagnosis, “makes you better doesn’t it, so it’s bound to be like dead helpful isn’t it, makes you better” (Service User 12).

Similarly, some participants struggled with the idea of conceptualising their distress in different ways, giving an indication of the effect of the reification of diagnostic categories. Rather than diagnosis being one way of seeing their difficulties, these participants saw their diagnosis as simply something they ‘have’ that cannot be changed or thought of in other ways. In a discussion of whether she could think of things differently, one participant replied, “I would like to be like normal, I would, I wouldn’t like to have schizophrenia, but, it’s the way it goes” (Service User 13).

7.5.2 Damaging effects of diagnosis

The damaging effects of diagnosis reported by participants are described within two subthemes; negative impact on the person and their identity, and stigma. The above descriptions of receiving a diagnosis, experiencing relief and an explanation for distress, combined with helpful functions of communication and accessing support, may be the ways that people described initially experiencing diagnosis. However, the data showed that since originally receiving the diagnosis, these first impressions could give way to a very different experience; “...when you’re told there’s a name for this, you think oh! You don’t realise that that diagnosis is actually quite malignant, and *will* affect the rest of your life” (Service User 5).

Of receiving a diagnosis that allowed them to have early retirement, one participant said,

I think the only time that the diagnosis really mattered was when I probably had to retire from teaching after 25 years, erm, and then the diagnosis floored me because to do that, it had to be decided I would never be fit to teach again, that my illness was so severe that there would be no time in the future when I would have the wherewithal... and to read that in black and white that you know, you're like a proper sort of basket case... (Service User 4)

7.5.2.1.1 Negative impact on identity

As Service User 4 described in the previous section, the data showed that the pragmatic functions of diagnosis could come at a cost to the individual themselves. The same participant went on to say, “the pension helped to be sure so you know, it was good that I had that diagnosis...but then that was probably the, the most damaging thing that’s ever happened to me as well” (Service User 4).

Other participants described the impact that receiving a diagnosis had had on their lives, “how could you not internalise the words that this person of quite a lot of authority and power has [used]?” (Service User 3). Another participant described:

I try not to make it part of me, I try and make it really separate, but there are times when I've really hid behind it, erm, it's been a reason for me to not engage with people, or keep me world really small, erm, because I have this and you know I don't have to get involved with other people (Service User 14)

Even before it has enabled access to support or other functions, the diagnosis can have an immediate negative impact on the person diagnosed:

I was given a diagnosis of schizophrenia, erm, it's about 10 years ago now, erm, which devastated me, erm, in the beginning, it really devastated me, erm, I haven't found it helpful in the least...for a while, I kind of walked around thinking that I was schizophrenic, I've got a chemical imbalance, I've got a brain disorder, erm, and that's not a good way of living. (Service User 17)

7.5.2.1.2 Stigma

7.5.2.1.2.1 Self-stigma

Awareness of stigma around diagnoses can also mean that people are wary of receiving and communicating a diagnosis for fear of others' responses and perceived stigma, “when I got a bit older, about 21 or so, I actually left home and went to live in another city, another country, well, simply because my mother had blurted it out over the neighbourhood” (Service User 7). Another participant explained his being cautious regarding what he said and did; “You know that stereotype of mental illness can or maybe equal violence, violent behaviour, so er, have to be careful, know what I'm saying? You know, I think about that stigma...you're mentally ill, oh he'll kick off” (Service User 10).

The diagnoses likely to have this immediate impact were those seen as longer term, such as a schizophrenia diagnosis, as above, or personality disorder diagnose; “being labelled with a personality disorder is a very disabling thing” (Service User 1). As participants remarked about borderline personality disorder, “...but BPD, it is a big deal because it's like they're saying there's something wrong with you, like there's something wrong with your personality” (Service User 22):

I thought it sounded quite horrible...if you put personality and disorder together it doesn't sound good as to what you might be like as a person, it makes it sound as if, erm, you haven't got any illness or difficulties, you've got a personality that's disordered, and therefore there's nothing you can do about it and you're just a bad person. (Service User 18)

7.5.2.1.2.2 Stigma and the behaviour of others

As described in Chapter 6, consequent to the recording of diagnoses for administrative or trust purposes but without informing the service user, the potential is raised for the service user to discover the recorded diagnosis by accident, "...what? Who gave me that diagnosis?" (Service User 18). Several participants described finding out about their diagnosis in this manner. The diagnoses the participants had not been informed of could be seen as more 'severe' than the ones they had or thought they had, for example diagnoses of personality disorders or bipolar disorder, perhaps explaining why clinicians had chosen not to convey that diagnosis. Participants who found out about their diagnoses by accident conveyed their shock at finding out, particularly as they were aware of the stigma associated with those diagnoses, in particular personality disorders, and had witnessed what they saw as stigmatising attitudes being used towards others with the same diagnosis:

I think this emotionally unstable personality disorder's the one that's like, because of the stigma with it, and I think is that why it's so difficult when I ask for something, they go oh she's an emotional personality one, take no notice of her, is that why I've got to fight? Does everybody have to fight like me to get what they need? And I'm thinking is this why, you know, is this why I've been being treated the way that I get treated, because that, that diagnosis is down? (Service User 19)

These descriptions of stigmatising treatment in clinical settings were experienced beyond mental health services in physical health services. One participant described a doctor's response to a complaint she had made about treatment received for an unrelated physical health condition:

...'well you know she has a mental health condition, she's over-egging this, it wasn't like that', and it will be held against you forever...no matter what complaint you bring anywhere, no matter what you do, there is always that, this is a person with mental health issues, therefore they are not a legitimate human being to actually have a go, have an opinion...' (Service User 5)

The implications for the diagnosed individual reveal the shift from the use of diagnosis as a bureaucratic category in the clinic or for other administrative purposes to one that has a very different effect in the social world:

[The psychiatrist] was like...it's just a way of describing your difficulties, which I can see, but then if you're trying to then, at some, point I don't know explain things to the wider public, or a different audience or you know, whatever, then bandying around terms like 'personality disorders' is not going to endear them to you. (Service User 18)

Beyond the individual's meaning making around diagnosis, its negative impact can be a result of others' responses, "I think the labelling thing is very very damaging, because it puts you in a situation where people will look at the label and judge you by your label rather than looking at the person" (Service User 1).

7.5.3 "I'm smelling a bit of a rat..." Questioning the value of diagnosis

In response to the negative impact of diagnosis described previously, an important theme was that of questioning the value of diagnoses, as illustrated by the above quote in the theme heading (Service User 4). This theme is divided into two subthemes reflective of this critique of diagnosis; finding the label meaningless in relation to distress; and avoiding diagnosis.

7.5.3.1 *Meaningless diagnoses*

In contrast with the positive functions of diagnosis described in Section 7.5.1, the data showed that diagnostic labels can lack meaning. Using the psychiatric model, the explanation of difficulties may not extend beyond the diagnostic label. Without a clear cause for the distress itself, and therefore a lack of information about what the person could do to help themselves, a diagnosis can feel insufficient, "...although you say I've got anxiety and depression, what does it really mean?" (Service User 8):

I didn't understand what it meant to me as a person, or, I didn't quite understand how it manifested, erm, I was told by one GP that it was brain chemistry, although I'd never had any tests done, so I'm thinking how can you tell me it's brain chemistry when you've, you know you've not tested my blood or anything, I've not had no imaging tests done. Another GP told me it was, I was reacting to difficult situations badly, so it was often termed as reactive depression...there was so many different labels it wasn't erm, it wasn't anything tangible that, you know, and the treatment options available was medication, at the time, so it didn't really mean anything to me

in terms of how I could self-manage, or what I could do... (Service User 14, discussing her diagnosis of depression initially, which was later described as PTSD)

Diagnoses, therefore, may not be useful as explanations of distress, and the categories may be seen as so wide as to become meaningless. Service User 18, for example, said of her diagnosis of borderline personality disorder, "I didn't like the name of it...so what I did was look it up, and I thought actually after I'd read it that an awful lot of people could get labelled that, because it's quite wide":

I just feel unsure about the whole, like there's four things now, on my diagnosis, and it's like, well what is it? Because all the symptoms seem to overlap into different diagnoses... I want an explanation as to why you think I've got this, I need to understand... (Service User 19)

One participant, in explaining his desire to understand how he had come to have particular experiences of distress, and how he could help himself to make helpful changes, suggested that his psychiatrist did not appear interested in helping him to develop this sense of meaning, "they're not particularly interested, you know, in that...they're only interested in suppressing it, so I'm not a harm, I'm not a danger to myself or anybody else anymore" (Service User 7).

7.5.3.2 *Avoiding diagnosis*

As has been shown, the data demonstrated that negative and lacking experiences of psychiatric diagnosis (described in the previous section) and traditional psychiatric care can lead people to shift from a position of acceptance to questioning their diagnoses:

I don't know if it is the case, but it might be, that if you're given a diagnosis like [borderline personality disorder], you do question the notion of psychiatric diagnoses more than you might do, you know if it's something that appears to be particularly poor language, or, you know you kind of perhaps think about rather more than if somebody had just said 'yes well you've got chronic depression' I might not have thought about things so much, maybe? But I don't know... (Service User 18)

Questioning and critiquing psychiatric diagnoses also lead to participants avoiding diagnostic services and understandings of their distress, "I fear that it's only through sad experience with the system that people come to the conclusion that a diagnosis is not your man. I fear initially they might be wanting, 'tell me what's wrong with me'..." (Service User 5):

At first, erm, I believed in the mental health system, because I'd never had experience of the mental health system, and I did believe, erm, and I was kind of the model patient to be honest, erm, took the medication, just accepted whatever, erm, and then it was just as I got to thinking over the years, and I thought there's something wrong here, there's something really wrong... it's like gradually over the years that I've kind of took a turn against the system... (Service User 17)

One participant spoke about what she called the illogicality of the biomedical diagnostic model, and coming to believe that the traumatic events that she and others had experienced may not be coincidental alongside their mental distress:

...when I started properly researching, and it was more, probably the day cen[tre], the illogicality of it, the, hang on, you know, this sort of, you know, when you're bright you're thinking I'm smelling a bit of a rat going on here, you know, and you've got all these stories of all these horrible traumas... (Service User 4)

7.5.4 Reframing distress outside of the diagnostic model

Further to questioning and even rejecting their diagnoses, the final theme centred around wanting to reframe, manage, or support distress in more meaningful ways. Where participants wanted to use non-diagnostic ways of understanding their experiences, they described two key ways of reframing their distress; de-problematizing their experiences, redefining them in more helpful terms than disorder or diagnosis, and using childhood adversities and other life experiences to understand distress as an understandable response to these experiences.

This theme is supplemented by data from interviews with clinical psychologists to demonstrate some of the similarities between service users' ways of reframing their experiences outside of the diagnostic model and the practices described by clinical psychologists.

7.5.4.1.1 De-problematizing distress

Participants described reframing their experiences as simply part of their own personality or idiosyncrasies, rather than as a fault, problem, or symptom of disorder: "I'd rather not think of my head as there being some kind of imbalance of chemicals that's not right, I'd rather just think of me as being me, that...I'm more or less sensitive to what's happening around me..." (Service User 3).

As part of this redefinition of difficulties, a common practice was to reject terms associated with the diagnostic model of mental health:

I have a problem with calling it an illness because I think that it's a way of being, the way I am is, and I hate the fact that we pathologise a personality, and a particular sort of personality... when I was given a diagnosis I looked on it as an illness, I had an 'illness', erm, I don't regard myself at all now as having an illness. (Service User 5)

Participants frequently described diagnostic labels as judgemental, particularly those that are less descriptive or experiential (such as personality disorders or schizophrenia, compared with depression, anxiety, or PTSD). By shunning a diagnostic label, some people sought to reject with it some of its consequences:

I don't think of myself as having a personality disorder, 'cause I don't think I do. So, I think yeah it's more helpful to not think of yourself as having one, 'cause otherwise you just like, you sort of just, like you don't think you've got any potential or anything, you just like, assign yourself to just like being sick for the rest of your life. (Service User 22)

7.5.4.1.2 Understandable responses to difficult life experiences

The second way service users described reframing their distress was linking it with past adverse or traumatic experiences. Some people did this by adding a contextual understanding to their diagnoses. This was particularly apparent for people given a diagnosis of PTSD, which by definition takes into account trauma. Service User 14, quoted earlier explaining her original diagnoses with various types of depression which had little meaning for her, explained that the PTSD diagnosis allowed her to attribute distressing visions as re-experiencing past trauma rather than to being psychic, which had previously been her only other explanation for the experiences "...the benefit of the diagnosis for me was 'oh ok, ok I understand now what's been going on'...the diagnosis kind of made sense of why there had been such chaos" (Service User 14). However, she went on further to discuss the disconnect between the diagnostic model and the concept of her distressing experiences being an understandable response to trauma, an approach she had found helpful:

I called it symptoms of trauma, traumatic experience, rather than post-traumatic stress disorder, erm, and that was more helpful for me...that it was you know it was tangible, it was tangible, 'you are like this because you experienced this, and that is

a natural reaction to that really unnatural experience', that feels much more healthy that saying you've got a disorder... (Service User 14)

Part of this theme highlighted where participants felt that opportunities for understanding had been missed as a result of clinicians not asking about their past experiences:

I just think like if they actually spoke to me, like they don't know anything about my experiences, like in life, they've not got anything on their notes about it because they've never asked me, and I just think if they actually knew stuff, like, that I'd been through and that, then every, the way that I've acted and that, it would make sense, they don't need to label it as like being ill or anything, because really if you think about my experiences, and then the way I behave, it all makes perfect sense... (Service User 22)

Others had researched different conceptualisations of mental distress that fit better with their experiences, and also felt that opportunities were lost at the start of their contact with mental health services:

I've looked into, like some sort of Soteria Houses and research that, I think happened first in America, and erm, and also Open Dialogue, and I believe I was just very stressed about erm, certain, well for me it was erm, a lot of the stress was around my dad... I think I could have just naturally come out of it, erm, but I don't, I'll never know really, because I didn't have that opportunity at the time, and I was, I do remember distinctly thinking on the ward, well when am I gonna get the chance to talk to anyone about anything? (Service User 21)

...there are other ways, there's like Soteria House, there's the Open Dialogue... I think because mental health is complex, and it's not, well I don't believe it's an illness, but it's not an illness like any other, erm, and it's so complex all avenues should be explored... at the beginning, erm, as I said I wouldn't have known any different, and I believed in the mental health system, but now looking back in hindsight, I think if I'd have been asked the right questions, with the right knowledge and experience...that instead of hospitals, if I'd have been put into a retreat...it all would have took a different course... (Service User 17)

Another participant described how his difficulties only started to make sense after several years' contact with mental health services, at which point a different psychiatrist took the time to listen to his story and the trauma he had experienced earlier in his life, and saw a connection between these experiences and his current distress (Service User 10).

Similarly, others went to lengths to access interventions that they thought would be more helpful:

I was like I need [psychotherapy] to get better. Medication alone is not gonna sort my problems out. And then I was discharged by her, so I never got it...I was told by, erm, up to now in the last 6 years, I've been told by 3 different psychiatrists 'you need psychotherapy' and I was saying 'I'm not leaving this hospital until I'm guaranteed that I'm getting the psychotherapy', and they can't, when you're in hospital, they can't accept a psychiatric referral...and that's why I got [senior management within the NHS trust] in... (Service User 19)

Where participants had received psychological interventions, some found that therapists or psychologists introduce a different perspective that takes a different focus. One participant described initially accepting a diagnostic view of difficulties until a counsellor explained to her a more helpful way of looking at distress as being a response to difficult life experiences:

...it was only when the counsellor at [service], I used to believe in like, all mental illnesses like schizophrenia, I used to not question them whatsoever, I just thought, because you just trust the doctors and that...And then when she explained it to me it's like, it's like a completely different way of thinking, and I'm like oh my god why didn't I see that before? (Service User 22)

The shift from locating problems within the individual towards difficulties that result from past experiences and inter-relational problems represented participants' descriptions of problems as being understandable consequences of these experiences. Several service users described how useful they felt they would find this approach. Psychologists' descriptions of their practices, and conceptualisations of mental health, including psychological formulation, were more closely aligned with and representative of this approach. One psychologist described this approach as:

...taking it away from... 'the problem is you and it's rooted in you', and just kind of really acknowledging all the other kind of factors that are relevant...seeing that something might feel really kind of chaotic or out of somebody's control, but actually if we...trace it, you can just kind of see that erm, yeah, any of us...would end up there" (Psychologist 7)

As one psychologist described: "...my sense about people using psychiatric services is that they are completely unexceptional people, who've dealt with exceptional circumstances..." (Psychologist 2)

Modes of support or frameworks for thought outside of NHS services and models were also used as a consequence of negative experiences of NHS care. One participant, for example, sought other frameworks that better fit their own experiences and meanings of their distress and found that spiritual explanations, with which they had always been familiar, were more helpful than the medical explanations given to them by psychiatrists:

...[the diagnosis] it threw me off track, erm, because I had to kind of consider the chemical imbalance and the brain disorder...I was thinking, well I've had spiritual experiences but I must have this chemical imbalance, this brain disorder as well, so I had two things to deal with...So there was a confusion there. Erm, and it's only through study and my own research...so then I could concentrate on my own experiences...it's not helpful for the mental health to be in that confusion, it wasn't good for me mental health, erm, what's been good for my mental health is sticking to my own explanation of my own experiences... (Service User 17)

Another participant discussed the hearing voices group that he attends outside of mental health services, highlighting a need to speak with others in the same situation, experts by experience who can share their knowledge and understandings from a unique perspective and without judgement:

...you don't have to watch everything [you say], you know, if I say this, you know I, I might be...pushed into another [diagnostic] category and all that, but in talking to other patients, you don't have that...I mean there's people in [hearing voices group] who, you know, I sort of switch off when they start talking, you know, cause of, oh no, he's, he's going to start talking about religion again [laughs], you know, but...you just tolerate that sort of thing, you know, they're, they're entitled to their opinion on what it's all about as I am, you know, but and if it helps them, why not, but, erm, you know, but I think there should be a lot more of that available where patients should be able to give their views and their experiences in, in a non judgemental environment... (Service User 7)

7.5.4.2 *A tension between rejecting diagnostic labels but needing to use them*

Outside of mental health services, service users may be forced to use a diagnosis they otherwise reject in order to access welfare benefit and other forms of support:

...I guess when I wasn't working it looked fairly impressive on erm, DLA forms, but that, you know that really is a, that's a kind of hindsight thing, I mean yeah, but you wouldn't want the diagnosis because of that [laughs] it's just a happy outcome that is not intended remotely... (Service User 18)

One participant described a struggle between needing commonly shared language to communicate, yet wanting to distance herself from the notion of diagnosis and it having an association with her identity: “I am the thing called, you know, I have what is called bipolar, or I become ill and it is called bipolar, I have the diagnosis of, but I don’t, I don’t say, I’m a bipolar person” (Service User 5).

One participant described what they felt as the futility of rejecting their diagnosis of schizophrenia in a public sense, “well I just disagree with it totally, erm, but that makes no difference ‘cause I’m kind of cursed with the label for life. Erm, it makes no difference in the mental health system but it makes a difference to me” (Service User 17).

Some psychologists also preferred to use language that avoided diagnostic terms, yet needed to maintain communication with other non-psychologist colleagues:

I used my own vocabulary...I do in such a way that other people who use diagnosis will, can, can append their diagnostic thinking to it if they wish...I don't talk in terms of symptoms, for example, I'll talk in terms of experience, erm, er, I don't talk in terms of disorders, I talk erm, about difficulties... (Psychologist 2)

Psychologists suggested that they may not use diagnostic labels in their own work, but that this represented a tension with needing to work with colleagues and systems that do use diagnostic categories. Of feeling she needs to use diagnosis for some purposes such as communication and record keeping, one psychologist said: “it’s...about surviving in a world that’s dominated by a medical model and psychiatry, and sort of, choosing your battles” (Psychologist 3). Others suggested:

it kind of feels like even though it’s, we’re not calling it schizophrenia, there’s still a bit of a, it’s still this thing...and...you can’t unpick that in team meetings, other people, because you’d have no colleagues wanting to work with you, every time they use a term like that if I was saying ‘exactly what do you mean by that?’ (Psychologist 1)

...it’s negotiating your way through it, because you don't want to collude with it, but you don't want to challenge it so much that other people become defensive and stop listening to you, so it’s trying to get that, that balance... (Psychologist 5)

7.6 Discussion

This chapter used data from interviews with service users who have received psychiatric diagnoses (supplemented by some data from interviews with clinical psychologists) to address each of the theoretical questions outlined in Chapter 2 (Section 2.4.2); 1) what are the conceptual underpinnings of diagnostic categories, and are these consistent across contexts and practices? 2) how are psychiatric diagnostic categories used in practice? And 3) what do diagnostic categories produce; what are their implications? The chapter explored the practices of participants in the context of their distress and the diagnostic labels given to them, and the impact and implications of receiving diagnostic categories.

