ENHANCING UNDERSTANDING OF THE EXPERIENCE OF PEOPLE WITH COMMON MENTAL HEALTH DISORDERS AND CO-MORBID PERSONALITY DISORDER TRAITS WHO PRESENT TO PRIMARY CARE IAPT SERVICES

A thesis submitted to the University of Manchester for the degree of Doctor of Philosophy (PhD) in the Faculty of Biology, Medicine and Health

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List of Contents

List of Contents	2-8
Appendices	9
List of Abbreviations	10-11
List of Tables, Figures and Photographs	12-13
Abstract	14
Declaration	15
Copyright statement	15
Acknowledgements	16
Dedications	17
The Author	18-19
Chapter 1: Introduction and Background	
1.1 Introduction	20
1.2 Aims and Objectives	21
1.2.1 Overall Aim	
1.2.2 Specific Objectives of the Thesis	21
1.3 Background	21
1.3.1 Personality Disorder	21-22
1.3.2 Presentation and Diagnosis	22-23
1.3.3 Epidemiology	24-25
1.3.4 Impact of Personality Disorder	25
1.3.5 Treatments	25-26
1.3.5.1 Specialist Secondary Service Treatments	26-29
1.3.6 Primary Care and IAPT	29
1.3.6.1 Primary Care	29
1.3.6.2 Improving Access to Psychological Therapies	29-30
1.3.6.3 The Stepped Care Model	31-32
1.4 Justification and Rationale for the Research	32-33
Chapter 2: Methodology	
2.1 Aims and Objectives	34
2.1.1 Overall Aim	34

2.1.2 Specific Objective of the Thesis	34-35
2.2 MRC Framework for Developing and Evaluating Complex	
Interventions	35-37
2.2.1 Developmental Phase	37-38
2.2.2 Feasibility and Piloting Phase	38
2.2.3 Evaluation Phase	38
2.2.4 Implementation Phase	39
2.2.5 Unexpected Research Outcomes	39
2.2.6 Limitations of the MRC Framework	39-40
2.2.7 Rationale for using Framework	40-41
2.3 Methodological Approaches	41
2.3.1 Positivism, Post Positivism and Interpretivism Paradigms	41-44
2.3.2 Quantitative Research	44
2.3.3 Qualitative Research	44
2.3.4 Mixed Methods	44-45
2.3.5 Qualitative Methodological Approaches	45
2.3.5.1 Ethnography	45
2.3.5.2 Phenomenology	45-46
2.3.5.3 Grounded Theory	46
2.3.5.4 Health Service Research – Justification of the Chosen	
Approach	46-48
2.4 Research Design	48
2.4.1 The Literature Review	49
2.4.1.1 Traditional Narrative Review	49
2.4.1.2 Systematic Reviews	49-50
2.4.1.3 Meta-Analysis / Meta Synthesis	50
2.4.1.4 Scoping Study	50-52
2.4.2. Justification of Methods used in the Qualitative Studies 2 a	nd 352
2.4.3 Data Collection	52
2.4.3.1 Observational Data Collection	52-53
2.4.3.2 Focus Group Data Collection	53-54
2.4.3.3 Individual Interview Data Collection	54-55
2.4.4 Recording of Data	55
2.4.5 Sampling	55-57
2.4.6 Recruitment	57

2.4.7 Data Analysis Methods	57-58
2.4.7.1 Thematic Analysis	58
2.4.7.2 Framework Analysis	58-60
2.4.8 Saturation	61
2.5 Rigour in Qualitative Research	61
2.5.1 Trustworthiness	61-62
2.5.2 Credibility	62
2.5.3 Conformability	62
2.5.4 Transferability	63
2.5.5 Dependability	63
2.5.6 Auditability	63
2.6 Reflexivity	64
2.6.1 Team Reflexivity	64-65
2.7 Patient and Public Involvement	65-66
2.8 Ethical Conduct in Research	66-67
2.8.1 Autonomy	67
2.8.2 Non Maleficence	67
2.8.3 Beneficence	67-68
2.8.4 Justice	68
2.9 Summary	68
Chapter 3: Literature Review	
3.1 Study 1 – Scoping Study Literature Review	69-70
3.2 The Research Question, Aim and Objectives	70-71
3.3 Personality Disorder – Policy Results	71-75
3.4 Review of Treatments, Treatment Experiences and Needs	75-77
3.4.1 Inclusion / Exclusion Criteria	78-79
3.4.2 Charting Methods	80
3.4.2.1 Charting Method for the Treatment and Interventions	
Objectives	80
3.4.2.2 Charting Method for the Treatment Experience Objective	80-81
3.4.2.3 Charting Method for the Needs Objective	81
3.5 Reporting Of Results	81
3.6 Treatment of Personality Disorder in Primary Care – Results	82-86

3.6.1 Participants	87
3.6.2 Interventions	87-91
3.6.3 Treatment of Personality Disorder in Primary Care – Finding	ıs91 - 92
3.6.4 Quality Appraisal	93-94
3.6.5 Critique	95
3.6.6 Treatment Results Conclusion	95-96
3.7 Treatment Experience – Results	96-98
3.7.1 Critique	98-99
3.7.2 Results	99-100
3.8 Needs – Results	100-105
3.9 Literature Review Summary	105
3.9.1 Strengths	105
3.9.2 Limitations	106
3.9.3 Literature Review Key Findings	106-108
Chapter 4: Working Research Methods	
4.1 Working Research Methods	109
4.1.1 Study 2 IAPT Healthcare Professional Interviews – Objective	ə109
4.1.2 Study 3 Patient Participant Interviews -	
Objective	109
4.2 Selection Criteria (Study 2 IAPT Healthcare Professional Interview	ews)
	109-110
4.3 Recruitment (Study 2 IAPT Healthcare Professional Interviews).	110-111
4.4 Selection Criteria (Study 3 Patient Participant Interviews)	111-112
4.5 Recruitment (Study 3 Patient Participant Interviews)	112-114
4.5.1 Patient Participant Screening Process	114-116
4.6 Consent	116
4.7 Data Collection Process	116
4.8 Data Analysis Process	117-119
4.9 Data Analysis Rigour	119-120
4.10 Patient and Public Involvement (PPI)	120-121
4.10.1 Research Advisory Group	121-123
4.10.1.1 Phase 1	123-124
4.10.1.2 Phase 2	124-126