This section is organised by the following discussion points:

- Summary of findings
- A process of responding to psychiatric diagnosis
- Removing the social relations of diagnosis
- The infrastructure of diagnosis becoming visible
- Reframing distress
 - Rebalancing the concept of 'expert'
 - Public versus private rejection of a diagnosis
- Clinical implications

7.6.1 Summary of findings

The findings in this chapter demonstrated a spectrum of opinion amongst participants; the themes derived from the analysis described positive functions of and responses to psychiatric diagnosis, however, critical voices were present. Four central themes were presented, exploring: the positive functions of diagnosis for service users, the damaging impact of diagnosis, questioning the value of diagnosis, and finally reframing distress outside of the diagnostic model. The findings demonstrated that service users use diagnosis positively as a form of recognising and legitimising their distress, and giving explanation to their experiences for themselves and for others. As highlighted in Chapters 4 and 6, diagnosis also has practical implications and is seen to facilitate access to financial support and mental health services. However, diagnostic labels can have a profoundly damaging impact on individuals, through impacting people's identities, and through stigma. As a result of negative experiences of diagnosis, including finding it limited in its explanatory power, some participants had come to question the utility of diagnosis and some had avoided or rejected the labels to which their experiences had been assigned. The data showed that some people chose not to problematise their experiences, seeing them as part of their personalities or sensitivities, but not as a disorder. Others conceptualised their experiences as understandable responses to difficult life experiences, such as trauma. This fourth theme

is informed by data from interviews with clinical psychologists to demonstrate some of the similarities between service users' ways of reframing their experiences outside of the diagnostic model. Both service users and psychologists discussed a tension between rejecting the use of psychiatric diagnoses, yet needing to use them within systems and services that continue to use a diagnostic model.

The findings of this chapter support previous research that suggests that being given a diagnosis can have both positive and negative impact for the individual (Hayne, 2003; Pitt et al., 2009). Furthermore, the findings of this and previous chapters support research showing the pragmatic ways that diagnosis is used by clinicians differs markedly from the personal meaning that it takes on for individuals receiving the diagnosis (Probst, 2013, 2015b). The findings broadly support Lewis' (1995) study, in which three types of responses were reported from those who had received a diagnosis; accepting the diagnosis as a relief, offering validation; accepting but questioning the diagnosis; and, rejecting the diagnosis as inappropriate. However, rather than representing separate responses to receiving a diagnosis, the four concepts in this chapter are seen as a potential process of practices from receiving to rejecting a diagnosis and using non-diagnostic ways of understanding distress.

7.6.2 A process of responding to psychiatric diagnosis

The four themes described in this chapter are not mutually exclusive. Some people's accounts of their experiences represented a little from one or several of these themes. The four themes can be seen as phases or stages of a process of using a diagnosis, a process whereby some people may move through more than one theme or stage, whereas others may remain at a particular stage, such as accepting the positive functions of diagnosis. The data suggest that negative experiences of the diagnosis and of psychiatric care tend to be the factors that drive a move through to later stages.

7.6.3 Removing the social relations of diagnosis

The positive functions of diagnosis demonstrate that the label is used as a tool for explanation, to the individual and to others around them, and. As a formal representation of a problem, clinically sanctioned, the diagnosis can be used to access care, support, and to justify allowances such as time off work, reflecting the findings of Chapter 6, where records of diagnosis were conceptualised as boundary objects. Informally, participants described using diagnoses to describe their difficulties in a medically recognised way, which helped to provide legitimisation and validation of distress, and understanding from others.

Diagnostic categories also provided an explanation of experiences for individuals themselves in spite of the categories not including information about cause. It could be said

that the social means that make it possible to use diagnosis in this way is the essentialisation of the diagnosis. This process supports the literature introduced in Chapter 1 (Section 1.3.2.1.1, Epistemological confusion, and Section 1.3.2.2.2, Essentialism and stigma), in which it is argued that colloquial language takes up realist, essentialist notions of the disorder or diagnosis causing a person's distress. This is in contrast with seeing diagnoses as nominalist categories that are used to represent or describe distress without necessarily including any information about how it is caused (Scadding, 1996).

In paring down or essentialising a diagnostic category for ease of communication, the 'social relations', i.e. the extensive literature on the limitations and debates around psychiatric diagnosis, and the social context of distress, are made invisible (Taussig, 1980). The diagnosis is simplified to a state in which it is provided as an explanation for the mental distress experienced. This way of thinking replicates the model used by psychiatric classification systems whereby problematic experiences are seen as symptoms of an underlying disorder (as discussed in Chapter 3, Sections 3.5.2.2 and 3.6.3.1, The role of trauma), or located as a fault within the individual, as opposed to having some external or inter-relational cause (Crowe, 2000). An important finding within this theme was the utility of removing the social context of distress. By providing a broad, shared understanding of what a particular diagnosis entails, participants used the label as a way of conveying only a socially and culturally accepted amount and type of information, rather than going into detail about their lives.

However, this conceptualisation and use of diagnostic categories is problematic for two reasons. First, the damaging impact of diagnoses reported by participants, alongside using diagnoses to explain distress, demonstrate a clear contrast with the clinicians' uses of diagnosis (described in Chapter 4) as a pragmatic, nuanced, flexible tool. Where the diagnosis moves from being a clinical and bureaucratic tool to the person, individuals internalise, interpret, or otherwise assign meaning to the diagnoses they have been given, demonstrating the diagnostic categories' new significance as more fixed categories that represent 'real' things in the world, which may be seen as identity changing, long-term disorders. These findings support the conclusions of Chapter 6 whereby diagnoses were argued to change in their conceptualisation to more reified categories beyond the clinic. Second, where explanations for distress are limited to the diagnostic category as a cause of symptoms, these ideas perpetuate an individual deficit model of distress that does not include contextualised understandings of how distressing experiences come about.

7.6.3.1 Conceptualising distress; diagnosing the person

Consequent to essentialised conceptualisations of psychiatric diagnoses, the data from this chapter show that the damaging impact of diagnostic labels is linked with a conceptualisation

of the *person* being diagnosed. The data suggest that diagnoses, especially those such as personality disorder and schizophrenia diagnoses, come to be viewed by recipients as attached to the person. This is in contrast with their *difficulties* being diagnosed, and the diagnosis being used as a way of describing mental distress, as is implied by the use of diagnosis as a clinical tool, described in Chapter 4.

This finding supports those of the previous chapter, whereby recorded diagnoses become more fixed or reified beyond their flexible use in the clinic. Just as the conceptualisation of diagnostic records becomes reified, so the categories' conceptualisation changes for some individuals when they are labelled. As introduced in Chapter 1 (Section 1.3.3.1), the data demonstrated that the diagnostic label can become a part of the individual's identity, which may have damaging consequences. The findings from this chapter support previous literature which states that recovery is related to shedding the 'mentally ill' identity and its effects (Coleman, 1999; Deegan, 1993).

7.6.4 The infrastructure of diagnosis becoming visible

For some participants, having their distress assigned to a diagnostic category was not simply a form of explanation or a tool for accessing support. The implications of the diagnosis were personal, and could be damaging. The findings of this chapter suggested that as participants had negative experiences of receiving a diagnosis or psychiatric care, their psychiatric diagnosis was seen as harmful or simply meaningless. This process might be compared to Bowker and Star's (1999) analysis of classification as infrastructure, whereby the negative experiences of diagnosis or of psychiatric care could be said to be making visible the diagnostic infrastructure to the person who is diagnosed. In becoming visible, this infrastructure can come in turn to be questioned. Consequently, as in Lewis' (1995) study, participants came to question its validity. The process of rejecting a diagnosis could perhaps be seen as a process of reintroducing the social relations surrounding it. The data suggested that participants made connections between their distress and difficult life experiences, and came to uncover the social, political, and historical context of diagnoses through their own research, and/or input from clinicians such as therapists or psychologists. This finding is supported by the experience of Coleman, who described his experiences of initially finding value in the medical model, but later began to see it as unhelpful, and he came to explore different ways of understanding his distress:

“For a number of years, I accepted the medical model as a framework of understanding... But I gradually came to appreciate drawbacks to the framework. My reading suggested the model might not stand up scientifically. The emphasis on distress as illness not only encouraged a resort to exclusively physical treatments (drugs, ECT) but pushed to one side any consideration of the content and meaning

of my crisis episodes. Thinking of myself as having a chronic and incurable illness robbed me of power and agency and confined me within an essentially negative category. By the time I was entering my second decade of service use, the medical model, which I had initially found reassuring, seemed increasingly unsatisfactory, without the capacity to encompass the complexity of my interior or exterior life and give it positive value. As a result, I began to actively explore frameworks that better met my needs.” (Coleman, 2010, p. 22).

7.6.5 Reframing distress

Revealing the social context or relations of diagnosis may allow people to question diagnoses and therefore seek new ways of thinking that diverge from the diagnostic model, both through NHS and non-NHS routes. This process may be linked with the impact of diagnoses on identity described in Section 7.6.3.1 and Goffman’s findings regarding the identity of the ‘mental patient’, whereby he argued, “to dodge a prescription is to dodge an identity” (Goffman, 1961, p.170). Distress was seen by some as an understandable response to traumatic or otherwise adverse experiences earlier in a person’s life, supporting the finding from Chapter 4 that more individualised information concerning people’s life experiences is needed to support clinical assessment. By assigning understanding to distress in this way, individuals described being able to better make sense of their difficulties in ways that feel more personally meaningful. Incorporating psychologists’ accounts of their approach to mental health demonstrated that psychological models of mental distress more closely reflect service users’ accounts of this nature.

However, in contrast with psychologists’ accounts, some service users saw experiences not as an ‘illness’ or even as ‘problems’. Participants described what would typically be referred to in the clinic as symptoms or difficulties as being ‘more or less sensitive’, or representative of a particular kind of personality. These ideas neutralised not only the diagnostic model of disorder but also the psychologists’ problematising of experiences as a focus for therapeutic work. This finding is supported by work by Plumb (1994, cited in Reeve, 2015) who suggests that the experience of being a ‘round peg in a square hole’ may be an important cause of mental distress. Rather than trying to conform to societal expectations, Reeve (2015) argues, some people are fighting for a society that instead recognises difference and diversity and “allows for new and creative ways of being” (Reeve, 2015, p. 103). This literature also relates to the resistance through language described in Section 1.3.3.3.1.1 of the literature review, in which madness is seen as “a positive assertion of alternative identity that distances itself from any biological signifier and which celebrates irrationality rather than seeking to erase it from public view” (Tew, 2015, p. 73).

7.6.5.1 *Rebalancing the concept of 'expert'*

Avoidance or rejection of diagnosis as an explanation for distress might be said to be associated with the rejection of the clinician as the expert. By not seeing the clinician as an expert with the power to hold the solution to a person's distress, the individual may themselves be empowered to find other frameworks for understanding elsewhere. Georgaca (2013), for example, argues that being positioned as the patient has an impact on the person's agency, and undermines their explanation of their distress. Disputing their position as 'patient', she argues, may enable individuals to "legitimate their version of reality" (Georgaca, 2013, p. 60). This process may explain participants' descriptions of initially being the "model patient" (Service User 17) to the clinician's expert prior to seeking alternative frameworks. Furthermore, factors that may enable this shift in how the clinician is viewed are negative experiences of psychiatric care in a broader sense as well as of diagnosis itself.

7.6.5.2 *Public versus private rejection of a diagnosis*

The way that systems within mental health services are set up, service users, many psychologists, and perhaps other clinicians, may personally reject the concept of diagnosis, but struggle, within the system, to have this idea accepted and to work alongside their care team or colleagues with this tension.

A dilemma faced by service users is the potential difficulty of openly challenging the viewpoint or model of the clinician. For example, clinicians can frame a service user's refuting of the diagnostic explanation as 'lacking insight', which in turn may be taken as further evidence of illness, thus reinforcing their 'madness'. 'Anosognosia', the name given in the DSM-5 to 'lack of insight', is seen as symptomatic of diagnoses such as schizophrenia. For example, the information about associated features supporting a schizophrenia diagnosis in the DSM-5 states, "[u]nawareness of illness is typically a symptom of schizophrenia itself rather than a coping strategy" (APA, 2013a, p. 101). The DSM-5 glossary, however, offers a potentially broader meaning that may relate to the rejection of a diagnosis or biomedical illness interpretation of distress: "[a] condition in which a person with an illness seems unaware of the existence of his or her illness" (p. 817). Roe and colleagues' (2008) qualitative exploration of insight showed four different representations of the ways in which people express insight about their diagnoses of schizophrenia or schizoaffective disorder, and their experiences of distress. One of which involved a person accepting that they have difficulties but rejecting the diagnostic label. However, this diagnostic rejection may be subsumed under a general perception of 'lacking insight', which can lead to professionals using more coercive treatment strategies, such as community treatment orders. For example, Stensrud and colleagues (2016) found that clinicians place greater emphasis on continuity of care (compliance with medication) over patient autonomy, and that

perceived lack of insight is used frequently as justification for coercive practices (Stensrud et al., 2016).

7.6.6 Clinical implications

Service users and some clinicians already find ways of reframing distress, privately and to some extent publicly. These ways of doing things differently demonstrate that other perspectives exist and are already in use. These might inform other ways of doing things formally within and outside of mental health services. For example, where service users find diagnoses damaging and disempowering, practices of taking part in valued activities such as peer support can help individuals to become re-empowered (Pitt et al., 2009). The success for some of accessing peer support and discussion with other 'experts by experience', for example through peer-led hearing voices groups, however, may be related to the reduced power differential between members. This problematic positioning of the clinician as expert links with Goffman's (1961) caution that "some activities...must remain unofficial if they are to be effective" (p.173). The inclusion of experts by experience in formal mental health services may also have limitations as a consequence of being a simultaneously a 'peer' and a paid employee of NHS mental health services. The open discussion of peer support may also be co-opted, towing the party line with regards to the psychiatric model. Peer support worker posts are also frequently under paid and under valued (Beresford & Russo, 2016). For example, a report from 2016 stated that there are eighty paid support roles in NHS versus many more unpaid (Christie, 2016).

7.7 Conclusions

This chapter has used data from interviews with service users who have received psychiatric diagnosis, supplemented by data from interviews with clinical psychologists, to explore service users' diagnostic practices and uses, the impact and implications of these receiving diagnostic labels, and how some individuals come to take up non-diagnostic ways of understanding their distress. The findings in this chapter presented four central themes exploring: the positive functions of diagnosis for service users, the damaging impact of diagnosis, questioning the value of diagnosis, and finally reframing distress outside of the diagnostic model. These themes were discussed as a process through which service users may travel through depending on their experiences. It is suggested that the social relations around diagnosis, including its limitations, history of debate, and the flexible uses by clinicians (described in Chapter 4), are minimised, as is, importantly the social context of distress. Participants saw this as an advantage when explaining their difficulties to other people, allowing a quick way of conveying a shared understanding without giving too much personal information. However, this means of viewing diagnostic categories as the cause of distress perpetuates the individual deficit model and minimisation of social causes.

The findings demonstrated that the minimisation of the social context of distress felt meaningless to some people. These participants sought other means of understanding, including reframing their distress as understandable responses to difficult life experiences. This perspective was supported by that of the clinical psychologists interviewed. The data demonstrated a tension, however, between rejecting the use of psychiatric diagnoses at a personal level, yet 'publicly' needing to use them within systems and services that continue to use a diagnostic model.

Section 4: Discussion and Conclusions

8 Chapter 8: Discussion

The following discussion incorporates an overview of the thesis, a summary of its findings, and implications and recommendations for mental health services. Reflections are offered on the research methodology and limitations of the study are discussed. A section on future research addresses these limitations. The possibilities and potential for change in the way that mental distress is worked with and conceptualised is explored. Finally, personal reflections on the research findings are discussed, and conclusions made.

8.1 Thesis overview

Psychiatric diagnoses have been developed to meet varying needs from individuals, service users and clinicians, to health systems and business needs including insurance and pharmaceutical companies. With these categories come both utility and costs. The thesis takes a critical realist social constructionist epistemological perspective to conceptualise psychiatric diagnoses not as reflecting a 'reality' of separate illnesses, but as active categories, constructed to perform various functions to meet socio-political needs. The way that 'mental health' is conceptualised need not look this way, and alternatives have already been proposed. These alternatives, however, have been developed from the perspective of either taxonomy or individual assessment, and struggle to provide pragmatic alternatives that meet myriad needs and functions across individuals, clinicians, and health systems. The point of departure for the thesis was the argument that the functions of psychiatric diagnosis should be more fully understood from multiple perspectives in order develop alternatives with greater utility and practical application, that also better meet individuals' needs.

This thesis maps the functions, practices, and consequences of psychiatric diagnoses from multiple perspectives. The findings were organised to represent the broadening out from the structure of diagnostic classification itself, to clinical uses by individual clinicians and mental health services, to beyond the clinical into other social worlds, including use by the people who are diagnosed. Three methods were used to gather data. A thematic document analysis examined five chapters of the DSM-5 as a protocol for practice, exploring the ways heterogeneity is represented across diagnostic criteria, and what is produced as a result, including the taken-for-granted assumptions embedded within the text. A series of Freedom of Information (FOI) requests was used to gather information regarding the service entry and eligibility criteria of NHS mental health trusts in the north of England. These were analysed to understand the ways in which diagnoses are used in gatekeeping decisions and to identify the non-diagnostic factors and methods upon which service entry criteria were organised. Semi-structured interviews were conducted with clinicians (GPs, psychiatrists, and clinical

psychologists) and mental health service users who had received psychiatric diagnoses, which explored clinical practices, the recording of psychiatric diagnoses and their travel beyond the clinic, and the ways in which service users make use of diagnoses and how distress may come to be reframed in different ways. The findings chapters were organised to reflect the travel of psychiatric diagnosis from the text of the classification itself, to clinical, and finally non-clinical uses of diagnostic categories.

8.2 Summary of findings

The following summary brings together the findings from the five empirical chapters of the thesis, within the context of the central research purpose and three central theoretical questions overarching the thesis, outlined in Chapter 2 (Sections 2.4.1.3 and 2.4.2, respectively). The central research purpose was: From multiple perspectives, what are the functions of diagnosis? To answer this question, the following theoretical questions were asked of the data.

- 1) What are the conceptual underpinnings of diagnostic categories, and are these consistent across contexts and practices?
- 2) How are psychiatric diagnostic categories used in practice, and in what ways does this differ (if at all) from diagnostic classification, and why?
- 3) What do diagnostic categories produce; what are their implications?

The thesis is structured according to the emergent finding of the process of diagnostic categories travelling from the text of the classification itself, to clinicians, services, and beyond the clinic to the individuals who receive them. This structure was used to highlight the functions and practices of diagnosis whilst they were situated within their different contexts of use. Analysis of the text of the DSM-5 in Chapter 3 demonstrated heterogeneity across diagnostic criteria, showing that the way that symptoms are presented in the DSM-5 construct some experiences of distress as inherently disordered or pathological. Alongside the symptom overlap between diagnostic criteria, the heterogeneity across the presentation of diagnostic criteria undermines the notion that the DSM-5 is a list of mental disorders, and instead supports the concept of psychiatric classification as a human system attempting to respond to distress and non-conforming behaviour. However, presenting diagnostic classification using a model of discrete categories of disorder nevertheless has implications for the way that cause is conceptualised. Trauma is seen as involved in only a limited number of diagnoses, discrete categories may lead to common 'transdiagnostic' causes being missed, and individual differences within diagnostic categories may be obscured. The findings of Chapter 4 demonstrated that for clinicians, certain diagnostic categories, such as schizophrenia, reflect these implicit conceptual understandings of cause and disorder.

However, these implicit ideas were not consistent across clinicians, and the themes from Chapter 4 predominantly reflected the pragmatic ways in which clinicians use psychiatric diagnosis as a tool to achieve particular clinical functions, such as pattern recognition and treatment planning. Diagnoses provide a heuristic for severity, cause, and intervention planning, through prototypical representations developed through clinical experience. This prototypical approach has limitations, however, and represents a departure from the criteria-matching protocol set out by systems of diagnostic classification, and the reliability of diagnosis and its clinical utility is therefore called into question. There is consequently a tension between diagnostic categories as a flexible assessment tool or as a system reflecting natural categories. There is, similarly, a tension between the expectation that expert clinicians will follow the classificatory protocol for 'accurate' diagnosis, and the demands on clinicians to use tools flexibly in the best interests of their clients. The variation in the use of diagnoses between clinicians also has important implications for routine data capture. The findings from Chapter 4 showed that diagnoses struggle to contain complexity, and are insufficient for many assessments, shown by clinicians' use of formulation to develop an understanding of distress and psychosocial difficulties, and the inter-relatedness between them.

The findings of Chapter 5 demonstrated that psychiatric diagnosis has limitations with respect to service entry and eligibility criteria, and is neither necessary nor sufficient for planning service entry. The analysis demonstrated that not all mental health services in the north of England use diagnostic labels as a central factor in their entry and eligibility criteria. The use of diagnostic categories in service entry criteria represented specific difficulties or experiences of distress. However, they were also used as proxies for a particular level of severity, risk, or need, rather than as discrete categories of disorder. As with the clinicians' uses in Chapter 4, Chapter 5 demonstrated that broad, quasi-diagnostic categories, such as "severe and enduring mental illness", are used by services. These broad conceptualisations again perform functions as representations of the type and severity of distress experienced. At the same time these ways of using diagnosis as a tool deteriorate the concept of a taxonomy of mental disorders. The data suggested that diagnoses were used as a proxy for a broad domain of competence, of the skills required to work with a particular presentation of difficulties. This is also reflected in the data from Chapter 4; the psychiatrist who tends to diagnose schizophrenia because they can treat it (Section 4.5.1.2.1, Problems with prototypes) is therefore using the diagnostic category as a way of identifying what can be worked with, rather than identifying a specific disease category as diagnostic classification prescribes. Indeed, the largest group of services in Chapter 5 was more explicitly oriented towards individual needs and team competencies, and innovative services worked with specific life circumstances, such as homelessness, rather than with diagnostic categories.

The findings from Chapter 6 demonstrated that the recording of diagnosis is ubiquitous in communicating information beyond the clinical assessment. Clinicians pragmatically apply diagnoses to achieve particular aims, and as such they can be framed as 'boundary objects' that facilitate cooperation across contexts. However, the analysis demonstrated that using diagnostic records in this manner has consequences for their conceptualisation beyond their nuanced, flexible clinical use by clinicians and mental health services. The data showed that diagnoses are represented as fixed, inflexible, and even reified categories when they are formally recorded and used on administrative and bureaucratic documents such as Mental Health Act (MHA) (1983) papers and applications for welfare benefits. Clinicians described the tension between the practical utility of diagnostic categories facilitating numerous clinical functions, and the personal impact for service users of receiving a diagnosis, which they acknowledged could be long-term and stigmatising. These findings again demonstrate the tension between diagnoses as flexible tools and as representing discrete categories of disorder. The implications for research and data capture are important; diagnostic data may be collected as representing certain, stable categories, yet this is at odds with their nuanced and pragmatic application by clinicians.

The findings from Chapter 7 demonstrated that psychiatric diagnoses can have several important positive functions for those who receive them, including relief that one's difficulties are recognised and legitimised, an explanation for oneself and others, and practical functions such as access to services and financial support. Another important theme, however, was the damaging effect that diagnoses can have on the individual. The data demonstrated that both the negative impact on a person's identity and the stigma experienced as a result of the label were associated with essentialised conceptualisations of diagnostic categories. These ways of viewing diagnostic categories were not aligned with clinicians' uses of diagnosis as a pragmatic tool. The data suggested that diagnoses became a way of labelling the people themselves, rather than their experiences of distress. As part of this process, the social relations around diagnosis, including its limitations, history of debate, and its flexible use by clinicians were minimised, as was the social context of distress. The diagnosis itself may even be seen as the cause of distress. These findings support the changed conceptualisations of diagnosis seen in Chapter 6. The data showed that this conceptualisation could be used to individuals' advantage, allowing a quick way of conveying a shared understanding without giving away too much personal information. However, this essentialised view of diagnostic categories perpetuates the individual deficit model and minimisation of social causes.

The data in Chapter 7 suggested that for individuals, negative or damaging experiences of diagnosis and of psychiatric care could begin to unravel this model of viewing distress. By questioning its meaning and validity, the infrastructure of diagnosis and its social, political, and historical context was revealed, allowing different ways of framing distress to be found.

As part of the process of avoiding psychiatric diagnoses, the final theme described other means of understanding distress. These included deproblematizing experiences altogether, or reframing distress as understandable responses to difficult life experiences. The latter perspective was supported by that of the clinical psychologists interviewed. The data demonstrated a tension, however, between rejecting the use of psychiatric diagnoses at a personal level, yet 'publicly' needing to use them within systems and services that continue to use a diagnostic model.

Described above are several tensions between the functions of psychiatric diagnosis. In its clinical functions, for example, there is a tension between psychiatric diagnosis as a tool and as a system of discrete disease categories, and likewise, clinicians are caught between following the protocol of diagnostic classification and using the categories flexibly to best meet clients' needs. Beyond the clinic, the data demonstrated the damaging personal impact that diagnoses can have on the individual, and this is at odds with its practical clinical, business, social, and personal functions. Because of this tension, individuals who may choose to avoid using diagnostic ways of framing their distress are not free to do so publicly across all the functions of diagnosis, in light of potential ramifications within mental health services, and because access to support, including benefits, is frequently seen as diagnosis-led. These tensions demonstrate the process by which diagnosis travels from the classification itself to different contexts of use. Its multiple functions and changing conceptualisations mean that the utility of one function may result in damaging consequences elsewhere. At the intersection of these functions is the person diagnosed.

8.2.1.1 Different conceptualisations of diagnosis in the literature

These multiple functions make a 'moving target' of psychiatric diagnosis in terms of evaluating its utility and implications. This is reflected in the debate by-line quoted in Section 1.6.1, "Felicity Callard and Pat Bracken argue that a psychiatric diagnosis can disempower people rather than help them, but Anthony David and Norman Sartorius think that the diagnostic framework ensures that resources are allocated appropriately", (Callard et al., 2013, p. 1). This quote demonstrates that different functions, conceptualisations, and consequences are invoked in order to argue the relative merits or issues with diagnosis, rather than comparing 'like for like', for example following through the process of particular functions and their consequences for both clinicians and service users, as this thesis has sought to do.

These multiple functions invoke different underpinning conceptualisations, which are inconsistent across contexts and as a result diagnostic categories have potentially damaging consequences for the individuals given these labels. Responses in the literature to these different conceptualisations and the divide that diagnoses creates between 'normal' and

disordered' are varied. Smail (2005), for example, argues that power pervades by creating difference, and that those in power exploit this 'difference':

Our common humanity rests upon our common embodiment. We are all made in exactly the same way. We all suffer in the same way. Most immoral enterprises seek in one way or another to deny this truth and to justify the greater suffering of the oppressed or exploited on the grounds of their being 'different' in some way...
(Smail, 2005, p. 93)

As discussed in the literature review (e.g. Section 1.3.2.3.5), proponents such as Kinderman (2014; Kinderman et al., 2013) therefore argue for a continuum model that entirely drops the separation of disorder from 'normality'. Others argue that a continuum model puts everyone at risk of being pathologised (Pilgrim, 2014). Converse to this, some have argued that a continuum model "trivialises" (Pies, 2015) or "domesticates" (Carroll, 2015) experiences at the severe end of the spectrum of distress. Commentators such as Frances (2013) argue for clear delineation of 'normal' from 'genuine mental illness'. However, the findings from Chapters 4 and 6 demonstrate that this divide between 'normal' and 'disordered' is not applied in a rigorous manner. The data showed that diagnostic criteria are applied flexibly, and decisions are nuanced, subject to socio-political contexts and clinicians' views on the needs of their clients, the resources available, and the implications for the individual. Chapters 6 and 7 demonstrate that beyond the clinic, diagnoses and this demarcation of 'genuine mental illness' perform important social and financial functions, however, essentialising diagnostic categories as reified, biologically caused illnesses can also be damaging for the individual, both personally and socially.

In Chapter 4, the GPs' descriptions of distinguishing between understandable responses to difficult life circumstances and "proper" mental illness reflected Frances' (2013) binary between "normal" and "genuine mental illness". If these distinctions were consistently applied across individuals, they may help a GP to make pragmatic care planning decisions. However, conceptually, by constructing an experience such as low mood as either understandable or as part of a formal (biomedical) diagnostic category, this binary may serve to de-legitimise or invalidate the understandable form of distress. Language such as "just a reaction" (GP6) versus "proper" (GP 6) and "actual" (GP 9) disorder suggests that distress in response to life circumstances or experiences may not be conceptualised as seriously as presentations of distress that are perceived as more biological. Research such as that of Lewis (1995) also demonstrates the potentially negative impact of one's experiences being on the wrong side of this demarcation, thereby being denied a diagnosis. Findings such as these reveal what Smith (1978, p. 26) calls the "complex conceptual work" needed in order to maintain the reasoning of the diagnostic disease model.

8.3 Implications and recommendations for mental health services

This research for this thesis began on the premise of seeking an alternative way of approaching mental health care. The findings demonstrated that psychiatric diagnosis acts as a proxy for multiple functions. The specific alternatives proposed in the literature discussed in Chapter 1 are therefore demonstrated to be too limited in their scope. Such alternatives included technical approaches such as the National Institute of Health Research's Research Domain Criteria, scientist-practitioner approaches, including problem-list assessment, and humanistic alternatives such as psychological formulation and Open Dialogue. Each of these proposed alternatives is limited to only a small number of the many functions of diagnosis, such as individual clinical work or research. Because psychiatric diagnosis acts as a proxy for many different factors, and its representation changes across clinical and other social worlds, the implications of these findings are complex. Replacing one assessment method with another would be insufficient. As stated by Kendell and Jablensky (2003) (discussed in Section 1.3.1.2.4), the utility of diagnosis (and other tools) must be considered within the contexts in which they are used. The implications for mental health services, therefore, must consider the functions and proxies that diagnoses represent, and the contexts within which these are used. As Millerand and Bowker (2009) argue, standards must be organisationally situated, and cannot exist outside of their social and organisational contexts. This thesis demonstrates that a wider process of system reform is necessary to take into account the different functions, contexts, and proxies that psychiatric diagnosis currently seeks to fulfil.

The following section outlines the implications of the findings of this thesis for mental health services, their delivery, and commissioning. These implications are grounded within the data and focus on largely technical findings that have been highlighted from each of the empirical chapters. Despite the thesis premise that alternative, or new, methods of assessment and working with mental health would be necessary to reform mental health services, the findings suggested that there are methods and conceptualisations that are already used by individuals and services. The following recommendations suggest making use of this existing infrastructure and related approaches. To address the multiple functions and proxies that diagnosis seeks to represent, it is anticipated that each of these recommendations should be followed, in keeping with the notion of system reform described above. Without a comprehensive process of system reform, individual changes are at risk of becoming incorporated into the existing diagnostic model, or falling prey to the same limitations. For example, broad groups of difficulties may become essentialised or used as labels without a change in the model underpinning the approach.

Table 8-1 outlines the recommendations and examples that will be discussed in this section. These recommendations are limited to implications for mental health services. Future

research is outlined in Section 8.5, and further reaching implications are discussed in Sections 8.6 and 8.7.

Table 8-1

Recommendations for mental health services & implementation examples

Recommendation	Implementation examples
Neutralising the model underpinning assessment	<ul style="list-style-type: none"> Using ICD 'symptom' codes to describe distress and difficult life experiences/environment
Changing the use of tools that stabilise diagnostic categories	<ul style="list-style-type: none"> Using the Equality Act to demonstrate impact and effect of mental distress Using non-diagnostic language to describe distress
Broad groups of difficulties and competency-based service organisation	<ul style="list-style-type: none"> Needs-led services
Representing heterogeneity by making explicit flexibility	<ul style="list-style-type: none"> Wider training in psychological formulation, e.g. for GPs

8.3.1 Neutralising the model underpinning assessment

The findings suggest moving towards a more neutral model of mental health, that does not 'ground' interpretations of mental health difficulties against a set of beliefs and assumptions about disorder. A truly descriptive account, compared with a disorder-driven descriptive account such as the DSM, can be used as a more neutral approach at least until patterns with greater utility for both service users and clinicians are identified. Diagnosis of an illness is very different from the description of phenomena. To use the example from service entry criteria, the need to identify specific difficulties in order to accept clients into a service that has a team with appropriate competencies or skills to work with those difficulties is distinct from the need to diagnose a medical illness or disorder. Patterns may be recognised, and the severity of distress judged, but this is distinct from the Oxford English Dictionary definition of diagnosis, which focuses on the identification of disease: "Determination of the nature of a diseased condition; identification of a disease by careful investigation of its symptoms and history; also, the opinion (formally stated) resulting from such investigation" (Oxford English Dictionary, 2017).

Proponents of the biological concept of 'mental illness' have argued that not using the diagnostic model would be to deny people's distress, under the notion that if a person's distress is not mental illness then it is not valid. Langford, a psychiatrist, argues:

...it would mean looking all your friends and family who've had a mental illness in the eye and telling them that their diagnoses were nonsense and they weren't really ill, they shouldn't have seen their doctor for that, they shouldn't have been allowed health insurance or sick leave or medication or treatment for that, that they were just sad, obsessed, stressed or weak. (Langford, 2014)

However, neutralising the diagnostic model in favour of a descriptive account of people's difficulties is not to argue that nothing is wrong (although the individual deficit model of mental distress has been challenged, see Section 1.3.3.1.2) or that services cannot be offered. Instead, distress is acknowledged, described, and even likened to difficulties to others have, but without the assumptions embedded within the diagnostic model.

Despite the history of debate around psychiatric diagnosis (described in Section 1.3 of the Literature Review), service users currently do not have a choice as to how their distress is framed because the diagnostic model is dominant, and used by the clinicians with which service users initially come into contact. However, if the diagnostic model does not always underpin assessment and conceptualisation of mental health difficulties, the meanings and narrative ascribed to a person's difficulties have greater opportunities to be negotiated between clinician and service user, rather than re-defining a person's difficulties within the medical model, which may not always be welcomed. With a neutral starting point of assessment, service users would at this point still have the option of understanding their difficulties within the framework of a diagnosis. Two of the service users interviewed were keen to keep the diagnostic labels they had been given. It is not possible to know at this stage, with the available literature, whether having alternative ways of conceptualising mental health difficulties from the initial point of assessment would negate this desire for a diagnostic label, but this implication could be empirically investigated.

The thesis findings suggest that the diagnostic model can obscure different methods or ways of thinking on an individual level, such as identifying trauma as a cause of distress. Within the organisational context of mental health, the infrastructure of diagnosis also obscures existing infrastructure that might usefully be taken up to further our understandings of mental distress. An example of using ICD codes to facilitate this approach is discussed below.

8.3.1.1 *Example: Using ICD 'symptom' codes to describe distress and difficult life experiences/environment*

Examples of existing infrastructure that offers different modes of data capture and ways of conceptualising distress are the descriptive, non-disease codes in the ICD-10 (World Health Organization, WHO, 1992) and DSM-5 (American Psychiatric Association, APA, 2013). The ICD-10 details descriptive codes for specific experiences of distress that can be used without use of diagnostic illness categories including, for example, auditory hallucinations (R44.0), restlessness and agitation (R45.1), unhappiness (R45.2). However, for record keeping or report writing, these current descriptors may be invalidating as they may not convey sufficiently 'significant' distress in comparison with the experiences contained within diagnostic criteria for mental distress. This issue relates back to the binary constructed by the diagnostic model, and the potentially invalidating impact of not using diagnostic language while the diagnostic model underpins conceptualisations of mental distress. Further ICD R codes could be included to better represent the severity of distress that is currently included within diagnostic categories, but without the overarching diagnostic model. Representing specific experiences in this way may even comprise a political act in the sense that psychological conceptualisations of mental distress would be represented within the ICD alongside medical, diagnostic conceptualisations.

Both the DSM-5 and the ICD-10 include codes for descriptive information that relates to difficult life experiences or living environments. For example, Chapter XXI of the ICD-10 lists factors influencing health status and contact with health services. Within this chapter, codes Z55-Z65 list 'persons with potential health hazards related to socioeconomic and psychosocial circumstances', which is a large section of codes relating to overarching difficulties associated with potential health hazards related to socioeconomic and psychosocial circumstances, including homelessness, negative life events in childhood, poverty, discrimination and persecution. These codes describe multiple situations and experiences that do not describe distress, but are of note for clinicians as potential social determinants of mental distress. For example, there are various codes for child sexual abuse, including problems related to sexual abuse by a person inside (Z61.4) or outside (Z61.5) of the primary support group. There are also codes, for example, relating to the effects of deprivation (ICD-10 section T73) and codes relating to maltreatment, including neglect, abandonment, and abuse ICD-10 section T74). Similarly, the DSM-5 (APA, 2013) includes V codes, described as issues that may be a focus of intervention, but that are not assigned to a disorder. These codes mirror the ICD-10 codes, including sections for 'Problems related to family upbringing' (p. 715), and 'Housing and economic problems' (p. 723).

8.3.2 Changing the use of tools that stabilise diagnostic categories

Chapters 4 and 6 demonstrate that diagnostic categories act as useful ways of conveying information quickly, particularly on written records and communication. However, Chapters 6 and 7 showed that these records of diagnostic categories change their conceptualisation from flexible categories applied pragmatically by clinicians to fixed, reified categories that can have harmful consequences for individuals who are diagnosed. This research, therefore, suggests that mental health services could change the ways that administrative functions are carried out, such that they more transparently represent individual needs, without using diagnostic labels that crystallise distress as long-term and unchanging. Chapter 5's analysis of the service entry criteria of NHS adult mental health trusts in the north of England showed that a hybrid model is already in use, utilising factors such as risk, severity, and support needs. Diagnostic labels, therefore, should not be required for service referrals, so long as sufficient need is demonstrated and that the required skill sets for intervention are matched with the services on offer. Two examples of this recommendation are given below: using the Equality Act (2010) to demonstrate mental distress, and the use of non-diagnostic language in formal documents such as legal reports.

8.3.2.1 *Example 1: Using the Equality Act (2010) to demonstrate impact and effect of mental distress*

Laws such as the Equality Act (2010) can be utilised as tools to help people to access appropriate care and support without recourse to diagnosis. In the Equality Act (Schedule 1, Disability: Supplementary provision, Part 1, Determination of disability, Office for Disability Issues, 2011b), the focus of the legal determination of disability is on the demonstration of impact and effect of the disability caused by mental distress. However this determination of disability does not rely on psychiatric diagnoses. Furthermore, its inability to rely on diagnoses (in comparison to the certain physical health diagnoses that are de facto accepted as disabilities; HIV diagnosis, multiple sclerosis, and cancer) is a demonstration of the fact that psychiatric diagnosis does not encapsulate the information required to make such decisions.

8.3.2.2 *Example 2: Using non-diagnostic language to describe distress*

Furthermore, Kinderman (2015) has demonstrated ways in which legal reports, such as those concerning forensic cases or detention in hospital, can be written using non-diagnostic language to identify the support needs of individuals, justification for care, and using psychological explanations of behaviour.

8.3.3 Broad groups of difficulties and competency-based service organisation

Chapters 4, 5, and 6 demonstrated that diagnosis is used as a proxy for many different factors by both clinicians and services, including demonstration of risk, severity, and level of need. The diagnostic model can be set aside in favour of making transparent what it represents.

Whilst services currently use the clustering system, associated with Payment by Results, broad selections of clusters were used in service entry and eligibility criteria (Chapter 5), such as clusters 1-3, representing mild to moderate difficulties, or 4-17, representing all other severities of psychotic or non-psychotic difficulties, and excluding organic problems such as dementia or other cognitive impairment. These findings suggest that broader groupings (than specific diagnostic categories) satisfy service requirements and represent differing levels of severity and need. Following the Section 8.4.1 on neutralising the model underpinning assessment of mental distress, these data suggest using broad groups based on pragmatic needs, such as required skillset, and ability to meet people's needs, without any assumption that these categories are a) discontinuous, or b) represent illnesses or disorders. This way of organising mental health services would be more closely aligned with a clinical description model, without the unwarranted influences of the diagnostic model that Hyman (2010) describes, such as dividing difficulties into 'highly specified disorders' or 'discontinuous categories' (p. 161).

Diagnosis at times gives utility and offers a tool for clinicians, whereas flexible, needs-based assessment is responsive to, and driven by, the personal, individual experience, meaning and need. The potential issues of creating a 'broken continuum' by marking at which point an individual becomes eligible for support from mental health services is discussed in Section 8.2.1.1. However, using a system that separates between differing levels of need does not create just one but several incremental divides, that recognises differing support needs and skills required to work with those needs, including people experiencing extreme distress and high risk of self harm or suicide. Rather than defining a case as 'complex', an informal category that may become attached to the person and associated with negative conceptualisations such as deviance (Jeffery, 1979), what is defined is their need and the type of resources they may require at that time. Deegan (1993) has cautioned about the impact of labelling of individuals, not only in terms of diagnoses, but also as high or low functioning. She describes how this type of labelling, like diagnosis, comes to be represented as an attribute within the person, rather than, as she sees it, a value judgement that is placed on that person. It would therefore be important to consider the potential implications of any new or different ways of conceptualising mental distress.

The concept of using broad descriptive groups of difficulties ties in with empirical literature studying transdiagnostic dimensional approaches. The potential value for keeping broad categories of common or severe mental disorders has been acknowledged (van Os et al., 2013). Research suggests that cross-cutting dimensions may better represent empirical findings, more flexibly representing transdiagnostic difficulties that bridge between categories, for example across psychosis and affective disorder diagnoses (Allardyce et al., 2007). Similarly, as discussed in Section 1.3.1.3.1 regarding dimensional approaches, McGorry and van Os (2013, p.343) discuss the feasibility for services of a precise separation between 'normality' and 'disorder', suggesting instead a "soft and flexible entry (and exit)" approach instead. An example of needs led services is given below.