4.10.2 Extended Research Supervisory Group	126-127
4.11 Ethical Considerations	127-128
4.11.1 Breaking Down Barriers, Overcoming Constraints	128-132
4.12 Rigour	132
4.13 The Role of Reflexivity	133
4.13.1 IAPT Healthcare Professional Interview Reflections (St	udy 2)
	133-134
4.13.2 Patient Participant Interview Reflections (Study 3)	135-136
4.14 Project Management	136
4.15 Research Governance	136
4.16 Expenses	137
4.17 Ethical Approval	137
Chapter 5: IAPT Healthcare Professionals Results	
5.1 Results	138
5.2 Sample	138-139
5.3 Main Analysis Results	140
5.4 Theme 1 – Recognising Complexity	140
5.4.1 The Bread and Butter of an IAPT Caseload	141
5.4.2 Gut Instinct and Identification	141-143
5.4.3 The Sensitive Label	143-145
5.5 Theme 2 – The IAPT System	145
5.5.1 Call it traits and send it to IAPT	145-147
5.5.1.1 The Gap	147-148
5.5.2 Education and Knowledge	148-149
5.5.3 Quantity Verses Quality	149-151
5.6 Theme 3 – Interactions with Patients	151
5.6.1 Chaos and Control	152-154
5.6.2 Perceptions of Patient Need	154-157
5.7 Theme 4 – Future Working	157
5.7.1 lo it your business?	
5.7.1 Is it your business?	157-159
5.7.2 Adaptions Verses Standalone Specialist Interventions	
	159-160

5.7.2.3 Standalone Specialist Interventions	161-162
5.7.3 Solutions for Clinical Practice	162-167
Chapter 6: Patient Participant Results	
6.1 Results	168
6.2 Sample	168-169
6.3 Main Analysis Results	170
6.4 Theme 1 – Process and Business	170
6.4.1 Help Seeking and Response	170-173
6.4.2 One Size Fits All	174-175
6.4.3 Step It Up	175-177
6.5 Theme 2 – Needs	177
6.5.1 Relationships and Emotions	177-178
6.5.2 Common Needs / Varied Outcomes	179-180
6.6 Theme 3 – Treatment Experience	180
6.6.1 Time to Talk	180-184
6.6.2 Rigid Treatment	184-186
6.6.3 Between Session Work	186-187
6.7 Theme 4 – What Matters	187
6.7.1 The Connection	188-190
6.7.2 Personalisation and Flexibility	190-194
Chapter 7: Synthesis	
7.1 Synthesis Introduction	195
7.2 Synthesis Method and Process	195-201
7.3 Synthesis Outcomes	202
7.3.1 Labelling Personality Disorder	202-203
7.3.2 IAPT Business	203-204
7.3.3 Patient Needs	204-206
7.3.4 Therapeutic Connections	207-208
7.3.5 Future Clinical Practice	208-209

Chapter 8: Discussion

8.1 Brief Method Overview	210
8.2 Summary of Main Findings	211
8.2.1 Study 1 – Scoping Study Literature Review	211
8.2.2 Studies 2 and 3 – Qualitative Interviews	211
8.2.2.1 Study 2	211
8.2.2.2 Study 3	211
8.3 Synthesis Overview – Key Conclusions	212
8.3.1 Labelling of Personality Disorder	212
8.3.2 The IAPT Business	212
8.3.3 Patient Needs	213
8.3.4 Therapist Connections	213
8.3.5 Future Clinical Practice	214
8.4 Limitations	214
8.4.1 Study 1	214-215
8.4.2 Study 2	215-216
8.4.3 Study 3	216-217
8.5 Strengths	217
8.6 New and Emerging Literature	218
8.6.1 New Academic Literature	218
8.6.2 New Policy Literature	219-220
8.7 Recommendations for Practice	221-228
8.8 Future Research	228-229
8.8.1 Intervention Modeling	229
8.8.2 Feasibility and Piloting	229-230
8.9 Research Impact	230
8.9.1 Impact Achieved	230-231
8.9.2 Impact Proposed	231
8.10 Conclusion	231-232
References	233-249

Total word count: 62,000 approx.

Appendices

Appendix 1 – Appendix 2 - NIHR CDRF Award Letter	250
Appendix 2 – PhD Offer Letter	251-252
Appendix 3 – Charting Excel Document Examples	253-254
Appendix 4 – Recruitment Flyer IAPT Healthcare Professional Participants	255
Appendix 5 – Ethical Approval Letter	256-260
Appendix 6 – IAPT Health Care Professional Participant Information Sheet	261-264
Appendix 7 – Consent Form IAPT Healthcare Professional Participants	265
Appendix 8 – IAPT Healthcare Professional Information Gathering Form	266
Appendix 9 – Research Protocol	267-279
Appendix 10 – Patient Participant Recruitment Flyer	280
Appendix 11 – Patient Recruitment Cover Letter	281
Appendix 12 – Patient Telephone Screening Script	282
Appendix 13 – Patient Participant Information Gathering Form	283
Appendix 14 - Cover letter to accompany Patient Participant Information Shee	et284
Appendix 15 – Patient Participant Information Sheet	285-288
Appendix 16 – Consent Form Patient Participants	289
Appendix 17 – Indexing Flow Chart	290
Appendix 18 – Example of NVivo/Excel Framework Matrix – Healthcare Profe	
Appendix 19 – Example of NVivo Framework Matrix – Patient Participants	295-298
Appendix 20 – Topic Guide – IAPT Healthcare Professional Participants	299-300
Appendix 21 – Topic Guide – Patient Participants	301-303
Appendix 22 – RAG Developed Conference Poster	304
Appendix 23 – GANTT Project Management Charts	305-308
Appendix 24 – NIHR Good Clinical Practice Certificate	309
Appendix 25 – List of Conference Presentations and Publications	310-313
Appendix 26 – Research Advisory Group Social Media Work	314
Appendix 27 – Research Governance Overview	314
Appendix 27 – PhD Results Power Point Presentation	315-322

Abbreviation list

ACT – Acceptance and Commitment Therapy

APA – American Psychiatric Association

ASG – Activities based support group

ASPD – Anti-social Personality Disorder

BABCP – British Association for Behavioural and Cognitive Psychotherapists

BDT - Brief Dynamic Therapy

BIGSPD - British and Irish Group for the Study of Personality Disorder

BPD – Borderline Personality Disorder

BRT - Brief Relational Therapy

BSc - Bachelor of Science Degree

CASP – Critical Appraisal Skill Programme

CAT – Cognitive Analytic Therapy

CBT – Cognitive Behavioural Therapy

CBT- PD - Cognitive Behavioural Therapy for Personality Disorder

CLAHRC - Collaboration for Leadership in Applied Health Research and Care

CQUIN - Commissioning for Quality and Innovation

DBT - Dialectic Behavioural Therapy

DBT- ST - Dialectic Behavioural Therapy Skills Training

DNA - Did Not Attend

DOH – Department of Health

DSM - Diagnostic and Statistical Manual of Mental Disorders

EBE's - Experts by Experience

EPHPP - Effective Public Health Practice Project Quantitative Critical Appraisal Tool

GCP - Good Clinical Practice

GP - General Practitioner

NIHR - National Institute for Health Research

IAPT – Improving Access to Psychological Therapies

ICD – International Classification of Disease Manual

IPT - Interpersonal Psychotherapy

IRAS – Integrated Research Application System

IPT - Interpersonal Psychotherapy

KUF - Knowledge and Understanding Framework

MBT – Mentalisation Based Therapy

MeSH – Medical Subject Headings

MRC - Medical Research Council

MSc – Master of Science Degree

NHS - National Health Service

NICE - National Institute for Health and Care Excellence

NIMHE – National Institute for Mental Health in England

NLMS – National Learning Management System

NPNR - International Network for Psychiatric Nursing Research

OCD - Obsessive Compulsive Disorder

P - Patient Participant

PD – Personality Disorder

PEPS - Psycho-Education with Problem Solving

PhD – Doctor of Philosophy

PPI - Patient and Public Involvement

PRISMA – Preferred Reporting Items for Systematic Reviews and Meta-Analyses'

PTSD – Post Traumatic Stress Disorder

PWP – Psychological Well-being Practitioner

RAG - Research Advisory Group

REC- Research Ethics Committee

RCT – Randomised Controlled Trial

SAPAS – Standardised Assessment of Personality – Abbreviated Scale

SCM - Structured Clinical Management

SFT – Schema Focussed Therapy

SP - Staff Participant

STDT – Short Term Dynamic Therapy

STEPPS - Systems Training for Emotional Predictability and Problem Solving

TFT – Transference Focussed Therapy

UK - United Kingdom

WHO – World Health Organisation

WLC - Waiting List control

List of Tables, Figures and Photographs

Tables

Table 1 – DSM Cluster Personality Disorder Types and Traits	23
Table 2 – Dichotomy of Qualitative and Quantitative Classifications	43
Table 3 – Qualitative Sampling Strategies	56
Table 4 – Search Terms	77
Table 5 –Inclusion / Exclusion Criteria	78
Table 6 – Appraisal of Expert Opinion Papers	81
Table 7 – An Overview of Personality Disorder Treatment Studies	84-86
Table 8 – Table of Interventions	89-90
Table 9 – Summary of Overall Quality Appraisal Ratings using the EPHP	P94
Table 10 – Qualitative Papers Overview	97
Table 11 – Author Expertise Table	102
Table 12 – Phase One Research Advisory Meeting Overview	124
Table 13 – Phase Two Research Advisory Meeting Overview	125
Table 14 – Demographics Table Healthcare Professional Participants	139
Table 15 – Demographics Table of Patient Participants	169
Table 16 – Synthesis Summary Table	.198-201
Table 17 – Recommended Education Matrix	221
Figures	
Figure 1 – Research Flow Chart	35
Figure 2 – Medical Research Council Framework	37
Figure 3 – Case and Theme Based Analytical Approach	60
Figure 4 – PRISMA Diagram	79

Figure 5 – Patient Needs Word Cloud103
Figure 6 – Linked Components of the Literature Review to the Qualitative
Studies
Figure 7 – Concern; Language and Sensitivities130
Figure 8 – Concern; Provision of Effective Treatments131
Figure 9 – IAPT Healthcare Professional Themes140
Figure 10 – IAPT Patient Themes170
Figure 11 – Commonalities Venn Diagram197
Figure 12 – Conflicts Venn Diagram197
Photographs
Photograph 1 – Early Post-it Note Familiarisation Process118

Abstract

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Doctor of Philosophy

Enhancing Understanding of the Experience of people with Common Mental Health Disorders and Co-Morbid Personality Disorder Traits who present to Primary Care IAPT Services.

9th August 2017

Background: There is strong evidence that many individuals presenting to primary care mental health services through 'Improving Access to Psychological Therapies' (IAPT) services have mild to moderate personality disorder traits and are less likely to benefit from routine IAPT treatment. Currently there are no specific treatments made routinely available to this patient group in IAPT services.

Aim: To understand the service provision for people who present to primary care IAPT services with common mental health disorders and co-morbid traits of personality disorder.

Methodology: The Medical Research Council (MRC) guidelines for developing and evaluating complex interventions with an emphasis on the theory and modeling phases were followed with three inter-related studies. These included a scoping study literature review and two qualitative studies exploring health professionals (IAPT Healthcare Professional) and service users (Patients) perspectives of working in, and using IAPT services. Analysis of the qualitative interviews was achieved using a thematic framework analysis approach.

Results: The scoping study literature review identified a lack of evidence based treatments and understanding of this patient group and their treatment in primary care IAPT services. Qualitative interviews were conducted with 28 health professionals and identified skills deficits for working with this patient group. A treatment gap was described between the interface of primary care and secondary care services for this patient group. Adaptions to clinical practice are suggested however significant deviation from IAPT core business was not supported. Qualitative interviews were conducted with 22 patients and found that this patient group valued flexible approaches to care and individualised treatment plans. A lack of choice and collaborative decision making process was described. Step 3 interventions appear to be preferred due to increased treatment duration, skill and flexibility of therapist. Patients commonly reported a deterioration in their mental health before seeking referral to IAPT services, often reaching points of crisis.

Conclusions: The scoping study literature review provided a rationale for further qualitative investigation of primary care IAPT treatments that led to studies 2 and 3. A synthesis of these results provides the necessary insight and depth of information required to provide recommendations for practice and identifies areas for future research. Four key recommendations have been proposed: (1) Education of the IAPT workforce (2) Clinical Interventions (3) Provision of Treatment at the Right Level and (4) National Recommendations.

Declaration

No portion of the work referred to in the thesis has been submitted in support of an application for another degree or qualification of this or any other university or other institute of learning.

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Dedications

This thesis is dedicated to my best friend and wife Sharon who has had unwavering belief and confidence in me. Your support and encouragement throughout my PhD has been commendable. I would also like to dedicate this to my two boys Bradley and Tobey who have never once complained when dad is working late into the evening. Collectively you are my world and I love you all with all my heart.

I also want to dedicate this to another special lady in my life my mum, who has sacrificed so much over the years to bring up 5 children with unwavering love and commitment. I do not know how you have done it, but you have done a fantastic job and we are all were we are in life now because of you and your resilience, determination and hard work which has rubbed off on us all.