8.3.3.1 Example: Needs led services

As well as broad groupings based on mental health difficulties themselves, and the specialist needs that may arise from these types of distress, the data from this thesis suggest service organisation also be based on the needs of service users. Data from predominantly the analysis of service entry criteria and clinicians' definitions of complex cases suggest competency-based services that are led by service user needs. For example, the support needs for increased risk, and multi-agency working to support those with multiple difficulties that may not always be mental health based, but instead may be complicating and/or causal factors in people's difficulties, such as financial and economic difficulties, or social problems such as housing and so forth. Specific skills may be provided by services that do not necessarily divide along the lines of the type of distress (e.g. psychosis) but working with other common factors such as providing trauma work. Trauma was important in the description of complex cases (Section 4.5.2.4.3), as well as in the consideration of different ways of working, particularly by psychologists and service users (Section 7.5.4.1.2). If services were organised around what the person needs at that time, the need, not the person, is categorised, and so moving away from labelling people. This may allow a greater focus on the individual and their experiences without overshadowing by the diagnostic label (Section 1.3.2.2.1). For example, essentialised societal discourses around danger may influence referring and interventions around psychosis in particular. The findings from Chapter 5 suggested that diagnoses were used predominantly within exclusion criteria, and that these may relate to concerns about engagement, for example disruption of group work. However to use psychosis within exclusion criteria, for example for Improving Access to Psychological Therapies (IAPT) or lower level services, imposes a blunt criterion that may be unhelpful if people are able to make use of an intervention.

There already exist examples of non-diagnostic services that work flexibly according to service users' needs. For example, the Psychology in Hostels project, a partnership between the London Borough of Lambeth, South London and Maudsley NHS Foundation Trust and

homeless charity Thames Reach Waterloo Project, was set up to support homeless people who struggle to maintain accommodation (Rhodes, 2016). Psychologically informed environments as used to support homeless people to stabilise and maintain accommodation, reduce psychological distress, drug and alcohol abuse, and contact with the criminal justice system (Williamson & Taylor, 2015; Woodcock & Gill, 2014).

8.3.4 Representing heterogeneity by making flexibility explicit

Heterogeneity could further be represented by transparently using assessment in flexible ways. The findings from Chapters 4 and 6 showed that diagnosis is adapted frequently, dependent on the situation, the individual, and the psychosocial factors impacting upon their distress. More flexible methods of assessment would make this heterogeneity explicit. Flexible assessment would allow different uses across services, for example, including the broad categories used by GPs. A key difference between clinicians' descriptions of psychological formulation, a suggested alternative to diagnosis (Section 1.3.2.3.3), and psychiatric diagnosis was that of flexibility. Formulations were seen by clinicians in this research as readily updated to represent changing information, needs, or discussion between clinician and service user as to what felt the most useful for therapeutic work. Whether or not a changing approach used formulation, the same philosophy of an adaptable description assessment could be utilised. An adaptable description would acknowledge changing needs and difficulties, dependent on the environment or situation and changing life circumstances, rather than a representation of a diagnosis that becomes a fixed and consistent entity, seen as impacting a person in similar ways across their lifespan.

Different timescales of assessment would be acknowledged by differing descriptions that represented either snapshot assessments carried out in one community mental health team (CMHT) appointment or in an emergency situation, versus patterns that had been developed and understood over a period of longitudinal assessment. The depth of assessment would be adapted according to the present needs and available support. In situations of very acute risk, for example, there may be less of a focus on in-depth exploration of the meanings the individual ascribed to their difficulties, compared with more 'here and now' information about the current difficulties. Where follow up support is not available, it may not be appropriate to explore more in-depth assessment, such as asking about trauma. Guidelines for why, when, and how to ask about childhood abuse (Read, Hammersley, & Rudegeair, 2007), for example, recommend a comprehensive psychosocial assessment, the time for which may not be available in a short GP appointment. Nevertheless, psychological formulation presents an opportunity for the flexible assessment of distress in a range of clinical settings. An example of offering wider training in formulation is given below.

8.3.4.1 *Example: Wider training in psychological formulation*

The findings of Chapter 4 demonstrated that diagnostic categories struggle to manage complexity and clinicians reported needing to incorporate psychosocial factors, which are not included with diagnostic criteria. More widespread use of psychological formulation could be used to better represent the heterogeneity in distress across individual experiences. For example, GPs in Chapter 4 described managing a “mishmash” of distress entangled with social and psychological causes (Section 4.5.2.2), thus this group of clinicians in particular may benefit from training in psychological formulation in order to capture this complexity.

8.4 **Research methodology and limitations**

In reflecting the above findings, it is important to take into consideration the research methods and their underpinning assumptions, which have produced these findings. Data are produced rather than simply collected (Green & Thorogood, 2014), and reflecting on the research methodology can allow space to consider how these factors impacted upon the research findings.

8.4.1 **Personal reflections on interviewing**

Research findings are constructed between the researcher and the research participants (Green & Thorogood, 2014). The relationship between these two perspectives is central to the findings produced by the research process. In line with the epistemological perspective taken in this thesis, the research findings need not look this way, and other conclusions might have been drawn from the data if analysed by another researcher with different experiences. Outlined in the methodology are the steps taken to use an iterative process of analysis, of moving between the data, my interpretations, and the research and theoretical literature, and back to the data. These steps were taken to continually reflect on the data and the analytic process, challenging my interpretations, to ensure that the findings are grounded in the data.

8.4.1.1 *Differing perspectives*

For interviews with clinicians particularly, I was mindful of my positioning within psychology and the background of debate about the DSM-5 and diagnosis in mental health (introduced in Section 2.2, Personal and political positioning). Perhaps revealing this concern, early reflections on my relationship with research participants did note a contrast between interviews with psychologists in contrast with psychiatrists. I noted feeling a greater affinity with psychologists, and often these interviews felt more relaxed, with perhaps more of a

feeling of 'being on the same side'. This was of particular note when psychologists described the challenges they faced in marrying their beliefs and ideas about mental health with those of other disciplines and those represented in the mental health system itself. By having a background in psychology, and likely my participants' knowledge of my main supervisor Professor Kinderman, a prominent figure in clinical psychology in the UK, I wonder whether this made it easier for psychologists to express their difficulties more freely, even when participants expressed concern that they were "colluding with the [diagnostic] system" (Psychologist 3). By contrast, some interviews with psychiatrists felt prickly at first, with some psychiatrists appearing defended about the ways that they work, which was understandable in the wider context of debate and critique between mental health professions. Some psychiatrists were keen, also, to show that they used diagnosis as a tool but not as something that they used uncritically. One psychiatrist, for example, said early on in the interview, in response to my focus on the use of diagnosis in clinical practice, "I'm not actually that bothered about diagnoses" (Psychiatrist 1). In the early stages of data collection, part of me expected to disagree with at least some of what was said by clinicians who used diagnoses, and perhaps in return this was expected by some participants. However, maintaining a methodological focus on the practices of diagnosis, rather than on opinion, helped me to develop a much richer understanding of the uses of diagnosis from the clinicians' perspectives. This understanding was particularly developed by hearing examples from clinicians' work, of clients' difficulties, and the challenges that clinicians face, from personal, professional, and organisational perspectives, such as holding clients' risk and often having very few resources to offer. As discussed in Section 2.8.3.1.4.1, my focus was not on making judgements as to the 'right' way to do things, but to understand how and why clinical practices come about, and what their implications may be. Taking a curious stance within interviews, of that of Schuetz's (1944) 'stranger', as someone who is not trained in diagnostic assessment, facilitated a perspective of not assuming or challenging but of seeking to understand, which I felt resonated with participants. The same psychiatrist (Psychiatrist 1) who had been keen to let me know her views on diagnosis remarked at the end of the interview, with some surprise, how "painless" it had been. This 'unfamiliar' stance was maintained throughout analysis, with a focus on representing data from participants' perspectives, not my own.

8.4.1.2 *The messiness of real life*

I noted a contrast between the accounts of clinicians and that of service users. In describing their practice, within the immediate clinic setting, clinicians' accounts represented what appeared to be a more sanitised version of mental health care. This fell in contrast with the stories shared by service users, many of whom painted a much messier picture of mental health services and the ways that they work, or at times fail to work. For example, participants described diagnoses losing meaning when their label had been changed or

updated so frequently over the years. This may be understood using the framework of Goffman's (1959) ideas about the presentation of self as a comparison with the theatre. The 'front stage' self is constructed with an awareness of having an audience, and the actor chooses what to portray to that audience in order to present a positive, consistent account. When analysing participants' accounts, it was important to consider what people had chosen to share, or not to share, with me. For the clinicians interviewed, and given the social and political contexts of the research which have already been described, clinicians might have felt in a position of having their clinical practice critiqued, whereas service users' descriptions of their experiences came from a different perspective, and to discuss the successes or failures of mental health services was perhaps less personally threatening.

Hearing service users' accounts of their experiences of diagnostic assessment over a longer period of time, often a lifetime, of interactions with mental health services provided important context for the consideration of clinicians' assessment practices. This context was considered alongside understanding why clinical practices occur, and the social and organisational contexts of these practices. When I compared the accounts of clinicians and service users in this manner, what I had originally seen as 'tensions' between the accounts, and the functions of diagnosis, I came to view more as a process. The process of diagnostic categories travelling from the text of the classification itself, to clinicians, services, and beyond the clinic that I used to structure this thesis became a useful way for me to understand the functions and practices of diagnosis whilst they were situated within their different contexts. I used this process to try to understand how and why such 'tensions' occur rather than judging them from one perspective or another. Rather than seeing the comparisons in the clinicians' and service users' accounts as contradictory or at odds, functions and consequences that appeared to clash, I understood these contrasts as a more contextualised account of the ways that the meanings of diagnostic categories change and practices differ beyond the individual clinic setting.

8.4.2 Limitations

8.4.2.1 *Design*

Given the positionality of my approach to the research (outlined in Section 2.2 of the Methodological background chapter), different approaches could have been taken with regards to the design of the research that took into account broader perspectives. For example, as well as clinical psychologists, the research could have included the perspectives of professionals from different disciplines such as psychiatrists and/or GPs in designing the research methodology and interview questions. This type of participation could be particularly beneficial with regard to service users, for whom it has been argued that there is a need to "create their own knowledge" (Faulkner, 2012, p.40). These types of approaches

are closely related to survivor research and emancipatory disability research (Beresford & Wallcraft, 1997), the process of which aims to empower service users through the process of research. This approach would tie in with the service user/survivor literature described in Section 1.3.3.

8.4.2.2 *Interview participants*

The semi-structured interviews focused on the most immediate stakeholders of mental health care; clinicians and the individuals who use their services. Qualitative research methods were used to gain a rich understanding of the ways clinicians and service users discuss and make sense of psychiatric diagnosis and its practices of use. Interviewing other types of participants would have offered further perspectives on the issues discussed regarding diagnosis and its uses. Other important stakeholders and users of diagnosis could include other clinicians, such as mental health nurses, who are involved in care planning, and those who work in a service organisational capacity, such as individuals responsible for commissioning and managing mental health services. Likewise, several participants spoke about their families wanting them to be given a diagnosis. Incorporating these broader perspectives within the findings could give further information as to the ways that diagnosis travels and is taken up beyond the client-clinician relationship. Broadening the discussion of issues and functions of diagnosis to a wider service level, speaking with commissioners and other key individuals involved in service planning would likely reveal wider functions, and potentially limitations, of diagnosis.

In addition, by interviewing service users who had received a psychiatric diagnosis, this research cannot offer information about those who do not access NHS services. Likewise, the research does not explore the experiences of people who access services but are not given a diagnosis. For example, a participant in Lewis' (1995) research described the damaging and de-legitimising experience of being told by her GP that she was not depressed, which Lewis describes as being denied a diagnosis. Interviewing these two groups of people could offer further information about perceptions of diagnosis and why people may want a diagnosis, the ways in which mental health services may not be appropriate for everyone, and how and why people come to manage their distress without support from NHS services.

Likewise, people may not access services through choice or as a consequence of the inaccessibility of services. For example, research has found that mental health services can perpetuate inequalities such as social exclusion for African Caribbean communities (Mclean, Campbell, & Cornish, 2003). Furthermore, if the purposive sampling method had sought to include more participants who had both been given diagnoses and who came from black and minority ethnic groups, different findings may have been drawn from the analysis that may

have reflected the literature discussed in Chapter 1 (Section 1.3.3.2.1, Ethnicity), which highlighted race bias and uses of psychiatric diagnosis that reflect oppression and discrimination on the basis of racial identity.

8.4.2.3 *Analysis*

The process of analysis for the interview data used initial open coding of a small proportion of the interview transcripts. The codes generated from this detailed analysis of a subsection of the data were used to form the coding framework against which each of the other interviews were coded. This process may have unduly influenced later analysis in two ways. First, the process may have limited the analysis of interviews by closing down alternative avenues of enquiry within the analysis of the full interview dataset. Second, it may have biased the analysis in the sense of establishing a set of assumptions, which then constructed a particular lens through which the other data was analysed. This approach may therefore have influenced the findings and conclusions that were drawn from the other interviews.

Furthermore, analysis of all the participants groups together, including both clinicians and service users, although chosen as a method of bringing together the groups and analysing the similarities across groups, may have resulted in a less in-depth exploration of the differences across the groups. Likewise, efforts to use as similar questions as possible across participant groups may have meant that some questions, including the theoretical questions used to guide the research, were less appropriate for participant groups who did not make psychiatric diagnoses, such as clinical psychologists and service users. This may have led to important information being lost or left unexplored during the interview process. For example, asking service users about the functions that psychiatric diagnosis had for them may have not have had sufficient meaning to some participants as a result of their not using or rejecting their diagnoses. Conducting and analysing a phase of pilot interviews, or taking a grounded theory approach, may have better identified which questions and avenues of enquiry were most fruitful in terms of topic exploration and relevant for participants. Similarly, a grounded theory approach (Charmaz, 2006) may have been usefully employed to identify gaps in the participant sample, such as the inclusion of more participants who identified with black and minority ethnic backgrounds, referred to above in Section 8.4.2.3. Furthermore, use of feminist analytic approaches (e.g. Kleinman, 2007), for example, may have elicited greater exploration of issues of power and oppression and differing experiences across gender from the data.

8.4.2.4 *Limitations of what the data can offer*

Each of the data sources used in this thesis, diagnostic classification, policy documents on service entry criteria, and interviews with clinicians and services users, can provide valuable information about the ways that diagnoses are described and conceptualised. Conclusions can be drawn about the ways that people and organisations conceptualise mental health, and the language used can indicate how sense is made of psychiatric diagnosis. However, a limitation of this type of data is that whilst documents can provide information about what should be done in clinical practice, or the ways that people talk about what they do, and what they choose to tell us about what they do, it cannot tell us what they actually do in real life, and in the case of clinicians, in their clinical practice.

This limitation applies both to the semi-structured interviews and the analysis of service entry and eligibility criteria in Chapter 5. In Chapter 5, for example, these data identify the main or publicly available criteria by which decisions are made. On a day-to-day basis, clinical decisions would be made on a case-by-case basis most likely by a working team. However, this might further support the argument that individual and other non-diagnostic factors may have an important influence on decision making over and above the criteria. In cases where both a diagnosis and other factors such as risk, need, and severity, are identified within the criteria, it is not possible to establish the extent to which diagnosis determines decision-making compared with the other factors. Other data that were not explored were service and trust reporting mechanisms, data capture, or information on which services were commissioned. Given the competing constraints on local commissioning, it is possible that influences such as the guidelines from the National Institute for Health and Care Excellence (NICE), which are organised along largely diagnostic lines, may impact upon service entry criteria, and demand that diagnostic categories play a specific role in making in/out decisions for clients.

It should be acknowledged with regards to the findings in Chapter 5 that although diagnoses may appear from these data to be neither necessary nor sufficient for service entry criteria, if all the stakeholders in a particular decision believe a diagnosis is necessary, then, pragmatically, it becomes so. For example, within a MHA decision, if the relevant psychiatrist, ward manager, and tribunal solicitor agree that a diagnosis is required, currently this is the way the system is working de facto. The letter of the law of the MHA or of the service entry and eligibility criteria may not require the use of specific diagnostic labels, however if each party involved in the decision-making process relies on a diagnosis, the use of diagnosis is subsequently maintained.

8.4.2.4.1.1 Representativeness

A range of participants for the semi-structured interview data collection was recruited across three clinician groups, who worked in a variety of clinical settings, and a group service users who had been given a mix of psychiatric diagnoses, some with a single diagnosis and others with multiple diagnoses. Participants were chosen with an aim of gathering data on differing views on psychiatric diagnosis. However, as representativeness is not the aim of qualitative research (Green & Thorogood, 2014), the data is not statistically representative of the populations from which they were taken. Qualitative research seeks to gather “information-rich cases for in-depth study” (Patton, 1990, p. 182, as cited in Green & Thorogood, 2014, p. 121), which this research provides, however, the data cannot be generalised to the wider populations from which the participants were drawn.

As described in Sections 4.4.3.1 and 7.4.2.1 (Sampling), the sampling approach was theoretically driven in the way that groups and types of participants were chosen for participation. Inevitably, however, those who responded to invitations to take part and consented to the interview were self-selected. Participants, therefore, may have been more likely to be interested in critiquing or looking beyond diagnosis in conceptualising mental distress. However, not all participants were in favour of changing the way that mental health is conceptualised or clinical work is carried out. In the analysis of interview data from this study, these perspectives of the participants were acknowledged, in that the data was therefore potentially likely to say more about when diagnosis does not work than when it does. However, this is nevertheless important information, particularly when diagnostic practices are damaging for the people who are diagnosed.

8.4.2.4.2 Would other frameworks have better outcomes?

From this research it cannot be identified whether or not doing things in a different way would be better. For example, Chapter 5 demonstrated that psychiatric diagnoses are neither necessary nor sufficient for service entry and eligibility criteria. However, the data analysed in this chapter cannot answer the question of whether care is better or worse across service provision that uses diagnosis to different extents. Quantitatively, this research cannot tell us whether alternative approaches would result in more positive outcomes for people using services. More qualitatively, the research cannot inform as to whether alternatives would remove the harmful effects of diagnosis, or what other (potentially unintended) consequences or implications would be created as a result of using different approaches. These limitations will be addressed in the following section on future research.

8.5 Future research

This chapter has acknowledged what the research findings of this thesis can and cannot tell us, and considered the implications and recommendations for mental health services. In taking forward the findings of this thesis, there are a number of clear areas in which future research could progress the exploration of alternative approaches to psychiatric diagnosis. Further empirical data is needed to support change. With better data capture from the recommendations in Section 8.4, we could contribute to this research. Further ways of contributing to the evidence base are outlined in the following sections below.

- Alternative qualitative methodologies
- Exploring patterns of distress that incorporate psychosocial factors
- Operationalizing levels of need
- Using non-diagnostic outcome measures that better represent improvement
- Evaluating alternative approaches

8.5.1 Alternative qualitative methodologies

The thematic analysis of the service users' interview data, presented in Chapter 7, showed that there may be a process by which people come to reject or avoid the psychiatric diagnoses given to them. In light of this finding, further research might better explore this process by using a narrative approach to interviewing and to the analysis of interview data. Narrative analysis explores the ways in which people organise their interpretations of their experiences into narrative form (Murray & Sargeant, 2012). Labov and Waletzky's (1967) analytic approach, for example, highlights different elements of participants' stories, centring on the 'complicating action'. This particular aspect is the essence of the story, and may relate well to the ways in which people come to frame their distress differently or view their diagnosis negatively, for example through the category having a damaging impact on their identity (e.g. Service User 4, Section 7.5.2.1.1) or when a professional such as a therapist introduces a different way of viewing distress (e.g. Service User 22, Section 7.5.4.1.2). Using a narrative approach may contribute richer data that would better represent the experiences of participants, particularly service users.

Alternative methods that may expand upon these findings might include more ethnographic approaches, whereby people and their practices are studied in naturally occurring settings in order to capture ordinary activities, without meanings being imposed externally onto those activities (Brewer, 2000). Within this approach, observations are used alongside interviews, field notes, and the gathering of data from documents and policies to bring together a rich dataset for analysis (Hammersley & Atkinson, 1995). This type of research could more directly analyse the everyday practices of diagnosis and assessment of mental distress,

whilst also including of wider net of stakeholders and those involved in decision making from a service level, for example through observing the ways in which service entry decisions are made.

8.5.2 Exploring patterns of distress that incorporate psychosocial factors

The findings of chapters 4, 5, and 7 demonstrated that using contextualising psychosocial information was valued by clinicians, services, and service users in making sense of and working with mental distress. Likewise, an increasing body of research literature documents the social determinants of mental health problems (see Section 1.3.2.1.2, Contextualising distress). By understanding mental health from the more neutral perspective described in Section 8.4.1, and gathering data accordingly using the existing psychosocial codes in the ICD-10 (WHO, 1992), it would be possible to establish different patterns based on research evidence. Such research might gather descriptive data about individual's distress alongside information about social determinants. For example, people who are street homeless may be 50-100 times more likely to be diagnosed with a psychotic disorder than the general population (Rees, 2009). Z62.2 codes individuals who have had an institutional upbringing, who are approximately eleven times more likely to experience paranoia than those with a less disruptive early history (Bentall et al., 2012). Sexual abuse has been strongly associated with onset of psychotic experiences in childhood (McGrath et al., 2017). Evidenced-based clusters of types of distress and their relation to psychosocial factors could provide a scientific basis for categories, but these need not be accompanied by an assumption of an underlying disorder causing the distress.

Broadening routine data capture within NHS health records could establish more inclusive, social, systemic, and psychologically comprehensive patterns of difficulties in order to standardise the knowledge that clinicians come to individually develop over time and with clinical experience. Such patterns might be established on the basis of commonly co-occurring types of distress and life experiences, but need not be underpinned by a causal assumption of a discrete or biological disorder. For example, recognised patterns regarding the trajectory of difficulties, and patterns associated with trauma. Such routine data collection would target information regarding established social determinants of mental health problems. Data could include measures of poverty, for example, relative income poverty (Wickham et al., 2017) and the index of multiple deprivation (Wickham, Taylor, Shevlin, & Bentall, 2014), and a simple measure of trauma, such as the Adverse Childhood Experiences scale (Felitti et al., 1998). The potential implications of such data capture should be noted; information should be gathered where the necessary therapeutic and support frameworks are in place in order to appropriately address disclosures of trauma, for example.

8.5.3 Operationalising levels of need

In order to assess need and help assign appropriate services to individuals according to team competencies, as described in Section 8.4.3, for example according to risk and severity, operationalising categories or levels of need may be necessary. If broad groups of difficulties are used, as suggested in 8.4.3, and reflecting the findings of Chapter 5, it would be clinically useful to identify evidence-based ways of delineating pathways for different levels of difficulty. For example, outcome measures may be used to empirically test the predictive validity of categories of need, to assess whether these ways of describing people's difficulties and needs are associated with how much therapeutic input is required, and their outcome.

8.5.4 Using non-diagnostic outcome measures that better represent improvement

The IAPT programme delivers interventions approved by NICE for depression and anxiety, and other related difficulties that fall under the bracket of common mental health difficulties. The IAPT programme is supported by extensive monitoring and reporting of routine outcome measures. The government target is that 50% of eligible referrals to IAPT services should meet defined criteria for recovery following IAPT intervention (NHS Digital, 2017). The concept of recovery hinges on the notion of 'caseness' at the start of an intervention, whereby referrals' scores on symptom measures of anxiety and depression are high enough to be considered a clinical case. The caseness threshold is typically derived from a score on the Patient Health Questionnaire-9 (PHQ-9) (Kroenke, Spitzer & Williams, 2001) and the relevant Anxiety Disorder Specific Measure (ADSM), for which there are different versions according to diagnosis, including obsessive-compulsive disorder and generalised anxiety disorder. Caseness is therefore diagnostic, despite being derived from questionnaire scores. Recovery is defined by a client no longer meeting the criteria for caseness once an intervention has been completed (NHS Digital, 2017).

Not only do IAPT outcomes use diagnostic measures, which are problematic in the context of the issues discussed in this thesis, they are somewhat blunt tools. Focusing on symptom numbers and severity does not take into account other factors that may be important to the individual receiving support, or the intervention undertaken, such as measures of functioning. Outcome targets that rely on no longer meeting the caseness for a diagnosis are also problematic with the imminent extension of IAPT to more complex difficulties, Improving Access to Psychological Therapies for Severe Mental Illness (IAPT-SMI). Trial demonstration sites have been set up across England, including IAPT-SMI early intervention in psychosis (EIP) sites (NHS England, 2016c). No longer meeting the diagnostic criteria for a psychosis or schizophrenia diagnosis, for example, is unlikely given the longer-term nature of experiences associated with the diagnosis. EIP support, for example, is typically funded

for three years, before clients may be referred to other secondary care teams such as CMHTs for longer-term support (NHS England, 2016c). The IAPT outcome measures of caseness and recovery, therefore, do not have utility as an outcome. Goal attainment scaling might provide a method of assessment to empirically research for mental health, representing individualised goal setting that represents the person's own aims for the intervention, but across a standardised measure so that outcomes may be compared.

8.5.5 Evaluating alternative approaches

Empirical research should subject both diagnostic-led approaches and the alternatives to empirical tests to compare their efficacy and implications across a range of variables, for example, identifying whether clients with different difficulties would receive a better service with one or other approach, and establishing in which contexts, for which type of problems, non-diagnostic (e.g. needs-led) versus diagnostic (or broad pseudo-diagnostic bands of difficulties) models would be best. Qualitative research could be used to gather detailed information regarding the impact and implications of receiving a non-diagnostic care approach, addressing common negative implications of receiving a diagnosis to compare the impact, such as stigma and the impact of language.

8.6 Possibilities and potential for change

Many have written about the persistence of psychiatric diagnosis (e.g. Harper, 2013; Pilgrim, 2007) therefore the opportunities and potentials for change are considered here. Reasons for its persistence in the face of several decades of criticism reflect the varied and powerful nature of its functions. The following represents an overview of the explanations that have been given, organised by technical and socio-political perspectives. In their paper outlining the wealth of evidence for social adversities, such as childhood trauma, in the development of difficulties defined within psychiatry as psychosis and schizophrenia, Read, Dillon, and Lampshire (2014) ask how much of such evidence will be necessary before a paradigm shift is effected within mental health that refocuses from predominantly biomedical to psychosocial explanations. Indeed, it has been argued that reification of psychiatric diagnoses has led to DSM categories becoming "largely immovable anchors" that are "impermeable to data and resistant to revision" (Patrick & Hajcak, 2016, p. 416). DSM categories have also been described as "locked in" (Cooper, 2015). Bowker and Star (1999) describe the way that QWERTY keyboards were originally designed to solve a no longer relevant issue of key clash on typewriters, however people and systems are so familiar with this design that new, more efficient keyboard layouts have failed to take hold. Likewise, Cooper (2015) argues, so the DSM committees themselves have failed to make significant changes. She cites examples of work-arounds needing to be developed in the face of the removal of Asperger's Syndrome as a diagnostic category, and the much-touted but

eventually side-lined dimensional model of personality disorders. Interestingly, these examples are arguably more technical and evidence-based than the social values-driven revisions described in Section 1.4.1, however they nevertheless remain more difficult to change.

Perhaps these arguments demonstrate the power of the socio-political, or what Harper (2013, p. 78) describes as the “social functions and institutional interests served by diagnosis”. Examples of these include the interests of psychiatry itself, and even clinical psychology (Boyle, 2011; Boyle, 2002; Harper, 2013; see Section 1.3.2.4); including the revenue from sales of the DSM by the American Psychiatric Association, and the legitimisation of psychiatry as a discipline and of the clinicians themselves (Boyle, 2002; Foucault, 2006; Harper, 2013). Most mental health research is organised around diagnostic categories (Harper, 2013) and administrative uses including health records and service planning is also frequently cited (Harper, 2013), however evidence from Chapter 5 suggests that service entry and commissioning is less reliant on diagnosis than perhaps is assumed. It has also been argued that diagnosis is a political device used to re-categorise social problems as medical, so as to sanction responses to negatively valued social behaviour that might otherwise be challenged (Moncrieff, 2010). Moncrieff describes the ways that diagnosis allows responses such as behavioural control to be reframed as ‘care’ and ‘treatment’, and therefore legitimated.

8.6.1 Changing practices within existing mental health care structures

By reframing people’s difficulties as medical, Moncrieff (2010) also highlights the process of apportioning these difficulties to the ‘experts’ of mental health care, so as to side step the need to address social problems within political arenas. This thesis considers mental health care and alternative provisions of such, but remains contained within the existing structure of mental health services and the NHS. By continuing to work within the existing structures of mental health ‘care’ and ‘treatment’, Smail (2005) suggests that we perpetuate the political avoidance that Moncrieff (2010) describes. Just as psychiatry has been criticised for the biomedical framing of problems at the level of the individual, as has psychology for its use of psychological frameworks that revolve around the individual and their difficulties (Burr & Butt, 2000; Pilgrim, 2014; Smail, 2005). Some have argued that both disciplines have a vested interest in conceptualising difficulties at an individual level, given the interventions traditionally employed by both disciplines are individualistic, such as drug treatment and individual therapy (Boyle, 2011; Smail, 2005).

Therefore, we might change the ethos behind mental health services, such as neutralising the diagnostic model, but in carrying out this work within this same structural system, Smail (2005) argues that the impact of these services remains set up to ‘help’ individuals rather

than address wider political and societal structures that create difficulties in the first place. Thus if working with individuals does not help or have the intended outcomes, it would be easy to look no further and hold responsibility with the individual themselves, rather than seeing beyond this to the situation and environment they are in, and question what structures, power, or societal issues create and maintain these problems. Smail suggests, therefore, that the tools of change are political rather than therapeutic.

These points are raised in the introduction, although it is acknowledged that this thesis takes a particular stance on mental health (as acknowledged in Section 2.4), which problematises mental distress. By problematising the types of experiences defined as mental distress, and focusing on mental health services that offer support through working with the individual, the thesis could be argued to perpetuate the notion of difficulties at the level of the individual, in spite of its contextualising difficulties within wider social and political contexts. The social model of disability (Oliver, 1983), discussed in Section 1.3.3.1.2, highlights the potential for oppression and social exclusion when individuals are labelled in this way. It could be argued that by individualising distress, non-diagnostic but psychological approaches may still contribute to this form of societal disability, even without explicit labelling. One way of considering this problem may be to open up opportunities for individuals to consider other narratives that do not problematise their difficulties (discussed below in Section 8.7.2).

Furthermore, Harper (2016) emphasises the limitations of individual work in mental health, and argues that clinical psychology should act beyond individual therapy. As the scientific literature grows regarding the social determinants of mental health problems, supported by the routine data collection above, measures should be taken to act upon this evidence in working towards preventative as well as reactive interventions. Current mental health services are set up to respond to the impact of trauma and other adversities on individuals. However, Patel (2003, 2011) has drawn from her work with refugees and asylum seekers to argue that a focus on trauma narratives still individualises distress, focusing on the traumatised victim rather than the causes of trauma, including social inequalities, human rights violations such as torture.

Primary prevention strategies would work towards preventing adversities so that they do not impact upon individuals in the first place. For example, in their meta-analysis of the association between childhood adversities, such as abuse, neglect, and bullying, and later development of psychosis, Varese and colleagues (2012) calculated that if the adversities they studied were prevented, the number of people experiencing psychosis would reduce by 33%. This would necessitate further integration between health and social care, and inter-agency working, such as policies and action plans towards the prevention of child abuse.

8.6.2 Are things changing already?

In spite of the above difficulties in making changes to psychiatric diagnosis, and therefore our conceptualisations of mental distress, there have been several recent developments in public treatment and discussion of mental health. These developments stem from several perspectives, representing a story advancing on multiple points. Some examples of the shifts in psychological, political and social arenas are outlined below.

8.6.2.1 *The psychological*

Reflecting some of the concerns raised in the previous section, the extension of the role of clinical psychology beyond the traditional individual therapeutic context has gained momentum in recent years. A new conference series, 'Beyond the Therapy Room', for example, champions psychological work outside of traditional contexts. Wider consideration has been given to the involvement in psychology of the arts and people with lived experience of mental distress, including the Clinical Psychology Fringe Festival (2017) that ran alongside the BPS Division of Clinical Psychology's annual conference in 2017.

There has also been a resurgence of community psychology, which focuses on expanding the reach of psychology, and takes a more preventative orientation (e.g. Albee & Ryan, 1998) akin to public health, with a focus on health inequalities, social change, and issues of social justice (Albee & Ryan, 1998; Wolff, 2014). The renewed interest in community psychology reflects a recent politicising of the discipline in some areas, for example, Lisa Cameron is the first clinical psychologist member of Parliament, who moved to politics to further her interest in social justice and inequality (Cameron, 2015). Browne (2017) explored psychologists' transitions from traditional clinical psychology practice to involvement in national health and social care policy in the UK, and recommended that clinical psychologists need to look to population-level issues, take a greater lead in policy making, and incorporate social action into their work.

Others have advocated a human rights-based approach to psychology (Hagenaars, 2016; Patel, 2011). Patel (2011) describes this approach as "not a therapy, or a method, rather a political and moral stance that reorients psychological practice..." (p. 247).

Recommendations related to Patel's extensive human rights work with torture survivors include re-defining mental health professionals as "political agents" (Patel, 2011 p. 252) who contribute to the prevention of mental distress and its causes, "towards individual, social, economic and political wellbeing" (p. 252). For example, Patel (2003) has argued that focusing on post-traumatic stress as a disorder experienced by refugee people has stunted possibilities for the development of a "just psychology" (p. 25) that could instead work towards the prevention of human rights violations. Referring to this individualised focus on

trauma, and post-traumatic stress services for refugee people, Patel (2003) stated, “[a] disturbing question to ask is: would psychologists remain so naively earnest and resistant to reflexivity if there were similar suggestions to develop say, ‘depression clinics’ for the unemployed or the homeless?” (p. 25). Almost 15 years later, however, exploration of UK government workfare schemes has demonstrated their coercive use of psychology that has been argued to “erase the experience and effects of social and economic inequalities, to construct a psychological ideal that links unemployment to psychological deficit...” (Friedli & Stearn, 2015, p. 40). Service users, carers, and psychologists have protested the BPS involvement in workfare programmes (e.g. Barnett, 2017). The BPS (2017) called for the government to suspend its system of benefits sanctions while a full review of its psychological impact is carried out. However, the BPS stopped short of withdrawing its support for psychological work in workfare policies, preferring instead to negotiate from a position of involvement (Barnett, 2017).

Further work involving the politicisation of clinical psychology in response to austerity politics has included ‘Walk the Talk’ in 2015, in which psychologists, service users, and activists joined for a 100-mile trek between the BPS offices in Leicester and London to raise awareness of the damaging psychological impact of food poverty, homelessness, and the benefits system (Foster, 2015; Walk the Talk, 2015). Follow-up events to raise awareness of damaging social policies included a conference on ‘Psychologists and the Benefits System’ (Walk the Talk, 2016). Similarly, the Psychologists Against Austerity group (later renamed Psychologists for Social Change) formed in 2014, and launched a briefing paper on the psychological impact of austerity at the House of Lords in 2015 (Psychologists Against Austerity, 2015). The paper identified five ways in which austerity policies can impact upon mental health, including humiliation and shame, and fear and distrust. The two central aims of the Psychologists for Social Change campaign are to mobilise psychologists to become politically involved and speak out about austerity, and to publicise psychological knowledge relevant to these types of social policies (McGrath, Walker & Jones, 2016). The shifts described above represent greater awareness and work within clinical psychology around issues of social inequalities and injustices, but the multiple calls to action demonstrate the work yet to be done.

8.6.2.2 *The political*

In their 2011 report *No health without mental health* (HM Government, 2011) the government and the Department of Health outlined their policy to bring mental health care into parity of esteem, or equal priority, with physical health care. The report outlined six key objectives around improved outcomes, better access to care, and reduction of harm, stigma, and discrimination. Building upon this, a working group within the Royal College of Psychiatrists published its priorities for action to introduce holistic ‘whole person’ care across health and

social care services in the report *Whole-person care: From rhetoric to reality* (Bailey, Thorpe, & Smith, 2013). Since then the government has outlined key areas for change (Department of Health, 2014a) introduced the first waiting time targets in mental health (Department of Health, 2014b). In 2016 the then Prime Minister David Cameron pledged a 'revolution' in mental health treatment, with almost a billion pounds of investment and the introduction of waiting time targets in new areas including early intervention in psychosis (Prime Minister's Office, 2016). Critics have, however, raised concerns regarding the parity of esteem objectives, highlighting that bringing mental health care closer in line with that of physical health prioritises the biomedical model of mental health, which is as yet poorly evidenced in terms of treatment outcomes, and has been shown to be linked with increased stigma and discrimination (Timimi, 2014). Others have demonstrated that the need for parity of esteem has been recognised for the last century but there have been consistent barriers to it being implemented effectively (Hilton, 2016). The recent influx of policies and introduction of waiting times is nevertheless evidence of political recognition and advances towards changing mental health in the UK. Mental health was included within the NHS Patient Choice as of 2014 (NHS England, 2014), initially giving people the choice of where they have their first outpatient appointment. This incorporation of mental health care into the choice agenda paves the way for people being able to choose social over biomedical approaches to their care. Furthermore, and reflecting the psychological shifts discussed above, a recent report from the United Nations Special Rapporteur (UN Human Rights Council, 2017), called for measures that redress the dominance of the biomedical model in mental health services, stating:

Reductive biomedical approaches to treatment that do not adequately address contexts and relationships can no longer be considered compliant with the right to health. While a biomedical component remains important, its dominance has become counter-productive, disempowering rights holders and reinforcing stigma and exclusion. (p. 17)

The crisis in mental health should be managed not as a crisis of individual conditions, but as a crisis of social obstacles which hinders individual rights. Mental health policies should address the "power imbalance" rather than "chemical imbalance"... The urgent need for a shift in approach should prioritize policy innovation at the population level, targeting social determinants and abandon the predominant medical model that seeks to cure individuals by targeting "disorders". (p. 19)

This report offers an important precedent from which service users, clinicians, and mental health services may continue to pursue and demand change.

8.6.2.3 *The social*

In recent years there have been changing and more positive attitudes towards mental health (Angermeyer & Dietrich, 2006). The proliferation of mental health festivals and campaigns suggest a greater openness towards discussing mental health difficulties. Initiatives include the *Only Us* campaign, which seeks to break down 'us and them' attitudes towards mental health, and the *Time to Change* campaign. *Time to Change*, headed by Mind and Rethink Mental Illness charities, was established in 2009 and aims to reduce stigma and discrimination. Survey research has suggested that compared with before the campaign was launched, public beliefs and attitudes towards mental health have significantly and moderately improved (Evans-Lacko, Corker, Williams, Henderson, & Thornicroft, 2014). For the first time, the Royal Family has fronted a mental health initiative, with the Duke and Duchess of Cambridge and Prince Harry representing the *Heads Together* campaign established to tackle stigma. Furthermore, public figures in positions of power have spoken up about difficulties with their mental health, including MPs in the UK parliament (*Time to Change*, 2012) and the Norwegian Prime Minister, Kjell Magne Bondevik (World Health Organization, 2011). With regards to the media, the stylebook of the Associated Press global news network recommended in 2013 that journalists stop using phrases such as 'schizophrenic', and instead use diagnostic labels as a description that moves the phrasing away from locating the problem within the individual, such as 'he was diagnosed with schizophrenia' (Siegel, 2017). In 2017 this recommendation was similarly extended to drug abuse, and referring to individuals 'having a substance use disorder' rather than being an addict or abuser (Associated Press, 2017; Siegel, 2017). These examples are based on diagnoses, but nevertheless represent a shift towards greater openness and more sensitive thought in the area of mental distress.

Research suggests, however, that stigma is still a barrier to accessing mental health support (Salaheddin & Mason, 2016), and that media portrayal of less common mental health difficulties, particularly diagnoses of schizophrenia, continues to impact upon people's beliefs about the dangerousness of people experiencing mental health difficulties (Reavley, Jorm, & Morgan, 2016). Reavley and colleagues' research suggests that knowing someone with mental health difficulties reduces the likelihood of holding stigmatising beliefs. This research emphasises the need to continue to build upon the developments that have already been made regarding openness about mental health difficulties and stigma reduction. The growing public awareness and official recognition of mental health difficulties, however, is reminiscent of the beginnings of the socio-political revolutions that led to homosexuality being removed from the DSM, outlined in Section 1.4.1.2.

8.7 Personal reflections on research findings

These reflections are more explicitly embedded with my own views, extrapolating from the clinical implications and incorporating my beliefs and personal reflections regarding the research.

8.7.1 Choice and the availability of alternative discourses

In their key paper on the discursive production of selves, Davies and Harré (1990) describe the ways in which people “actively produce social and psychological realities” (p. 45). They quote Frazer (1990), who argues from her interviews with adolescent girls, that their “experience of gender, race, class, their personal-social identity, can only be expressed and understood through the categories available to them in discourse” (Davies & Harré, 1990, p. 45). I argue that the same statement can be applied to people experiencing mental distress. Some participants who had been given diagnoses appeared to struggle to conceptualise the idea of ‘alternatives to diagnosis’, because the medical framing of their difficulties was seen as simply ‘how it is’. As an interview participant was quoted in Kinderman (2014, p. 53), the diagnosis is “what they’ve got”. There was a sense that some participants were ‘stuck’ in the models and discourses that they had been exposed to, even biomedical clinicians, both due to disciplinary frameworks and lay discourses on mental health. Of the service users I interviewed who had come to question the concept of diagnosis, none had been offered different ways of looking at their distress at the outset, rather, each of them described a process of being given a diagnosis and going through a process of gradually questioning or even rejecting it. As Service User 5 described, “I fear that it’s only through sad experience with the system that people come to the conclusion that a diagnosis is not your man. I fear initially they might be wanting ‘tell me what’s wrong with me’”. Currently socially accepted and lay discourses about mental health tend to focus on finding out what is wrong, and getting treatment for mental illness. Speed (2006) describes the survivor discourse as rejecting medical causes of difficulties and replacing these ideas with non-medical causes, in ways that suit the person, such as a spiritual crisis or family difficulty. This is only possible, however, if alternative discourses about mental distress and its causes are in some way available to the person. Whether, as some of my participants described, this taking up of an alternative discourse is enabled through doing personal work to revisit childhood experiences, trying to re-frame significant events such as trauma in relation to current difficulties and personal belief systems, or through accessing networks of alternative ways of thinking, such as hearing voices groups and activist organisations.