The Author

Biography

I am a Registered Mental Health Nurse and a BABCP (British Association for Behavioural and Cognitive Psychotherapists) accredited Cognitive Behavioural Therapist with 22 years of experience working in mental health nursing. Various nursing and psychotherapy positions have been held throughout my career within a wide variety of settings. Throughout my career I have developed both my clinical and academic expertise, completing a BSc (Hons) 'The Psycho-social Management of Psychosis' and MSc 'Advanced Practice Interventions in Mental Health Care' both at the University of Manchester.

In my previous role as an 'Advanced Practitioner in Personality Disorder', I led the development of a multi-agency strategy for treating and managing people diagnosed with personality disorder that was the first of its kind in the UK. The strategy embraced the collaboration of people with lived experience of personality disorder and brought together an array of multi-agency partners who were working with people with personality disorder outside of secondary mental health services as key stakeholders. The main objective of the strategy was to raise awareness of personality disorder, challenge stigma and improve knowledge and responses. In excess of 600 training places were made available in the first three years of the strategy. Whilst working with multi-agencies, a common theme that was reported throughout this project was the lack of treatment available specific to personality disorder outside of secondary mental health services. Many reported how personality related symptoms and behaviours were allowed to escalate to crisis levels and only then would treatment be made available in specialist secondary mental health services. The same themes also emerged from a series of service user research development group meetings. The above deficit areas guided the development of this research idea and my enthusiasm to make a difference in this area.

Awards and Recognition

In 2011 I was awarded the prestigious National Nursing Times Award in 'Mental Health Nursing' and a Regional Trust Award in the category of 'Inter-Agency and Partnership Working'. Both awards were presented after I developed the above

multi-agency strategy from a blank canvas to become a nationally recognised model of good practice. This recognition is a further indication of how underdeveloped service responses are nationally for people with personality disorder outside of secondary mental health services (Lamph and Hickey, 2013). It was also through this recognition that I was encouraged to apply for an NIHR Clinical Doctoral Research Fellowship which was subsequently awarded £208,231(Appendix 1) and led to the commencement of my PhD at the University of Manchester (Appendix 2).

On completion of the fellowship I have taken up the position of 'Lecturer in Mental Health' at the University of Salford, Manchester but have maintained my clinical connections within the NHS. I am in the process of working with NHS colleagues to carry out a service evaluation of a new personality disorder pathway and also review the impact of a personality disorder carer support group, with a plan to jointly publish the findings.

Prior to commencing the PhD I published 4 papers 3 of which are personality disorder specific (Lamph, 2011; Lamph and Hickey, 2012; Lamph et al. 2014). I have an additional paper submitted for publication that outlines an evaluation of an e-learning personality disorder awareness programme. I was co-lead expert contributor on the development of this E-Learning Programme alongside Dr Mark Sampson, this programme is now hosted on the NHS National Learning Management System (NLMS) and is currently available to all mental health trusts across the North West of England.

The 2014 paper received a 'Highly Commended Paper Award in the Emerald Literati Network Awards for Excellence in 2015'. In 2016 I also won first prize for his poster presentation outlining this research at the 'NIHR Celebrating Clinical Nurse Researchers Conference'. More recently my PhD project was nominated as a finalist in the category of 'Outstanding Contribution to Patient and Public Involvement in Research Award at the NIHR Clinical Research Networks North-West Coast, Research and Innovation Awards 2017. In 2017 I was honoured to be appointed as the joint secretary for the British and Irish Group for the Study of Personality Disorder Conference.

Chapter 1

Introduction and Background

1.1 Introduction

This thesis provides an overview of the research completed whilst studying for a fulltime PhD in the Division of Nursing, Midwifery and Social Work, in the Faculty of Biology, Medicine and Health at the University of Manchester. The research was funded by the National Institute of Health Research (NIHR) via the Clinical Doctoral Research Fellowship Scheme. The aim of this work is to understand the service provision for people who present to primary care 'Improving Access to Psychological Therapies' (IAPT) services with common mental health disorders and co-morbid traits of personality disorder. The Medical Research Councils (MRC) framework for developing and evaluating complex interventions was used to guide this research (MRC, 2000; Craig et al., 2008a).

Personality disorder is often referred to a psychological development disorder that develops and is characterised by interpersonal difficulties, emotional regulation, impulse-control and self-image deficits (Lieb et al., 2004). Psychological, biological and social / environmental factors are thought to influence the development of personality disorder (Reichborn-Kjennerud, 2010).

Patients who present with personality disorder have until recently largely been excluded from services (Sampson et al., 2006) and can evoke negative feelings and responses from healthcare workers (Lewis and Appleby, 1988). For many years people with personality disorders were excluded from a multitude of services including healthcare (National Institute for Mental Health in England [NIMHE], 2003a). Psychological therapies have a growing evidence base for working with this patient group (National Institute for Health and Care Excellence [NICE], 2009) and the key features of the therapies include; a clear focussed and structured longer term intervention that is integrated with other involved services, with attention placed upon the therapist / patient relationship (Bateman and Fonagy, 2000).

1.2 Aims and Objectives

1.2.1 Overall Aim

To understand the service provision for people who present to primary care IAPT services with common mental health disorders and co-morbid traits of personality disorder.

1.2.2 Specific Objectives of the Thesis

The MRC framework (Craig et al., 2008a) for developing complex interventions has been used as an underpinning theoretical model to support the necessary preparatory work. Three separate but interrelated studies were conducted:

Study 1. Scoping literature review – To carry out a broad scan of the literature and critically examine the findings.

Study 2. Qualitative interviews with IAPT healthcare professionals - To explore the views and experiences of therapists working within IAPT services with this patient group.

Study 3. Qualitative interviews with patients - To explore and understand their needs and treatment experiences within IAPT services.

Results from studies two and three were synthesised to look collectively at both the IAPT healthcare professionals and patient participant results, hence strengthening any recommendations made.

1.3 Background

1.3.1 Personality Disorder

Personality Disorder (PD) is a bio-psycho-social developmental disorder that affects people's ability to function in their everyday lives. It is often attributed to significant childhood experiences and trauma (NIMHE, 2003a). A variety of

factors have been identified that can be attributable to the development of personality disorder these include: biological, psychological, social and environmental factors, hence determining individual vulnerability is complex and multi-faceted (Sampson et al., 2006).

Personality disorder has been defined as:

"An enduring pattern of inner experience and behaviour that deviates markedly from the expectations of the individual's culture, is pervasive and inflexible, has an onset in adolescence or early adulthood, is stable over time, and leads to distress or impairment."

(American Psychiatric Association [APA] 2013, page 645).