Returning to the language used to describe difficulties, diagnoses has persuasive uses, particularly to service users, of having a common word or phrase to identify other people with similar types of distress, to communicate difficulties without going into details, or to

simply use as a starting point to find further information. Problematic to the development of alternatives is that the medical language of diagnostic labels, of 'illness' and 'disorder', is the lay language used in everyday descriptions of mental health. Mobilising the social, through publicity and awareness raising, might provide an effective means of promoting and making available different and more empowering discourses about distress (Georgaca, 2013). By making other discourses available, this in turn may help to shape the everyday language used to describe distress.

8.7.2 Driving forward the social

In discussing the possibilities for change, I raised the potential difficulty of trying to change attitudes and interventions in mental health within existing health care structures. Although the Health and Social Care Act (2012) made steps towards bringing health and social care together, I believe further steps can be taken in this respect. In considering the impact of psychosocial determinants of mental distress, including poverty, inequality, and childhood trauma, a truly integrated support system would actively acknowledge these risks and take steps to prevent the occurrence of these problems, as well as respond to and minimise their impact. Another way of bringing closer social and health worlds might be the greater involvement of experts by experience, or people who have experienced mental distress themselves, in mental health care. Much valued by several of the service users I interviewed, this model of care might offer people a broader understanding of their difficulties, and create a more socially centred model of mental health care that does not solely focus on the medical or psychological.

Similarly, in taking steps to reform and improve our conceptualisations of mental health and the ways that we support people's distress, it seems clear that the technical challenge of diagnosis and its medical model have as yet made little dent (e.g. Read et al., 2014). Indeed, Harper (2013) notes, in his application of Smith's (2012) discussion of political revolutions to psychiatry, that where resistance movements struggle as a result of using only one or two methods, attempts at mental health reform have focused largely on 'intellectual argument [and] empirical research' (p. 81) and that more social campaigns have focused on specific diagnostic categories only. When historical changes to diagnostic classification are reviewed (see Section 1.4.1, Historical development of the DSM), it becomes evident that the most significant changes to diagnoses have been as a result of socio-political pressure and changing values and norms, such as homosexuality, PTSD, and gender dysphoria. I believe, therefore, that driving forward socio-political change, alongside further research evidence, is likely to effect change at a greater rate than the technical alone. Of the potential power of the population, those who are not typically considered experts or powerful who may believe they cannot influence change, Smail states:

If the many can be persuaded that they have no say in the shaping of material reality, and that personal satisfaction is purely a matter of self-doctoring and private consumption, the world is left wide open for exploitation by the few (Smail, 2005, p. 95).

Moncrieff (2010) describes one of the roles of psychiatric diagnosis as to “re-designate social problems as medical ones” (p. 381). If these problems can be redefined as social problems, greater political pressure would be mounted in order to provide services to both prevent and work specifically with their causes. We should question the effectiveness of providing medication or psychological work, no matter how effective in the short-term on an individual basis, if the person in distress must return to the same problematic social and/or economic environment.

8.8 Conclusions

The findings of this thesis demonstrate that diagnostic classification, and its uses, are at times underpinned by epistemological assumptions that support a disease model. However, these assumptions are not consistently applied by those who use diagnosis. Supporting technologies, including the recording of diagnosis for administrative processes, reinforce this underpinning diagnostic model, which shapes the foreground of how mental distress is viewed. In spite of repeated diagnostic revisions towards ever more ‘precise’ diagnoses, many of the ways of using diagnosis outlined in this thesis are far from the specific diagnostic categories described in the ICD or DSM. The need for such highly specified criteria can therefore be questioned. Likewise, diagnoses may be used for data capture, for administrative and organisational uses, but ‘fudged’ numbers are not useful to planners. Flexibly and pragmatically applied categories are not useful for public health departments.

Mirowsky and Ross (1989) have said, “[m]any psychiatrists and epidemiologists who are not inclined to reify [diagnostic categories] nevertheless accept them as politically necessary” (p. 22). Almost thirty years later, (Frances, 2015) argues, “[h]owever flawed, we have to use the available diagnostic tools” (p. 577). This thesis, however, demonstrates that diagnostic infrastructure has obscured existing infrastructures that could be used, such as the descriptive psychosocial codes within the ICD-10. As well as different assessment approaches that are already used, such as psychological formulation, there are existing infrastructures and practices that are currently used under the guise of diagnosis, such as organising service entry upon needs-led factors for competency-driven teams. The notion of ‘alternatives to diagnosis’ has been taken up by some as a way of politicising the issue, but this concept may distract from seeing current infrastructures and processes that could be put to use more transparently.

Moving beyond the clinical environment, this thesis has demonstrated how what begins as a seemingly neutral category for describing a person's difficulties, which is applied in order to help that person by opening access to treatment plans and support systems, travels beyond this setting and becomes a stabilised, crystallised category that becomes essentialised and stigmatised for the person who bears that label. Some of the people interviewed in this research who had been given psychiatric diagnoses told powerful stories of profoundly negative experiences of diagnosis and the psychiatric system, a framework of understanding that they had, through difficult work, come to replace with more personally meaningful understandings.

Receiving a diagnosis clearly remains an affirmative juncture in many people's care, but for those for whom it is not a positive experience, there are already existing opportunities for different approaches that may fit better for some. It is hoped that through a process of comprehensive system reform, existing and novel approaches may be utilised that have clinical, administrative and social utility. Most importantly, however, such approaches may enable those in distress to find approaches that suit their needs and perspectives without the "sad experience with the system" (Service User 5) that typically preceded the more positive reframing of distress described by participants in this research.

Interviewing clinicians for this research emphasised how the psychiatrists, GPs and clinical psychologists were frequently doing their best to help people in distress within the limitations that they had in clinical practice, and that were imposed by service commissioning and so forth. However, people do have choices, and there are opportunities within the system as it is at the moment to do things differently, although it nonetheless takes tremendous effort to work against the grain of a well-established model. Those in professional roles nevertheless hold greater power than the people who are trapped by diagnostic labels that they may feel are inappropriate, marginalising, and damaging, and yet on which they are simultaneously reliant for essential care and support. Many, therefore, do not have the privilege to reject diagnosis outright. Those who do should be using it.

9 References

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10 Appendices

Appendix 1: University of Liverpool confirmation of sponsorship approval



Professor Kinderman
 Institute of Psychology, Health and
 Society
 University of Liverpool
 Waterhouse Building, Block B, 2nd
 Floor
 1-5 Brownlow Street
 Liverpool
 L69 3GL

Mr Alex Astor
**Head of Liverpool Joint Research
 Office**

University of Liverpool
 Research Support Office
 2nd Floor Block D Waterhouse
 Building
 3 Brownlow Street
 Liverpool
 L69 3GL

19 June 2014

Tel: 0151 794 8739
 Email: sponsor@liv.ac.uk

Sponsor Ref: UoL001058

Re: Sponsorship Approval

**“Alternatives to psychiatric diagnosis - Development and validation of non-diagnostic
 assessment methods in mental health care”**

Dear Professor Kinderman

After consideration by the Chair of the JRO Non-Interventional Sponsorship Sub Committee I am pleased to confirm that the University of Liverpool is prepared to act as Sponsor under the Department of Health's Research Governance Framework for Health and Social Care 2nd Edition (2005) for the above study.

The following documents have been received by the Joint Research Office

Document title	Version	Date
Protocol	No Version	June 2014
Study 1 Service Users Participant Information Sheet	Version 1	April 2014
Study 1 Clinicians Participant Information Sheet	Version 1	April 2014
Study 1 Participant Consent Form	Version 1	April 2014
Study 2 Participant Information Sheet	Version 1	April 2014
Study 2 Participant Consent Form	Version 1	April 2014
Study 3&4 Participant Information Sheet	Version 1	April 2014
Study 3&4 Participant Consent Form	Version 2	April 2014
Study 4 Raters Participant Information Sheet	Version 1	April 2014
Study 4 Raters Participant Consent Form	Version 1	April 2014

Please note this letter does **NOT** allow you to commence recruitment to your study.

A letter detailing Sponsor Permission to Proceed will be issued when governance and regulatory requirements have been met. Please see Appendix 1 to this letter for further information and a list of the documents required.

If you have not already applied for regulatory approvals through IRAS you may now do so at <https://www.myresearchproject.org.uk/Home.aspx>.

In order to meet the requirements of the Research Governance Framework 2nd Ed 2005, the University requires you to agree to the following Chief Investigator responsibilities:

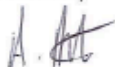
1. Comply with the Research Governance Framework 2nd Ed 2005 and all relevant legislation, including but not limited to the Data Protection Act 1998, the Mental Capacity Act 2005 and the Human Tissue Act 2004;
2. Inform the Research Support Office as soon as possible of any SAE's;
3. Approval must be gained from the Research Support Office for any amendments to, or changes of status in the study prior to submission to REC and any other regulatory authorities;
4. It is a requirement that Annual Progress Reports are sent to the NHS Research Ethics Committee (REC) following Favourable Ethical Approval. You must provide copies of any reports submitted to REC and other regulatory authorities to the Research Support Office;
5. Maintain the study master file;
6. Make available for review any study documentation when requested by the sponsors and regulatory authorities;
7. Upon the completion of the study it is a requirement to submit and an End of Study Declaration and End of Study Report to REC. You must provide copies of this to the Research Support Office;

The University also requires you to comply with the following:

1. University professional indemnity and clinical trials insurances will apply to the study as appropriate. This is on the assumption that no part of the clinical trial will take place outside of the UK. If you wish to conduct any part of the study in a site outside the UK or you wish to sub-contract any part of the study to a third party specific approvals and consideration of appropriate indemnity would be required;

If you have any queries regarding the sponsorship of the study or the above conditions please do not hesitate to contact the Joint Research Office governance team on 0151 794 8373 (email sponsor@liv.ac.uk).

Yours sincerely

A handwritten signature in black ink, appearing to read 'A. Astor', with a stylized flourish at the end.

Mr Alex Astor
Head of Liverpool Joint Research Office

Appendix 2: NRES Committee North West – Greater Manchester East confirmation of favourable ethical opinion



NRES Committee North West - Greater Manchester East

3rd Floor, Barlow House
4 Minshull Street
Manchester
M1 3DZ

Telephone: 0161 625 7820

19 August 2014

Professor Peter Kinderman
Institute of Psychology, Health & Society
University of Liverpool
Waterhouse Building, Block B, 2nd Floor
1-5 Brownlow Street
Liverpool
L69 3GL

Dear Professor Kinderman

Study title:	Alternatives to psychiatric diagnosis - Development and validation of non-diagnostic assessment methods in mental health care
REC reference:	14/NW/1075
Protocol number:	UoL001058
IRAS project ID:	155494

Thank you for your response to the Committee's request for further information on the above research and submitting revised documentation.

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

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

Confirmation of ethical opinion

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

Conditions of the favourable opinion

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

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

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

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

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

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

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

Additional conditions

As previously requested, the consent forms all need to include the paragraph

" I understand that data collected during the study may be looked at by responsible individuals from The University of Liverpool, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to the data." This is a standard research governance paragraph to enable audit of research studies to take place. Please therefore add the paragraph to the consent forms for raters and clinicians.

Suggestion

It is suggested that in point 10 of the information sheets for service users, a telephone number and address are given for the Research Governance Office in addition to the email address.

Please notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Registration of Clinical Trials

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

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

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

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

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

Ethical review of research sites

NHS sites

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

Approved documents

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

Document	Version	Date
Copies of advertisement materials for research participants [Flyer for service user participants]	1	07 August 2014
Copies of advertisement materials for research participants [Flyer for care teams]	1	07 August 2014
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only)		05 August 2013
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Email confirming insurance]		16 July 2014
Interview schedules or topic guides for participants [Study 1 - Clinicians]	1	18 June 2014
Interview schedules or topic guides for participants [Study 2 - Service Users]	1	18 June 2014
IRAS Checklist XML [Checklist_23062014]		23 June 2014
Letter from sponsor		04 June 2014
Non-validated questionnaire [Complaints-Based Assessment]	1	18 June 2014
Other [CV - John Read (Academic Supervisor 2)]		19 June 2014

Participant consent form [Phases 3 & 4 Service users]	2	07 August 2014
Participant consent form [Phase 1 Clinicians]	2	07 August 2014
Participant consent form [Phase 1 Service users]	2	07 August 2014
Participant consent form [Phase 4 Raters]	2	07 August 2014
Participant consent form [Phase 2 Service users]	2	07 August 2014
Participant information sheet (PIS) [Phase 2 Service users]	2	07 August 2014
Participant information sheet (PIS) [Phases 3 & 4 Service users]	2	07 August 2014
Participant information sheet (PIS) [All studies - debriefing sheet]	1.0	18 June 2014
Participant information sheet (PIS) [Phase 1 Service users]	2	07 August 2014
Participant information sheet (PIS) [Phase 4 Raters]	2	07 August 2014
Participant information sheet (PIS) [Phase 1 Clinicians]	2	07 August 2014
REC Application Form		19 June 2014
Referee's report or other scientific critique report [Evidence of Peer Review]		22 April 2014
Research protocol or project proposal [Project Protocol]	2	17 June 2014
Response to Request for Further Information		
Summary CV for Chief Investigator (CI) [Peter Kinderman]		16 June 2013
Summary CV for student [Kate Allsopp]		
Summary CV for supervisor (student research)	1	18 June 2013
Validated questionnaire [Summary of the Structured Clinical Interview for DSM-IV Axis 1 Disorders (SCID-I)]		
Validated questionnaire [Global Assessment of Functioning (GAF) summary]		
Validated questionnaire [Symptom Checklist 90 Revised (SCL-90-R) Items]		

Statement of compliance

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

After ethical review

Reporting requirements

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

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

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

User Feedback

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

<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at


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

14/NW/1075

Please quote this number on all correspondence
--

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

Yours sincerely



pp

Mr Francis Chan
Chair

Email: nrescommittee.northwest-gmeast@nhs.net

Enclosure: "After ethical review – guidance for researchers"

Copy to: Alex Astor, University of Liverpool

Ms Karen Bruce, Mersey Care NHS Trust

Kate Allsopp

Appendix 3: Confidentiality agreement between researcher and interview transcriber



THIS AGREEMENT is made on 17th February 2015

BETWEEN:

- (1) **Kate Allsopp**
(The "AUTHORITY"); and
- (2) **Vanessa Adams**

IT IS HEREBY AGREED as follows:

That I Vanessa Adams will not disclose any information that is passed on to me, either in audio format, or written, or verbal, in relation to Kate Allsopp's work programme, to any party other than that named above, [the "Authority"].

SIGNED

V. Adams

Vanessa Adams

DATE

17/2/15

WITNESSED BY

[Signature]

DATE

17.2.15

Appendix 4: Interview questions / topic guides

Appendix 4.1: Clinicians who make psychiatric diagnoses as part of their clinical practice

Introduction: In the first part of the interview, I'll ask you about your experiences of diagnosis and assessment in mental health, ideally with reference to your current practice and case examples, and in the second part I'll ask you about your opinions and ideas about different ways of assessing mental health problems.

Do you make psychiatric diagnoses as part of your clinical practice?

If yes:

How often and in what circumstances?

Can you tell me about how you go about assessing mental health difficulties & making a diagnosis, with reference to specific cases if possible?

Prompts:

- How do you rule out other diagnoses?
- Boundaries between diagnoses; clear vs. overlap? What makes the difference, what would steer you towards one diagnosis or another?
- What sort of factors might be included in your assessment that don't come under diagnosis specifically? Eg history, trauma, functioning, relational difficulties, risk
- How is severity determined?

Could you tell me about a more difficult case? / one that was more straightforward?

Can you tell me what you use diagnosis for, with reference to specific cases if possible?

Prompts:

- Treatment / intervention plans
- Would you do the same thing for every person with that diagnosis? If not, what would make the difference? Examples – what is it about a particular person that leads you to a particular plan?
- Referrals – how are decisions made re referrals, acceptance into services [eg would you just give the diagnosis, or additional information as well? Given any additional information, what does a diagnosis add to the referral?]
- Communication [with the client, with colleagues, other professionals/agencies]
- Record-keeping

- [Prescription]
- [Any other consequences of using diagnosis?]
- How often do you use the diagnosis? Other info referred to/relied upon?
- What info used in making decisions re care for ppl with multiple diagnoses? How would each diagnosis influence intervention? - eg prioritise, one at a time, all difficulties at once (separate interventions within care plan dependent on dx?)

How well do you think diagnosis achieves its functions? Does it meet all your needs for those functions?

Prompts:

- Are there any other problems or needs that clients present with that are not covered by a psychiatric or medical diagnosis? How does diagnosis fit into that?
- Relational difficulties, social care, financial needs
- Causal / contextual information
- Descriptive info
- Psychological processes vs behaviours / emotions / thoughts
- What about problem- or needs-based referrals, such as to non-NHS agencies (eg police, foodbank) – how does diagnosis fit in here? [eg would they use the diagnosis, or something else? What are they using diagnosis for here? A description of the person's problems/needs?]
- Risk
- Functional difficulties

If there were another approach to assessing mental health that might better meet your needs, what would it look like?

Prompts:

- What other ways are there that might capture that information?
- What information would be lost if a diagnosis were not used?
- [Could the same method of assessment be used across services/professional disciplines etc?]

How would a simple list of people's problems, operationally defined, meet the needs of assessment that we've discussed?

Appendix 4.2: Clinicians who do not make psychiatric diagnoses as part of their clinical practice

Introduction: In the first part of the interview, I'll ask you about your experiences of diagnosis and assessment in mental health, ideally with reference to your current practice and case examples, and in the second part I'll ask you about your opinions and ideas about different ways of assessing mental health problems.

Do you make psychiatric diagnoses as part of your clinical practice?

If no:

Can you tell me in what context you make assessments of clients' difficulties, and how you go about the process of assessment, with reference to specific cases if possible?

Prompts:

- Elements included eg
- Causal / contextual information
- Descriptive info, functioning
- Psychological processes vs behaviours / emotions / thoughts
- Difficult case vs more straightforward
- Timeframe?

Can you tell me about ways you use and encounter psychiatric diagnoses in your practice?

Prompts:

- How are decisions made re entry to services & referrals?
- Communication [with the client, with colleagues, other professionals/agencies – are there any situations where you are required to use diagnosis?]
- Record-keeping
- Treatment / intervention plans
- [Prescription]
- [Functions from the client's point of view]

How well do you think diagnosis achieve its functions & meet clinicians' needs?

Prompts:

- [Refer to functions discussed above]
- Are there any other problems or needs that clients present with that are not covered by a psychiatric or medical diagnosis? How does diagnosis fit into that?
 - Social care, financial needs, relationships
 - [Other things that are used in their assessments] eg:
 - Causal / contextual information
 - Descriptive info
 - Psychological processes vs behaviours / emotions / thoughts
- What about problem- or needs-based referrals, such as to non-NHS agencies (e.g. police, food bank) – what information would you give in these referrals? A description of the person's problems/needs?
 - Risk
 - Functional difficulties

If there were another approach to assessing mental health that might better meet your needs, what would it look like?

Prompts:

- What other ways are there that might capture that information?
- [What information would be lost if a diagnosis were not used?]
- [Could the same method of assessment be used across services/professional disciplines etc?]

[Given what you've just said] How well would a simple list of people's problems, operationally defined, meet the needs of assessment that we've discussed?

Appendix 4.3: Demographic questions – Clinicians

- Occupation; How long have you been practicing as a clinician?
- Age
- Gender
- What ethnic origin do you identify with?
- Do you consider yourself to have a disability?
- Which service(s) do you work in currently? e.g. inpatient, outpatient, adult mental health, specialist services etc.

Appendix 4.4: Service users who have been given a psychiatric diagnosis

Introduction: Overall we're looking at how people assess mental health difficulties, how useful these ways are, and what the impact is. In the first part of the interview, I'll ask you about your experiences of diagnosis and having assessments of your mental health, and in the second part I'll ask you about your opinions and ideas about different ways of assessing mental health problems.

Have you been given a psychiatric/mental health diagnosis?

Prompts:

- When?
- [If multiple diagnoses] was that a diagnosis that was revised over time, or additional diagnoses?

Can you describe your experience of being given a diagnosis?

Prompts:

- e.g. the assessment you had and the kinds of questions – just about difficulties? Context?
- What services were involved?
- How did you get the diagnosis? Who gave it to you?
- Has the diagnosis changed at any point? How did you experience this?
- [If multiple psychiatric diagnoses – how does that experience of getting a diagnosis compare with getting the other diagnosis? Separate diagnoses for same problems (e.g. a revised diagnosis, for example from bipolar to schizophrenia) or multiple diagnoses at one time (e.g. for different problems?)

How did you make sense of your difficulties after you were given the diagnosis?

Prompts:

- What does the diagnosis mean for you? (A label, an identity, a description of symptoms or difficulties, a result of things that have happened?)
- eg a different understanding of problems
- Positive impact?
- Negative impact?
- Label / identity
- Illness / disease model
- Do you refer to it much?

What uses or functions does having a diagnosis serve?

Prompts:

- Practical uses, e.g. access to services/care, support, benefits
- Communication (friends/family, medical professionals)
- Explanation of difficulties
- Avoidance? E.g. events/commitments/conversations?
- How well do you think the diagnosis meets your needs?

If there were another way of assessing your mental health, what might that look like?**How would you feel about having a description of your difficulties rather than a diagnostic label?**

Prompts:

- In what ways would it serve the same functions as you described about diagnosis?
More? Less?
- Language

Appendix 4.5: Demographic questions – Service Users

- Age
- Gender
- What ethnic origin do you identify with?
- Do you consider yourself to have a disability? (Is the mental distress discussed in the interview the source of disability, or something separate?)
- Currently working?

Appendix 5: Participant information sheet - Clinicians

**Participant Information Sheet
Phase 1: Clinicians**

What if I am unhappy or there is a problem?

Please feel free to let us know by contacting Professor Peter Kinderman on 0151 794 8041, and we will try to help. If you remain unhappy or have a complaint that you feel you cannot come to us with then you should contact the Research Integrity and Governance Manager at the Research Support Office, University of Liverpool, Warehouse Buildings, 3 Brownlow Street, Liverpool, L69 3GL, Tel: 0151 794 8373 or sponsor@liv.ac.uk

When contacting the Research Integrity and Governance Manager, please provide details of the name or description of the study (so that it can be identified), the researcher(s) involved, and the details of the complaint you wish to make.

Assessing specific needs & concerns of service users

Who can I contact with further questions?

Using the details below, please feel free to contact Kate Allsopp in the first instance. You may also contact Professor Peter Kinderman.

Institute of Psychology, Health & Society
Warehouse Building, Block B, 2nd floor
University of Liverpool
1-5 Brownlow Street, L69 3GL

Principal Investigator: Prof. Peter Kinderman
Phone: 0151 794 8041
E-mail: p.kinderman@liverpool.ac.uk

Student Researcher: Kate Allsopp
Phone: 0151 795 5375
E-mail: kallsopp@liverpool.ac.uk



UNIVERSITY OF
LIVERPOOL

Kate Allsopp, University of Liverpool

0151 795 5375
kallsopp@liverpool.ac.uk

What happens after I take part?

What will happen if I want to stop taking part?

You are free to withdraw from the study at any time. Please note that as all data is anonymised after the interview, you will not be able to withdraw your data indefinitely; after your participation if you decide you want to withdraw your data, you can inform the researcher (kallsopp@liverpool.ac.uk) within 1 month of the finished interview(s), and your data will be withdrawn.

What will happen to the results of the study?

The results of the study may be written up and submitted for publication in scientific journals. If you are interested in the receiving the results of the study and information on how to access these publications you will be asked to provide your address details at the end of the study. No publication deriving from this study will include your personal details or information that can identify you in any way.

Phase 1, Clinicians: 03/12/14 v4

You are invited to take part in a research study developing new assessment methods in mental health care, combining specificity with the 'recovery approach and avoiding stigma.

Please take the time to read the following information about the research. Please feel free to contact us if you would like any further information or would like to take part.



Kate Allsopp, University of Liverpool

0151 795 5375
kallsopp@liverpool.ac.uk

What is the research about?

What is the purpose of the study?

We need more focused, specific, approaches to mental health, and we're developing a new assessment to do exactly that. This study will bring together views from mental health service users and clinicians about the current system of diagnosis in mental health, and about the new assessment we're developing. The study will contribute to a PhD qualification.

Why have I been invited to take part?

You have been invited to take part because you are a clinician who works with service users with mental health difficulties. Psychiatrists, psychologists and GPs are being interviewed.

Do I have to take part?

Absolutely not – taking part is your choice. If you do take part, you are free to withdraw at any time without giving a reason, and without your legal rights being affected.

Which ethics committee has approved the research?

The reviewing Research Ethics Committee was the NRES Committee North West – Greater Manchester East.

What does the research involve?

What will happen if I take part?

If you agree to take part, you will be asked to meet with the researcher for one interview, lasting approximately an hour. During the interview, you will be given a brief outline of the proposed new assessment tool, and asked questions around how useful you think it would be in clinical practice, for example in assessment, communication, record keeping, or treatment planning, as well as how practical it would be to use clinically. You will also be asked about the ways in which you use psychiatric diagnosis as part of your practice, for example, in assessment of patients or communication with other clinicians.

The interview session will be audio-recorded; this is so that your responses can be considered in greater detail after the interview. The interview can take place either at your place of work, or at the University of Liverpool, depending on your preference.

Please be assured that the information you provide as part of the study will be kept confidential.

Are there any risks to taking part?

We do not anticipate that there will be any risks to your taking part in the study.

Are there any benefits to taking part?

There are no direct benefits to you, but your participation will help us to develop a new mental health assessment tool that will potentially be used in clinical and/or research settings.

Will my participation be kept confidential?

All the information generated from the interview will be kept confidential. The digital files of the audio-recordings from the interview will be password protected and kept on a desktop computer at the Institute of Psychology, Health & Society (University of Liverpool). Although the files will be routinely destroyed when no longer needed, with all the tapes having been destroyed by the end of the study (December 2017), you can request the destruction of your recording at any point in time.

Kate Allsopp, University of Liverpool

Institute of Psychology, Health & Society
Waterhouse Building, Block B, 2nd floor
University of Liverpool
1-5 Brownlow Street, L69 3GL

Phone: 01 51 795 5375
E-mail: k.allsopp@liverpool.ac.uk

Appendix 6: Participant information sheet – Service Users

Participant Information Sheet Phase 1: Service Users

What if I am unhappy or there is a problem?

Please feel free to let us know by contacting Professor Peter Kinderman on 0151 794 8041, and we will try to help. If you remain unhappy or have a complaint that you feel you cannot come to us with then you should contact the Research Integrity and Governance Manager at the Research Support Office, University of Liverpool, Waterhouse Buildings, 3 Brownlow Street, Liverpool, L69 3GL. Tel: 0151 794 8373 or sponsor@lv.ac.uk

When contacting the Research Integrity and Governance Manager, please provide details of the name or description of the study (so that it can be identified), the researcher(s) involved, and the details of the complaint you wish to make.

Who can I contact with further questions?

Using the details below, please feel free to contact Kate Allsopp in the first instance. You may also contact Professor Peter Kinderman.

Institute of Psychology, Health & Society
Waterhouse Building, Block B, 2nd floor
University of Liverpool
1-5 Brownlow Street, L69 3GL

Principal Investigator: Prof. Peter Kinderman
Phone: 0151 794 8041
E-mail: p.kinderman@liverpool.ac.uk

Student Researcher: Kate Allsopp
Phone: 0151 795 5375
E-mail: kallsopp@liverpool.ac.uk



UNIVERSITY OF
LIVERPOOL

Kate Allsopp, University of Liverpool

0151 795 5375
kallsopp@liverpool.ac.uk

What happens after I take part?

What will happen to the audio recordings?

The digital files of the audio-recordings from the interview will be password protected and kept on a desktop computer at the Institute of Psychology, Health & Society (University of Liverpool). Although the files will be routinely destroyed when no longer needed, with all the tapes having been destroyed by the end of the study (December 2017), you can request the destruction of your recording at any point in time.

What will happen if I want to stop taking part?

You are free to withdraw from the study at anytime. Please note that as all data is anonymised after the interview, you will not be able to withdraw your data indefinitely; after your participation if you decide you want to withdraw your data, you can inform the researcher (Kate Allsopp kallsopp@liverpool.ac.uk) within 1 month of the finished interview(s), and your data will be withdrawn.

What will happen to the results of the study?

The results of the study may be written up and submitted for publication in scientific journals. If you are interested in the receiving the results of the study and information on how to access these publications you will be asked to provide your address details at the end of the study. No publication deriving from this study will include your personal details or information that can identify you in any way.

Phase 1, Service Users: 03/12/14 v4

What is the research about?

What is the purpose of the study?
We need more focused, specific, approaches to mental health, and we're developing a new assessment to do exactly that. This study will bring together views from mental health service users and clinicians about the current system of diagnosis in mental health, and about the new assessment we're developing. The study will contribute to a PhD qualification.

Why have I been invited to take part?

You have been invited to take part because we'd like to hear the views and experiences of people who have used mental health services.

Do I have to take part?

Absolutely not – taking part is your choice. If you do take part, you are free to withdraw at any time without giving a reason, and without your medical care or legal rights being affected.

Which ethics committee has approved the research?

The reviewing Research Ethics Committee was the NRES Committee North West – Greater Manchester East.

What does the research involve?

What will happen if I take part?

If you agree to take part, you will be asked to meet with the researcher for one interview, lasting about an hour. During the interview, you will be given a brief outline of the proposed new assessment tool, and asked questions about how useful you think this sort of interview would be. You will be asked how it compares with your own experiences of assessment interviews, and your thoughts and experiences around receiving a mental health diagnosis.

If the interview takes place in your home, the researcher will contact a member of your care team before organising the visit, in order to ask the care professional for information relevant to the health and safety of the researcher. No other personal information will be shared with the researcher.

The interview session will be audio-recorded; this is so that your responses can be considered in greater detail after the interview.

Please be assured that the information you provide as part of the study will be kept confidential.

Will I be paid to take part?

You will be given £10 at the end of the interview as a gesture of thanks for your time and for taking part, and you will also be refunded your travel expenses. Please be aware that a cash payment may affect any benefits that you might be receiving.

Are there any risks to taking part?

We do not anticipate that there will be any risks to your taking part in the study, however it is possible that you might find it upsetting to discuss some of your experiences. Should you find this distressing, you can take a break from the interview, or decide not to continue. You will have the opportunity to talk through your distress with the researcher.

Are there any benefits to taking part?

There are no direct benefits to you, but your participation will hopefully help us to develop a new mental health assessment tool that will potentially be used in clinical and/or research settings.

Will my participation be kept confidential?

All the information generated from the interview will be kept confidential. However, if you disclose information indicating that you wish to harm yourself or others, confidentiality will have to be broken and the researcher will inform your clinical team. The researcher will let you know if they intend to do this.

Kate Allsopp, University of Liverpool

Institute of Psychology, Health & Society
Watehouse Building, Block B, 2nd floor
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Phone: 01 51 795 5375
E-mail: k.allsope@liverpool.ac.uk

Appendix 7: Participant consent form – Clinicians



PARTICIPANT CONSENT FORM – PHASE 1: CLINICIANS

Title of Research Project:

Development and validation of non-diagnostic assessment methods in mental health care

Researchers:

Kate Allsopp, Professor Peter Kinderman, Professor John Read

Please initial
box

1. I confirm that I have read and have understood the information sheet dated December 2014 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my legal rights being affected. In addition, should I not wish to answer any particular question or questions, I am free to decline.
3. I understand that, under the Data Protection Act, I can at any time ask for access to the information I provide. I understand that once my data is submitted it will become anonymised and I can request the destruction of that information only within 1 month of completion of the interview.
4. I understand that my responses will be kept strictly confidential. I give permission for members of the research team to have access to my anonymised responses. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research.
5. I agree to my participation being audio recorded during the study interviews.
6. I understand that data collected during the study may be looked at by responsible individuals from The University of Liverpool, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to the data.
7. I agree to be contacted by the researcher to be invited to take part in another study as part of the same research project.
8. I agree for the data collected from me to be used in future research, provided that the data is anonymised and contains no identifying information.
9. I agree to take part in the above study.

Participant Name

Date

Signature



_____ Name of Person taking consent	_____ Date	_____ Signature
_____ Researcher	_____ Date	_____ Signature

Principal Investigator:
 Professor Peter Kinderman
 Institute of Psychology, Health and Society
 University of Liverpool
 Waterhouse Building, Block B, 2nd Floor
 1 - 5 Brownlow Street
 Liverpool
 L69 3GL
 Work Telephone: 0151 794 8041
 Work Email: p.kinderman@liverpool.ac.uk

Student Researcher
 Kate Allsopp
 Institute of Psychology, Health and Society
 University of Liverpool
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 1 - 5 Brownlow Street
 Liverpool
 L69 3GL
 Work Telephone: 0151 795 5375
 Work Email: kallsopp@liverpool.ac.uk

Version 4 - December 2014

Appendix 8: Participant consent form – Service Users



PARTICIPANT CONSENT FORM – PHASE 1: SERVICE USERS

Title of Research Project:

Development and validation of non-diagnostic assessment methods in mental health care

Researchers:

Kate Allsopp, Professor Peter Kinderman, Professor John Read

Please initial
box

1. I confirm that I have read and have understood the information sheet dated Dec 2014 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. In addition, should I not wish to answer any particular question or questions, I am free to decline.
3. I understand that, under the Data Protection Act, I can at any time ask for access to the information I provide. I understand that once my data is submitted it will become anonymised and I can request the destruction of that information only within 1 month of completion of the interview.
4. I understand that my responses will be kept strictly confidential. I give permission for members of the research team to have access to my anonymised responses. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research.
5. I understand that if the researcher considers that I may be at risk of harming myself or others, they may contact my clinical team. I understand that if this is the case, the researcher will discuss this with me before contacting the clinical team.
6. I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from the University of Liverpool, from regulatory authorities, or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.
7. In the event that the interview session might take place at my home, I agree for the researcher to contact a member of my care team before the session in order to ask the care professional for information relevant to the health and safety of the researcher. I understand that no other personal information will be shared with the researcher.
8. I agree to my participation being audio recorded during the study interviews.
9. I agree to be contacted by the researcher to be invited to take part in another study as part of the same research project.



10. I agree for the data collected from me to be used in future research, provided that the data is anonymised and contains no identifying information.

11. I agree to take part in the above study.

_____	_____	_____
Participant Name	Date	Signature
_____	_____	_____
Name of Person taking consent	Date	Signature
_____	_____	_____
Researcher	Date	Signature

Principal Investigator:
 Professor Peter Kinderman
 Institute of Psychology, Health and Society
 University of Liverpool
 Waterhouse Building, Block B, 2nd Floor
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 Work Email: p.kinderman@liverpool.ac.uk

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Version 2 - August 2014

Appendix 9: Debrief pack – Service Users*Debriefing Sheet*

Title of Study: Development and validation of non-diagnostic assessment methods in mental health care

Researchers: Kate Allsopp, Professor Peter Kinderman, Professor Rhiannon Corcoran

Dear Participant,

Thank you very much for taking the time to participate in this study developing an alternative assessment of mental health problems. We aim to assess mental health difficulties without using psychiatric diagnosis, and hopefully improve the assessment, care and wellbeing of people with these difficulties. If you have any questions regarding this study please feel free to contact me on the number provided below (or if you prefer you can send me an e-mail). I will be more than happy to talk to you about any concerns or doubts that you may have about the study or your participation.

In the event that you feel distressed by your participation in this study, we encourage you to contact us. If, for whatever reason, you are unable to do so please contact someone directly involved in your care (e.g. psychiatrist, community nurse, social worker or support worker). If you are not currently seeing a mental health team please contact your GP. It is important that you receive support from someone involved in your care and who knows your difficulties but also your strengths. Out of hours, you can access the primary care service for an emergency (**Urgent Care 24 Patient Access Telephone Number: 0151 220 3685** for Merseyside residents only) or the NHS advice line (**Dial 111**).

If you feel that you may benefit from psychological therapies or counselling (commonly known as ‘talking therapies’) please ask your Primary Care Doctor (GP) to refer you to Inclusion Matters (website: <http://inclusion-matters-liverpool.org.uk/>). This is a service staffed by skilled professionals that have been trained to help people with mental health difficulties. They have a vast range of expertise and substantial experience helping people with low mood, anxiety and related problems. Another service that you may find helpful is *Careline* (0151 233 3800) which is a 24-hour phone line staffed by Social Services. *Careline* staff can provide you with advice on how to access extra support on issues related adult and child safeguard and social care (e.g. housing, debt, benefits, etc.).

Alternatively, if you feel that due to your distress you or people around may be unsafe please don't hesitate to contact the Access Team at the Royal Liverpool University Hospital (**mental health crisis line from 7:30-21:00 contact 0151 250 5056; from 21:00-8:00 contact 0151 706 2782**) or the Mental Health Team at University Hospital Aintree (**mental health crisis line 0151 529 8145**). These teams work 24 hours, 7 days a week and will provide you with professional advice on how to access emergency mental health services out of hours. These teams can also quickly engage you with acute mental health services.

Attached to this sheet you will find a range of helplines and services that you may find helpful,

Again thank you very much for your participation,



Kate Allsopp
Institute of Psychology, Health and Society
Waterhouse Building, Block B, 2nd Floor
University of Liverpool Brownlow Street
Liverpool
L69 3GL
0151 795 5375
kallsopp@liverpool.ac.uk

Whether you're concerned about yourself or a loved one, these are helplines and services that can offer you help:

MIND

Mind is a charity that provides independent information and advice about mental health problems and treatments. They also offer advice on legal issues related to mental health and can put you in touch with local community members and networks.

Phone: 0300 123 3393

E-mail: info@mind.org.uk

Website: www.mind.org.uk

Facebook: www.facebook.com/mindforbettermentalhealth

Twitter: www.twitter.com/MindCharity

Blog: www.mind.org.uk/blog).

Hearing Voices Network (HVN)

The Hearing Voices Network is a self-help user-run organisation for people who hear voices (to what psychiatry generally refers to as 'auditory hallucinations') or have other unusual experiences. The organisation provides information about local support groups where people have an opportunity to talk freely with the aim of understanding and learning from these experiences.

Phone: 0114 271 8210 (this is not a helpline)

E-mail: nhvn@hotmail.co.uk

Website: <http://www.hearing-voices.org/>

CALM

This charity is aimed at helping young men aged 15-35. They offer help and advice on a range of different issues from depression and anxiety to issues related to victimisation of minority and ethnic groups.

Phone: 0800 58 58 58 (Monday-Sunday 5pm-12am)

E-mail: info@thecalmzone.net

Website: www.thecalmzone.net

You Tube <http://www.youtube.com/thecalmzonenet>

Facebook <http://www.facebook.com/pages/The-CALMzone/49764419689>

Twitter: www.Twitter.com/theCALMzone

Rethink Mental Illness

This is a charity that runs a helpline that provides advice and support for people living with mental problems.

Phone: 0300 5000 927 (Monday-Friday 10am-2pm)

Email advice@rethink.org

Website: www.rethink.org

Facebook: www.facebook.com/RethinkCharity

Twitter: <https://twitter.com/rethink>

Blog:

www.rethink.org/about_mental_illness/personal_stories_blogs_forum/blogs/index.html

Depression Alliance

This is a charity for people who experience depression. The website has information about local self-help groups.

Phone: 0845 123 23 20 (this is not an helpline)

Website: www.depressionalliance.org

Samaritans

This is a charity that provides confidential support for people experiencing feelings of distress or despair.

Phone: 08457 90 90 90 (24-hour helpline)

E-mail: jo@samaritans.org

Website: www.samaritans.org.uk

Facebook: <https://www.facebook.com/samaritanscharity>

Twitter: <https://twitter.com/samaritans>

Sane

This charity offers emotional support for people with mental health problems.

Phone: 0845 767 8000 (Monday-Sunday 6pm-11pm)

E-mail: sanemail@org.uk

Website: www.sane.org.uk

Facebook: <https://www.facebook.com/charitySANE>

Twitter: <https://twitter.com/CharitySANE>

Forum: http://www.sane.org.uk/what_we_do/support/supportforum/

RASA (Rape and Sexual Abuse Centre)

RASA is a charity that works with all individuals who have been victims of sexual violence at any time in their lives.

Phone: 0151 707 4313 (Friday 2pm-4pm). Calls to this helpline outside of this time will be responded to within 48 hours.

E-mail: rasa@rasamerseyside.org

Website: <http://www.rasamerseyside.org/>

NAPAC (National Association for People Abused in Childhood)

This is a national support helpline for adults who have suffered any type of abuse in childhood.

Phone:

0800 085 3330 for free from landlines, 3, Orange & Virgin mobile phones

0808 801 0331 for free from O2, T-Mobile and Vodafone mobile phones

(Monday – Thursday 10am-9pm; Friday 10am-6pm)

E-mail: support@napac.org.uk

Website: www.napac.org.uk

Victim Support

This is a charity that provides support and information to people affected by crime, including rape and sexual abuse, as a victim or a witness.

Phone: 0845 30 30 900 (Monday-Friday 9am-9pm; Saturday-Sunday 9am-7pm)

E-mail: supportline@victimsupport.org.uk

Website: www.victimsupport.org

Survivors UK (for men only)

Provides support for men who have been raped or sexually abused at any point in their lives.

Phone: 0845 122 1201 (Monday – Tuesday 7pm-9:30pm; Thursday 12pm-2:30pm)

E-mail: info@survivorsuk.org

Website: www.survivorsuk.org

Rape Crisis (for women only)

Provides support for women who have been raped or sexually abused at any point in their lives.