Personality disorder is often difficult to identify and overlooked due to the high comorbidity of conditions such as anxiety and depression, that are often viewed as separate problems (Department of Health [DOH], 2009). Co-morbidity refers to the occurrence of more than one identifiable mental health difficulty that can cause complexity to the clinical presentation. People with personality disorder are often undetected and will present across a range of medical and multi-agency settings. Due to this lack of detection, they are often treated ineffectively and in some cases an iatrogenic effect can occur (Tyrer et al., 2015).

Personality disorder is one of the most excluded and stigmatised of all mental health problems due to a lack of knowledge and recognition of the condition (DOH, 2009; NIMHE, 2003a; NICE, 2009a; HM Government, 2011). It is a pejorative label that has been used by both services, health professionals and to a lesser extent the public to exclude people, instead of the diagnosis promoting understanding, support and treatment (Tyrer et al., 2015).

1.3.2 Presentation and Diagnosis

There are two diagnostic manuals used to confirm diagnosis in the United Kingdom (UK), the 'Diagnostic and Statistical Manual of Mental Disorders' (DSM 5) (APA, 2013) and the 'World Health Organisation' (WHO) diagnostic manual

called the 'International Classification of Diseases Manual' (ICD) (Coid et al., 2003). The ICD-11 remains in development (Tyrer et al., 2015) and is likely to be released in 2018. The DSM 5 is the most frequently used diagnostic manual in clinical research and defines ten different types of personality disorder across three clusters, which are identified below (Table 1).

Table 1 – DSM Cluster Personality Disorder Types and Traits

Personality Disorder Ty	pes / Clusters Typical traits / Characteristics	
Clus	ster A (Odd or Eccentric Behaviour)	
Paranoid	Paranoia / distrust of others	
Schizoid	Flattened affect, socially detached	
Schizotypal	Uncomfortable socially, eccentric and cognitive distortions	
Clust	Cluster B (Dramatic, Emotional or Erratic)	
Borderline	Impulsive, interpersonal and emotional difficulties, poor self-image and maladaptive coping responses	
Anti-Social	Lack of remorse, disrespect for rules, authority and the rights of others	
Histrionic	Highly emotional and attention seeking	
Narcissitic	A need for admiration, grandiose self-importance and lack of empathy for others	
Cluster C (Anxious Fearful Behaviour)		
Avoidant	Poor self-esteem, social recluse, anxious	
Dependant	Clingy and dependant on others, needs to be taken care of	
Obsessive	Perfectionism and obsessively orderly and controlling	
Compulsive	without the anxiety cognitive component seen commonly in obsessive compulsive disorder	

Table adapted from Sampson et al (2006).

Personality disorder is viewed as a long standing and enduring way of being. Remittance of personality disorder has been described as occurring over time with or without intervention, although social adjustment remains poor (Zanarini, 2008). It has been suggested that Cluster B type personality disorders will improve naturally, whilst Cluster A and C personality disorder are less likely to change (Yang et al., 2010).

1.3.3 Epidemiology

Personality disorder is highly prevalent affecting up to 13% of the population (DOH, 2009). It is estimated that 1 in 4 General Practitioner (GP) consultations in deprived areas will be with people with personality disorder related difficulties (NIMHE, 2003a, Moran et al., 2000). Borderline Personality Disorder (BPD) affects 1-2 % of the population (Lieb et al., 2004) and are frequent and high users of specialist mental health and general health services (NICE, 2009a). However avoidant or paranoid personality disorders are most likely to present to primary care. Both avoidant and paranoid personality disorder present to primary care with an equal 8.3% prevalence rate (N=303), however all of the ten types of personality disorder will be seen in primary care populations (Moran et al., 2000).

The most common presentations to criminal justice and specialist secondary mental health services are those with BPD and Anti-Social Personality Disorder (ASPD) (Kendall et al., 2009). The National Institute for Health and Clinical Excellence (NICE) developed guidance for working with people with BPD (NICE, 2009a) and Anti-social personality disorder (NICE, 2009b). People with BPD are at particular risk of suicide, up to 10% will die from suicide, which is 50 times higher than the general population (Lieb et al., 2004). Most of the research literature for treatment are directed at those with BPD in specialist secondary services, suggesting that the remaining 12% of people with other types of personality disorder in the general population receive very little in the form of evidence based personality disorder specific interventions (DOH, 2009; Lamph, 2011).

Personality disorder is a significant public health concern particularly in criminal justice settings, with estimates suggesting that 66% of the prison population could be diagnosed with a personality disorder (Seymour, 2010). A systematic review which included 23,000 prisoners found anti-social personality disorder was the most frequent type with a prevalence rate of 47% (Fazel and Danesh, 2002).

Accurately estimating prevalence rates in personality disorder has proven difficult. Coid et al (2003) critiques the estimation of prevalence rates, stating that they are not being accurately defined. Instead ambiguities in the validity and reliability of

personality disorder diagnosis and its identification, impacts on the accurate reporting of prevalence. This is further marred by the high levels of co-morbidity of people with personality disorder, including a crossover of personality disorder types, clusters and other common mental health conditions (Coid et al., 2003).

1.3.4 Impact of Personality Disorder

Personality disorder has a profound impact on society, the individual sufferers and their families (NIMHE, 2003a). Personality disorder is clearly not confined to specialist secondary mental health services, but instead is seen across a wide range of services (DOH, 2009) and it presents a significant economic burden on both secondary and primary care health services (Palma, 2006). Research into the financial impact of personality disorder in primary care patients identified that co-morbidity of personality disorder and common mental health disorder significantly impacted on increasing combined mean health and non-health costs (Rendu et al., 2002).

The personal impact of personality disorder can be damaging to individuals and society, especially when the disorder goes unrecognised and untreated. Those with personality disorder are more likely to have social difficulties including health damaging behaviours (substance / alcohol abuse), higher incidences of offending behavior, relationship difficulties, housing problems, and reduced academic and occupational performance (NIMHE, 2003a). People with personality disorder are known to use a vast array of multiple services. This creates a resource burden to services supporting or managing them with little knowledge of personality disorder or available evidence based treatments to turn too, particularly outside of secondary mental health services (Yang et al., 2010).

A high prevalence of people with personality disorder have been identified to be in receipt of disability living allowance; further demonstrating the negative impact that personality disorder has on public health and occupational functioning (Knudsen et al., 2012). Higher levels of unemployment are seen in those with more severe personality disorder. Those with lower levels of personality disorder severity are recognised to have significant social and occupational functioning impairment caused by their difficulties (Yang et al., 2010).

1.3.5 Treatments

The provision of evidence based psychological treatments has increasingly become available for people with complex / severe personality disorder and high levels of risk to self or others in specialist secondary care mental health services and forensic services (NIMHE, 2003a; NICE, 2009a). There is a growing body of evidence for the effective psychological treatment of personality disorder with particular attention focused on BPD (Stoffers et al., 2012). NICE (2009a) provided evidence based guidelines to support and guide the effective treatment of people with BPD. The focus however was directed to specialist secondary care long-term treatments (NICE 2009a). A 6 year surveillance review (NICE, 2015) was carried out and found nothing new to add to the original guidance.