Phone: 0808 802 9999 (Monday-Sunday 12pm -12:30pm & 7pm – 9:30pm)

E-mail: info@rapecrisis.org.uk

Website: www.rapecrisis.org.uk

**Appendix 10: A section of the list of codes generated from initial open coding
(alphabetically organised by nVivo)**

OPEN CODING CODES
'Illness' as illogical, un-understandable
'Social prescribing'
A dramatic change indicating more organic illness
Absence (seemingly) of contextual triggers inferring biological cause
Absence of context in diagnostic criteria & the implications
Acceptability of diagnoses or conceptualisations varying across diagnoses
Accepting people's need to categorise & name things
Acknowledging different purposes of assessment
Acknowledging different purposes of communication & documentation
Acknowledging the heterogeneity within a diagnostic label
Advancing mental health care - expectation of using better more helpful language
Aiming to ensure that all patients have a diagnosis
Alluding to adversity
Alluding to adversity or life experiences as linked to MH problems
Anger at being labelled in a particular way
Applying rigour to make diagnoses
Arrogance of clinicians; clinicians as expert
Asking a person's diagnosis to understand their perspective
Asking according to interests
Asking the patient to define the 'problem'
Asking the patient; using general medical training
Asking the standard questions - making assumptions about what these are
Assuming a contextual cause of a problem
Assuming everything can be explained within a formulation
Assuming that formulation incorporates everything whereas diagnosis doesn't
Assumptions made about diagnosis from one or 2 symptoms
Attributing even 'normal' responses to the diagnosis
Attributing overwhelming responses or thoughts to a disorder
Attributing past difficulties to an undiagnosed problem
Attributing unusual or not typical responses to diagnosis
Being aware of possible negative impact of diagnosis
Being confused as to why difficulties not acknowledged as a diagnosis
Being forced to talk about difficulties by worsening severity (threshold for seeking help)
Being lost without a structure to start from
Being more interested in experiences other than 'symptoms'

Being offered fewer opportunities for treatment because diagnosis seen as too big, too difficult to treat
Being overpowered by the patient
Being reluctant to make diagnoses; perhaps due to training or point in care pathway
Being told you've 'got' a disorder
Being treated differently as a result of PD diagnosis
Being unsure about how difficulties are conceptualised
Biological symptoms as being more organic than life related
Boxing off difficulties into separate diagnoses being helpful
Broad diagnostic criteria could fit to a lot of people
By fixing a certain model or explanation (diagnosis), making changes is more difficult
Certain behaviours being judged more harshly in the context of certain diagnoses
Challenging (medical model) clinicians to better understand the individual
Challenging the notion of a 'typical' person with that diagnosis
Changing a (comfortable) structure is difficult
Changing the conceptualisation of MH changes the treatment
Clear ends of the spectrum of severity being 'much easier' to decide
Clinician needing to ascribe a diagnosis
Clinician understanding difficulties
Coming to an agreement
Comparing MH with alcoholism; seen as always an alcoholic, always having MH problems
Complex and long-term patterns needing more time & info to diagnose
Complexity & risk denoting progression from primary to secondary care
Complexity - long history of difficulties
Complexity - lots of different difficulties attracting multiple diagnoses
Complexity - lots of intertwined difficulties
Complexity - trauma
Complexity of patterns & how to identify these
Conceptualising in a particular way having implications for treatment
Confirmation bias of diagnosis - missing other information
Conflict related to diagnosis, not internal
Confusing diagnoses & indistinct lines between them
Connecting primary & secondary care; overriding risk-complexity divide to access psychological interventions
Considering availability of other (supportive) resources
Considering long-term implications of treatment & association with certainty
Considering the implications of not using multi-axial system
Consistency being important across individuals
Continual updating of formulation
Conveying a degree of severity
Creating implications for people when labelling them

Appendix 11: Example of the organisation of codes generated from open coding into subthemes

SUBTHEMES	CODES FROM OPEN CODING
BENEFITS TO THE INDIVIDUAL (general)	<p>Individual benefit of diagnosis</p> <p>Positive impacts (uses) of diagnosis (for the patient)</p>
UNDERSTANDING DIFFICULTIES	<p>Offering understanding</p>
RECOGNISING OWN DIFFICULTIES; A STARTING POINT	<p>Diagnosis helpful in recognising difficulties, giving insight</p> <p>Diagnosis used to 'know what I was dealing with'</p> <p>Diagnosis being used as a starting point for fighting difficulties</p>
MAKING SENSE OF DIFFICULTIES BECAUSE OF THE DIAGNOSIS VS. AGE & EXPERIENCE	<p>VS - making sense of difficulties via age & experience vs. being given a diagnosis</p>
ACCESSING PRACTICAL SUPPORT	<p>Diagnosis conveying a degree of severity (access to benefits)</p> <p>'Playing the game'</p> <p>Using diagnosis where its useful - e.g. getting access to things</p> <p>Diagnosis being the only method of access (practical uses)</p> <p>Diagnosis getting access to things - a by-product, hindsight, not a main aim</p> <p>Using diagnosis for practical uses (individual level)</p>
SICK NOTES	<p>Having to use diagnosis on sick notes</p>

ACCESSING
INTERVENTIONS,
TREATMENT, THERAPY

Using diagnosis to access specific, targeted therapy

Using diagnosis to access therapy

Diagnosis allowing access to treatment

Diagnosis as a way of getting access to services elsewhere

GIVING PERMISSION

Using diagnosis to allow people to feel what they're feeling

Giving permission to feel this way

IDENTIFYING WITH OTHERS

Identifying with others with the same diagnosis

SHARED UNDERSTANDING:
CLINICIAN-PATIENT

Developing a shared understanding - clinician to patient,
clinician to other clinicians

Direct pathway from problem to intervention being about
having shared goals

RISK MANAGEMENT;
INDIVIDUAL

Using diagnosis for both individual and population safety

A WAY TO MOVE PEOPLE
OUT OF THE SERVICE
(RATIONING)

Diagnosis being used to move people on to different (more
specific) services to help with rationing

DEVELOPMENT OF
SERVICES

Diagnosis & prevalence figures allowing development of
services for people perhaps otherwise neglected

TREATMENT/RESOURCE
PLANNING

Accuracy of diagnosis used for accuracy in treatment planning,
research, audit

AUDIT & ADMIN (SERVICE
LEVEL)

Using diagnosis at a broad, group level (audit, service
planning)

Service uses of diagnosis; broad non-individual categories

	<p>Accuracy of diagnosis used for accuracy in treatment planning, research, audit</p> <p>Using diagnosis at a broad, group level (audit, service planning)</p> <p>Using diagnosis for non-clinical needs</p> <p>Acknowledging different purposes of communication & documentation</p> <p>Aiming to ensure that all patients have a diagnosis</p> <p>Clinician needing to ascribe a diagnosis</p>
RISK MANAGEMENT; POPULATION	<p>Using diagnosis for both individual and population safety</p>
CATEGORISING FOR RESEARCH	<p>Psychological research being diagnosis-based</p> <p>Accuracy of diagnosis used for accuracy in treatment planning, research, audit</p>
TIMES WHEN DIAGNOSIS IS NOT USED	<p>Not having a PD diagnosis even though criteria met</p>
INDIVIDUAL (SU) VS. INDIVIDUAL (CLINICIAN) NEEDS	<p>Diagnosis capturing what is important to the clinician but missing what is important to the client</p> <p>VS - separation between own experience & needs vs. the needs of psychiatrists</p> <p>VS - Managing patient vs. managing self</p> <p>VS - Public vs. personal uses of diagnosis</p>
USEFUL FOR SOME THINGS VS. CONFUSING FOR OTHERS [INDIVIDUAL]	<p>VS - multiple diagnoses as confusing for treatment planning vs. giving a guide to a person's difficulties</p>
RESEARCH (STRICT) VS. CLINICAL (FLEXIBLE) USES OF DIAGNOSIS	<p>VS - differing uses - strict research criteria vs. more flexible clinical adaptations</p>

TECHNOLOGICAL USES VS. INDIVIDUAL NEEDS/ EXPERIENCE/ USES	VS - diagnosis as a categorisation vs. a representation of what the experience feels like
TECHNOLOGICAL NEED OVERRIDING THAT OF THE INDIVIDUAL [OPPOSITE TO ABOVE] INDIVIDUAL OVERRIDING THE TECHNOLOGICAL/ADMIN USES	<p>VS - diagnostic uses; categorisation & classification vs. explanation of difficulties to SU</p> <p>VS - diagnosis is shared always vs. formulation shared only if consent given</p> <p>VS - diagnosis always on records but not always shared with patient vs. formulation always shared with patient but not always on records</p> <p>VS - technological vs. individual needs</p>
SERVICE VS. INDIVIDUAL USES OF ASSESSMENT	<p>VS - Provision of services vs. individual patient work</p> <p>VS - for the person vs. for the system or service</p> <p>VS - different uses of diagnosis (non-individual) eg providing services vs. 1to1 work</p>
[BEST FOR THE PERSON VS. RATIONING SERVICES] INDIVIDUAL VS. GROUP/POPULATION LEVELS (NON-CLINICAL)	<p>VS - finding the most relevant support vs. needing to establish sufficient need to see a psychologist</p> <p>VS - non-clinical uses of diagnosis; individual vs. group or population level</p>

Appendix 12: Organisation of subthemes into themes and main themes using an example of the main descriptive theme 'Uses of diagnosis and other assessments'

MAIN THEME	THEME	SUBTHEMES	(Subthemes)
USES OF DIAGNOSIS & OTHER ASSESSMENTS	<p>Different purposes of diagnosis/ assessment; in whose interest is diagnosis</p> <p>Individual</p> <p>Individual (clinicians)</p> <p>Individual (service users)</p>	<p>To classify is human</p> <p>Giving a broad understanding, idea of how clients likely to be, what to expect</p> <p>Communication shorthand</p> <p>Predicting course of illness Informing treatment planning</p> <p>Understanding clients; managing self</p> <p>Being pragmatic about when diagnosis is used</p> <p>Equating diagnosis with treatment Benefits to the individual (general)</p> <p>Understanding difficulties</p>	<p>Telling you how other people have made sense of a client's difficulties</p> <p>An end to uncertainty</p>

		A way to take away blame Using diagnostic-type language for client benefit (to name specific difficulties)
	Recognising own difficulties; a starting point	
	Making sense of difficulties because of the diagnosis vs. because of age & experience	
	Accessing practical support	
	Sick notes	
	Accessing interventions, treatment, therapy	
	Giving permission	
	Identifying with others	
	Patients & families liking a diagnosis, label	
	Diagnosis removing responsibility	
	Having an 'actual' problem	
Clinician-service user relationship/interaction		
Risk management; individual	Shared understanding: clinician-patient	
Service needs		
	A way to move people out of the service (rationing)	
	Development of services	
	Treatment/resource planning	
	Audit & admin (service level)	

<p>Legal uses</p>	<p>Mental health act</p>	
<p>Broader & population/ National uses</p>	<p>Criminal justice system</p> <p>Risk management; population</p> <p>Categorising for research</p>	
<p>Tensions & conflicting uses of diagnosis, assessment</p>	<p>Individual (su) vs. individual (clinician) needs</p> <p>Useful for some things vs. negative for others [individual]</p> <p>Research (strict) vs. clinical (flexible) uses of diagnosis</p> <p>Technological uses vs. individual needs/ experience/ uses</p> <p>Technological need overriding that of the individual</p> <p>[Opposite to above] individual overriding the technological/admin uses</p> <p>Service vs. individual uses of assessment</p> <p>Individual vs. group/population levels (non-clinical)</p>	<p>[Best for the person vs. rationing services]</p>

Appendix 13: Example of the reorganisation of themes and subthemes to represent clinicians' uses and conceptualisations of psychiatric diagnosis

THEME	SUBTHEME	(SUBTHEME)
<p>Clinicians being aware of potential negative implications of diagnosis</p>	<p>Different diagnoses having different conceptualisations & therefore connotations</p> <p>Recognising negative impact</p>	<p>Negativity of judgements depends on diagnosis</p> <p>'Scary labels' (eg psychosis)</p>
<p>Conceptualisations & beliefs, ideas about cause</p>	<p>Continuum between the social & the organic</p> <p>Defining disorder, MH problems Identifying external, experience, contextual cause of difficulties</p> <p>Illness being illogical, un-understandable Inferring organic or biological cause</p> <p>Interaction between brain & experience Particular services having different conceptualisations of difficulties</p>	<p>Untangling the understandable from not understandable Continuum or dimensional experience</p> <p>Presence of external trigger</p> <p>Understandability</p> <p>Absence of contextual triggers</p> <p>Biological symptoms of depression</p> <p>Dramatic change</p> <p>Family history</p> <p>CAMHS</p> <p>Early Intervention</p> <p>Diagnostic uncertainty</p>

		<p>Offering meaning in relation to experiences</p> <p>IAPT</p> <p>Older adults</p>
Implications	<p>Problems seen as fixed across situations (because within the individual)</p> <p>Shifting conceptualisations of dx over time</p>	
Implications for treatment	<p>Impact on client-clinician relationship</p> <p>Positive impact</p> <p>Tensions around the implications of diagnosis</p>	
Individual functions of dx (clinicians)	<p>Changing conceptualisations for MH has implications for treatment</p> <p>Meeting the client at their point of conceptualising MH</p> <p>Academic exercise</p> <p>Certainty</p> <p>Containing complexity (& limitations of this)</p> <p>Conveying impact, severity</p> <p>Giving a broad understanding, idea of how clients likely to be, what to expect</p> <p>Telling you how other people have made sense of a client's difficulties</p> <p>Using diagnosis as a broad guide to the person</p> <p>Managing own responses (towards client behaviour; getting an understanding)</p> <p>Practical uses</p>	
		<p>Clinician using diagnosis pragmatically; where it would help the client</p> <p>Being pragmatic about when diagnosis is used</p> <p>Communication shorthand</p> <p>Informing treatment planning</p>

Limitations of diagnosis -
Individual (clinician)

Risk management

To classify is human

Defining, pathologizing
normal responses

Diagnosis stops you going
further to understand the
person

Not being able to relate
diagnosis to the person

Diagnostic categories don't
fit with complex, longstanding
problems

Diagnosis as a short
circuit; bypassing complexity

Leads to simplistic
intervention & management
strategies

Diagnostic model assumes
straightforward pathways into
MH whereas usually complex

Multiple diagnostic
categories missing underlying
problem

Diagnostic clusters lacking
added value (in practical uses)

Diagnostic overshadowing

Difficulty trying to get rid of a
diagnosis

Effective intervention is
more than just a biomedical
diagnosis-treat model

Gives limited information

Excludes systemic,
developmental & other
environmental factors

Needs & information
outside of diagnosis can be
more important

Not giving information
about the experience of the
person

Problem of multiple
diagnoses in treatment
decisions

Using diagnosis to connect with
evidence to inform practice

Justify treatment planning

Predicting course of illness

Record keeping

Standardised care

Limitations of diagnosis -
Technological aspects
(categorisation,
classification)

Limitations of biomedical
model

Limitations of medical
treatment

Limits explanations other
than biomedical model

Uncertainty, grey areas,
difficulties in applying in
practice

Official, expert view of diagnosis
vs. subjective & changing

Technical (criteria, cut offs) vs.
idiosyncratic clinical decisions,
heuristics

Uncertainty impacting on treatment
decisions

Categorical vs. dimensional,
transdiagnostic classification

Categorises presenting
symptoms but not underlying
difficulties

Comorbidity

Creating (unhelpfully) strict
or artificial distinctions
between people

Heterogeneity of diagnoses

Broad diagnostic criteria

Diagnosis being nebulous,
ill-defined

Diagnostic labels masking
individual differences

Heterogeneous diagnoses
treated as whole rather than
addressing specific difficulties
within

Managing heterogeneity

Multiple forms of variation
within diagnoses

Some diagnoses more
heterogeneous than others

Tensions around
heterogeneity

Implications - downplaying
symptoms that don't fit

Non-aetiological diagnoses

Overlapping diagnoses

Problematic nature of cross-
sectional assessment

Reifies diagnostic
categories

Reliability

Too many diagnoses in the
DSM to be useful

Prototypes differing between
clinicians

Appendix 14: Example of the reorganisation of themes and subthemes to represent the travel of psychiatric diagnosis beyond the clinic, through an examination of the practices of recording diagnosis

THEME	SUBTHEME	(SUBTHEME)	(SUBTHEME)
<p>Reification of diagnoses</p> <p>Tension between SU & clinician's conceptualisations of difficulties</p>	<p>Tensions & conflicting uses of diagnosis, assessment</p> <p>Political, financial vs. individual needs Research (strict) vs. clinical (flexible) use of diagnosis</p> <p>Service uses</p>	<p>Different purposes of diagnosis, assessment; in whose interest is diagnosis</p> <p>Individual (SU) vs. individual (clinician) needs</p> <p>Individual vs. group or population levels (non-clinical)</p> <p>Individual vs. legal needs</p> <p>Legal uses</p> <p>A way to move people out of the service (rationing)</p> <p>Audit & admin</p> <p>Clustering</p> <p>Planning & development of services</p>	<p>Criminal justice system</p> <p>Limitations - Legal uses Mental Health Act</p>

<p>Service vs. individual uses of assessment</p>	<p>Treatment, resource planning Service entry criteria Service payment</p>
<p>Technological need overriding that of the individual Technological uses vs. individual needs, experiences, uses Useful for some things vs. negative for others (individual)</p>	<p>Best for the person vs. rationing services Formulation</p>
	<p>Tensions across conceptualisations Helping people transition to different services with different conceptualisations</p>

Appendix 15: Example of the reorganisation of themes and subthemes to represent service users' uses and conceptualisations of psychiatric diagnosis

THEME	SUBTHEME	(SUBTHEME)	(SUBTHEME)
Clinician to service user power imbalance	<ul style="list-style-type: none"> Clinician as expert Negative implications of status in psychiatry Us & Them in MH care 		
Conceptualisations & beliefs, ideas about cause	<ul style="list-style-type: none"> Difficulties as survival mechanisms Interaction between life experiences & biological causes MH diagnosis & difficulties seen as lifelong vs. not permanent or lifelong Mentioning life problems alongside MH problems Experiences of trauma, difficult events (not necessarily attributed as cause) Not understanding cause Seeing different diagnoses as separate illnesses Separation between self and diagnosis (illness) Using biomedical explanations Using life experience as explanation 		
Experiences of MH problems Experiences of services	<ul style="list-style-type: none"> Criticisms of MH services 	<ul style="list-style-type: none"> A mess Difficulty accessing the right help Feeling unsupported Lack of communication 	

Helpful aspects of care, of clinicians	<p>Asking about wider living situation & experiences</p> <p>Availability of support, contact time</p> <p>Holistic, seeing the person rather than the label</p> <p>Less medical model focused</p> <p>Offering understanding</p> <p>Understanding the person</p>	Trauma not asked about, understood
Unhelpful aspects of care, of clinicians	<p>Judgement or other responses by MH professionals</p> <p>Not considering non-medical causes eg trauma</p> <p>Explanation of problems by clinicians</p>	
Implications	<p>Diagnosis becoming part of you, defining you</p> <p>Diagnosis inviting intrusive questions from people</p> <p>Experiences interpreted within biomedical model</p> <p>Importance & implications of language</p> <p>Negative impact (individual responding)</p> <p>Stigma</p>	<p>Association with criminality, violence</p> <p>Barriers of the label, being judged by the label</p> <p>Media</p> <p>Negative attitudes towards the person diagnosed</p> <p>Not wanting to be associated with the diagnosis</p> <p>Pejorative associations, stereotypes & negative attitudes towards particular diagnoses</p>

Individual
functions of dx
(service users)

	<p>Personality disorder diagnoses Language implying a fault with the self Language implying a permanent problem Seeing self as damaged, flawed</p>	
<p>A battle Addressing stigma Communicating with others Diagnosis as an indication of level of need Explaining & understanding problems</p>	<p>Explaining problems (with the diagnosis) Information about course of 'illness' Making sense of difficulties because of diagnosis vs. due to age & experience Understanding difficulties</p>	
<p>Knowing what's wrong (certainty perhaps)</p>	<p>An end to uncertainty Diagnosis being containing</p>	<p>Using diagnostic-type language for client benefit (to name specific difficulties)</p>
<p>Patients & families liking a diagnosis, label Practical uses</p>	<p>Accessing information about the diagnosis Accessing interventions, treatment, therapy</p>	
		<p>Equating diagnosis with treatment Getting a</p>

Limitations of
diagnosis -
Individual (service
user)

<p>Recognition</p> <p>Arbitrary diagnoses</p> <ul style="list-style-type: none"> Being meaningless to the person Vagueness of diagnosis Benefits of diagnosis vs. negative impact of the label Diagnosis as disabling; people see the label not the person Enabling unhelpful uses of label Excludes people from services Focus on the negative Hindering people's understanding of you Negative impact on the self Problem located within the individual 	<ul style="list-style-type: none"> Accessing practical support Identifying with others, finding like-minded others Sick notes Support & security of contact with services Triggering making changes in life Diagnosis removing responsibility Giving permission Having an 'actual' problem Problems are genuine Others (eg family) recognising problems Recognising own difficulties; a starting point 	<p>cure</p> <p>A way to take away blame</p>
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Making sense of
difficulties

Diagnosis not necessarily
giving access to treatment
Diagnosis itself does not
treat underlying distress
Does not offer
understanding or help make
sense of things
Being diagnosed needs
additional explanation,
understanding, meaning
Biomedical explanations
limit possibilities for changing
model, explanation
Does not represent lived
experience
Difficulties not quite fitting
with diagnosis
Holding back details for
fear of being judged,
sectioned
Negative language

Rejecting
biomedical model,
finding alternatives

Biomedical ways of
understanding
Difficult to understand
what's going on
Making sense of childhood
experiences
Making sense of difficulties
being about understanding,
moving forward
Not wanting to use
medical language
Shifting conceptualisations
since initial diagnosis
Changing beliefs about
cause
Not about illness but just
who you are
Being more or less
sensitive to environment
Pathologising normal or
understandable experience
Thinking critically about
diagnosis having had a
negative experience of it