Evidence based treatments are only available in the current system to those who meet criteria for a specialist secondary service treatment. This has been attributed to fears of overstretching services due to the high incidence of personality disorder in the general population (Yang et al., 2010). There is no clear guidance for less severe symptomatology or specifically the other types of personality disorders (Paris 2013; NICE 2009a) with the exception of the anti-social personality disorder guidance (NICE, 2009b). NICE (2009a) recommended psychological treatments in excess of 12 months duration. A systematic review was conducted that explored the impact of treatment frequency and duration, on outcomes of people with BPD. It was identified from this study that when treatments are offered in a condensed format with a group component and more than once weekly sessions, that this impacts positively on patient outcomes (Omar et al., 2014).

1.3.5.1 Specialist Secondary Service Treatments

Effective evidence based treatments that are provided in specialist secondary services for personality disorder, have been recommended by NICE (2009a) and include;

Dialectic Behavioural Therapy (DBT), which is underpinned by a combination of cognitive behavioural interventions and mindfulness meditation (Linehan, 1993).

In a recent Cochrane systematic review of personality disorder treatments, Stoffers et al (2012) found DBT to have the strongest evidence.

Mentalisation Based Therapy (MBT) is underpinned by psychoanalytic approaches and has in recent years built up momentum to be seen as the leading intervention of choice for people with personality disorder (Bateman and Fonagy, 2012). However, it does not yet have the depth of replication studies that present in the DBT literature with only two RCT's included in the Cochrane systematic review (Stoffers et al., 2012).

Schema focused therapy and transference focused therapy are both effective interventions for the psychological treatment of people with BPD, however further replication studies are required (Stoffers et al., 2012). Schema focused therapy is underpinned by Cognitive Therapy but is particularly focused on early childhood and developmental experiences (Young et al., 2003).

Cognitive Behavioural Therapy for Personality Disorder (CBT-PD) is also indicated as an effective treatment for borderline personality disorder and avoidant personality disorder (Davidson, 2008). An RCT was carried out to test the effectiveness of CBT-PD in the 'Borderline Personality Disorder Study of Cognitive Therapy' (BOSCOT) (Davidson et al., 2006). This study showed a decline in many of the problematic symptoms associated with BPD such as self-injury, distress and dysfunctional cognitions. Treatment lasted on average for 27 sessions, each lasting for an hour and taking place over a 12 month period, however results showed minimal impact on social functioning. One of the main benefits from this trial is described in its ability to easily train staff who already have cognitive behavioral therapy experience (Davidson et al., 2006). A six year follow up found that just over 50% no longer met BPD criteria. No significant cost benefits were reported however it was argued that projected longer term costs of overall service use displayed potential cost benefits (Davidson et al., 2010).

Dialectic behavioural therapy and MBT are long term psychological interventions using a mixture of individual and group-based therapies and are delivered in specialist secondary services (Richards et al., 2012). Cognitive behavioural therapy, schema focused therapy and transference focused therapy are usually

delivered on an individual basis with a focus on cognitions that are often referred to as intellectual processes, thinking, reasoning and memory (Williams, 2003).

Stop and Think therapy is a problem solving therapy that is underpinned by problem solving skills development (McMurran et al., 2008). A recent RCT evaluated a short term intervention (4 Sessions of Individual Psycho-education and 12 problem solving group interventions) compared against treatment as usual, which was not specified. This trial was prematurely stopped after a number of adverse events were reported in the intervention group. The adverse events were attributed to the sudden end to support when therapy finished with no follow up and also the lack of any other supported comprehensive care package. From the results it is recommended that this intervention should not be used for patients with a diagnosed personality disorder in mental health services, this study was carried out within a specialist secondary service community mental health population (McMurran et al., 2016).

Other problem solving therapies have however shown promising results; Systems Training for Emotional Predictability and Problem Solving (STEPPS) (Black et al., 2004) and Structured Clinical Management (SCM) (Bateman and Krawitz, 2013). Neither however can be described as short term and in SCM alongside problem solving is the addition of a comprehensive package of support.

Furthermore, there is a small but growing body of evidence to support the use of other novel third generation cognitive behavioural therapy approaches such as 'Mindfulness based Cognitive Therapy' for the treatment of personality disorder (Sachse et al., 2011) and acceptance and commitment therapy (Chakhssi et al., 2015). Many of the newer generation treatments often have a key group component to the intervention (Sachse et al., 2011; Chakhssi et al., 2015). Group interventions can be particularly useful in working in real time on interpersonal relationships and the challenges social interactions can place upon people with personality disorder (Linehan, 1993).

Stoffers et al (2012) argued that although there is a growing body of evidence supporting the treatment of BPD there is a need for more research, replication of studies and more robust evidence is required before firm conclusions can be

reached. The existing evidence based personality disorder treatments are focused on treatment for people with severe presentations in specialist secondary services. It is however unclear if such long term treatments are necessary for those with less severe presentations such as those who present to primary care (Paris, 2013). Hence there is a need to develop interventions that are shorter term to determine their clinical and cost effectiveness.

1.3.6 Primary Care and IAPT

At a primary care level a high prevalence of personality disorder is reported (Moran et al., 2000; Hepgul et al., 2016). To date there is a lack of research in the primary care treatment of patients with personality disorder or for those with less severe, co-morbid or emerging difficulties (Paris, 2013; DOH, 2011). Research is therefore required to explore the impact of shorter term interventions for personality disorder, as currently there is no evidence to support short term interventions being effective (Paris, 2013; Omar et al., 2014).

1.3.6.1 Primary Care

Primary care mental health services include: general practitioner care, third sector counselling and IAPT services. The role of primary care mental health services should ensure that services are easily accessible and provide short term treatments that locally meet the needs of the general population (World Health Organisation (WHO) and Wonca Working Party on Mental Health, 2008). Those who present to primary care with co-morbid personality disorder will often seek out support for their secondary difficulties, such as, depression or anxiety disorders, but will rarely request or receive support for their underlying personality disorder related difficulties (Coid et al., 2009).

1.3.6.2 Improving Access to Psychological Therapies

IAPT was established in 2008 (DOH, 2008) and is one of the most ambitious English initiatives to increase access to evidence based psychological therapies to a general population (Gyani et al., 2013). It was established to predominately treat depression and anxiety disorder in a timely manner and to improve access to psychological treatments (Gyani et al., 2013). The most common form of treatment in IAPT services is cognitive behavioural therapy (Richards et al., 2012). However in recent years the treatment provision has expanded to include other evidence based interventions and modalities of treatment (Radhakrishnan et al., 2013).

An naturalistic cohort study explored the impact of co-morbidity in IAPT (N=147) 18% were found to meet criteria for borderline personality disorder and 69% were described as being at high risk of personality disorder (Hepgul et al., 2016). The results from Hepgul et al (2016) whilst specifically investigating the presence of IAPT co-morbidity, had a much smaller sample than the earlier described primary care study (Moran et al., 2000). People who present to IAPT with co-morbid personality disorder traits, on the basis of screening positively on the 'Standardised Assessment of Personality – Abbreviated Scale (SAPAS), are also known to have poorer treatment outcomes (Goddard et al., 2015; DOH, 2011). Despite the high prevalence of personality disorder and the identified poorer outcomes, personality disorder recognition, awareness and treatments are not routinely covered in IAPT staff core training. This may be due to the lack of any evidence based treatments identified for delivery at a primary care level. This highlights an important gap in service and treatment provision for personality disorder at a primary care level and the need for further exploration (DOH, 2011).

The DOH (2011) set out a four year plan of action to further extend the IAPT programme outlining the need to expand access to psychological interventions for people with complex mental health difficulties including personality disorder. The following key principles guide this plan:

- Easier access to services
- Improved clinical recovery and improvement
- Improved educational, social and occupational achievements
- Increased patient choice and satisfaction.

Improving access to psychological therapy based personality disorder treatments would enable multi-agencies to be more equipped to support those with personality disorder using their services (Huband and Duggan, 2007).

1.3.6.3 The Stepped Care Model

Primary care IAPT services provide psychological interventions using a stepped care model which commences at the lowest possible dose of psychological intervention to achieve a health benefit (Gilbody and Bower, 2005). Stepped care is defined as a self-correcting model. When the lower level treatments are ineffective, patients will be escalated to the higher steps to receive a more intensive therapy. The stepped care model is a fundamental component of IAPT services that ensures the provision of time limited accessible treatments in the least intensive format to provide a cost effective health benefit. National Institute for Health and Care Excellence (NICE) guidelines recommend the use of stepped care for many disorders including depression and anxiety but no such model has been developed for personality disorder (DOH, 2008).

Step 1 is described as GP support and treatment. Step 2 when discussed in the context of IAPT services provides short term interventions between 6-8 half hour sessions of CBT informed directed self-help delivered by a Psychological Wellbeing Practitioner (PWP) and often referred to as a 'Low Intensity Treatment'. Step 3 would generally offer between 12-20 hour long sessions of CBT provided a Cognitive Behavioural Therapist or Psychologist and often referred to as a 'High Intensity Treatment' (Richards et al., 2012).

The stepped care model provides different levels of treatment intensity. Progressing through the steps can be achieved in two different formats:

- 1. Stepped care model, 2. Stratified model.
 - Stepped care model This is a self-correcting model as patients are stepped up to more intensive therapies if they are not progressing at a lower level.
 - 2. Stratified model This model looks to direct patients to the correct level of interventions based on levels of complexity, risk, diagnosis or other criteria that deem the lower levels as ineffective. However this model is constrained by the need to identify and accurately understand the patient needs and the requirement to provide a rationale for the bypassing of the

lower more cost effective steps (Richards et al., 2012). Currently only Post Traumatic Stress Disorder (PTSD) and social anxiety have been identified as suitable to bypass Step 2 and enter IAPT at Step 3 but this can vary from service to service (Gyani et al., 2013).

A correlation has been identified between IAPT services that more frequently step patients up as having a positive impact on recovery rates, highlighting the importance of adherence to the model and the full use of the service from low intensity to high intensity when appropriate (Gyani et al., 2013).

Specialist secondary service treatments are usually delivered at Step 4 or 5 interventions dependent on the configuration of the service and the particular disorders being treated.

1.4 Justification and Rationale for the Research

The development of psychological treatments for people with personality disorder, are required for primary care (DOH, 2011). A high prevalence of personality disorder is identified (Moran et al., 2000; Hepgul et al., 2016) and ineffective treatments are currently being offered in IAPT to this patient group (Goddard et al., 2015; DOH, 2011). It is also reported that the needs of this patient group are unmet (NIMHE, 2003a). These unmet needs for some will continue to go unaddressed and will continue to be treated in primary care without escalation to specialist secondary services. For others unmet needs may result in an escalation in their problems, hence leading to an unnecessary transition to specialist secondary services for treatment directed specifically at their underlying personality disorder (Paris, 2013; DOH, 2009).

It is anticipated that by understanding and exploring this field of enquiry and providing the preparatory work to develop a more accessible primary care based psychological intervention, that this will enable a more timely development of life coping skills to aid and support resolution of the common problematic symptoms and difficulties that present across the different types of personality disorder. Providing an earlier intervention specific to meeting these difficulties, it is anticipated will reduce the negative impact of personality disorder on service

resources and on the individual and will improve the effectiveness of IAPT services for this patient group.

Most research attention to date has been placed on longer term interventions specifically directed towards the treatment of Cluster B disorders, which it is argued will over time improve in a high proportion of cases without intervention (Zanarini, 2008; Yang et al., 2010). However Cluster A (Paranoid, Schizoid and Schizotypal personality disorders) and Cluster C (Avoidant, Dependant and Obsessive Compulsive personality disorders) are less likely to improve without intervention (Yang et al., 2010) and it is this patient group that are most likely to present with personality disorder in primary care and currently receive treatments that are ineffective (Goddard et al., 2015).

Furthermore, Paris (2013) strongly challenges the notion of 'no short term treatment' for people with personality disorder, suggesting instead that people with personality disorder fluctuate in their presentation and that shorter-term treatments should be provided via a stepped care approach when required. The evidence base for longer term interventions verses shorter term interventions are inconclusive, under researched and by sticking rigidly to this guidance only causes a bottle neck effect and waiting lists (Paris, 2013).

There is no evidence based treatments available for personality disorder in primary care IAPT services. Therefore attention is required to address the development of interventions and treatment. However there is a substantial amount of preparatory work required (DOH, 2011). The preparatory work undertaken within this research will begin to address these gaps by gaining a greater understanding of the service provision for people who present to primary care IAPT services with common mental health disorders and co-morbid traits of personality disorder. This will provide a thorough gathering of evidence, identification and theory development that will inform the development of interventions or recommendations for practice. This research is a timely and an important addition to the growing body of literature.

Chapter 2

Methodology

This chapter will provide details of the aims and objectives of the study and justification of the theoretical framework and research methods used.

2.1 Aims and Objectives

2.1.1 Overall Aim

To understand the service provision for people who present to primary care IAPT services with common mental health disorders and co-morbid traits of personality disorder.

2.1.2 Specific Objectives of the Thesis

The MRC framework (Craig et al., 2008a) for developing complex interventions has been used as an underpinning model to support the necessary preparatory work. Three separate but interrelated studies were conducted (Figure 1):

Study 1. Scoping review – To carry out a broad scan of the literature and critically examine the findings.

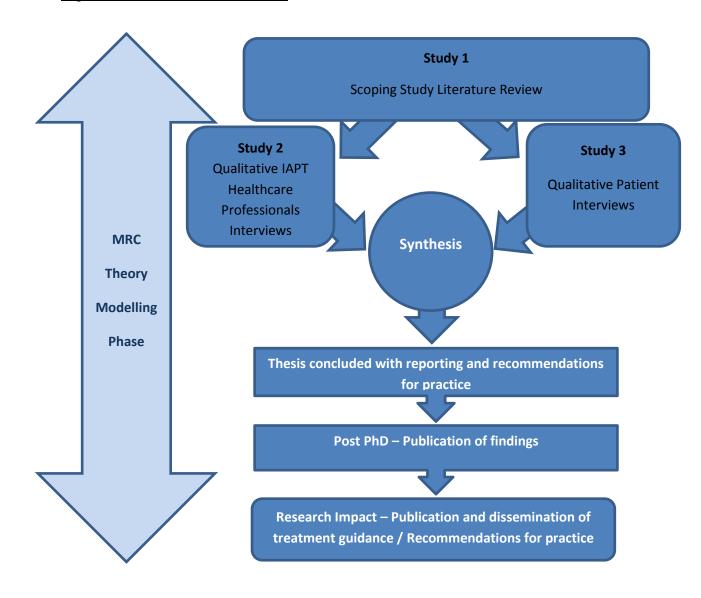
Study 2. Qualitative interviews with IAPT healthcare professionals – To explore the views and experiences of therapists working within IAPT services with this patient group.

Study 3. Qualitative interviews with patients – To explore and understand their needs and treatment experiences within IAPT services.

Study 1 informed the development and rationale for studies 2 and 3. Studies 2 and 3 were synthesised to inform the development of treatment recommendations for practice. This thesis will conclude once synthesis is reported and recommendations for practice emerge within the discussion chapter.

The flow chart (Figure 1) shows how the proposed series of inter-related studies interlink. This particular research is focussed in the developmental phase of the MRC framework and guides this preparatory research.

Figure 1 - Research Flow Chart



2.2 MRC Framework for Developing and Evaluating Complex Interventions

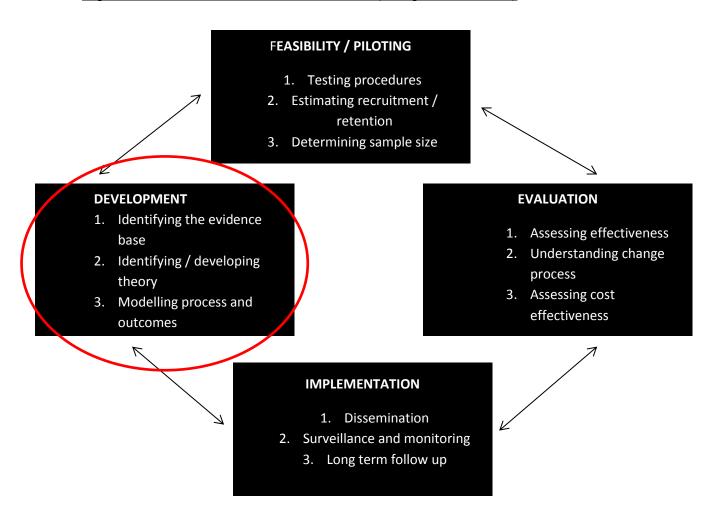
The Medical Research Council's (MRC) framework for complex interventions was developed to provide researchers with a structured phased approach to developing and evaluating complex interventions. Rarely will simple interventions occur in clinical healthcare settings, complex interventions are identified when various interacting components to an intervention present (Campbell et al., 2000). The MRC framework provides a model that accounts for complexities and

interacting components hence ensures that complex interventions are thoroughly developed and rigorously evaluated in research (Campbell et al., 2000).

The framework was first developed in 2000 (MRC, 2000) and then revised and updated in 2008 (Craig et al., 2008a). Within the original framework limitations were identified that led to the revised model, which included the need to pay greater attention to preparatory work in the development and piloting phases of research trials (Craig et al., 2008b). The original MRC framework was criticised for following a linear process to the development of interventions, despite this not being the intention it was revised. The revised framework advocated that the model should be viewed as following an 'iterative process' that may involve repetition of phases (Campbell et al., 2000). Hence a cyclic diagram has been used to provide an overview of the model and its phases taking account for this. The developmental phase is circled as this is the phase that has been used to guide and support the preparatory work being undertaken in this research study with particular focus on the identification of evidence and identification and theory development stages (Figure 2).

[Intentional Space]

Figure 2 – Medical Research Framework (Craig et al., 2008a)



The phases of the MRC framework can be used interchangeably and also revisited at any stage to fine tune interventions or research proposals, each phase will be described below:

2.2.1 Developmental Phase

With any new or refined intervention the first task is to identify any existing and supportive evidence base (Study 1). A focus is placed upon the identification of an intervention that has enough evidence and justification to deem its evaluation as being worthy of further investigation (Craig et al., 2008b).

Identifying and developing theory is achieved by linking in with those who the research will impact upon, for example those who are involved in the delivery of interventions (Study 2) and the recipients of interventions (Study 3). Developing a theoretical insight that is reflective of known theory and new knowledge informs

the development of acceptable research proposals. This process should be carried out even when the intervention of choice is well established (Craig et al., 2008a). Modelling is the final component of this phase and is focussed upon refinement of interventions and research proposals, but can also include the exploration of economic benefits and the value of proceeding onto a pilot or a feasibility study to evaluate the intervention (Craig et al., 2008b).

2.2.2 Feasibility and Piloting Phase

This phase enables the developed intervention to be trialled to measure acceptability and feasibility of the proposed interventions. It also provides an opportunity to facilitate estimations of effect size for larger definitive trials and effectiveness of interventions before progression to larger scale evaluations (Craig et al., 2008a). The piloting component of this phase can include small exploratory clinical trials to refine the intervention and further explore the consistency of its application, acceptability and feasibility in routine clinical practice. This can also allow for an early comparison of effectiveness via a control group. Additionally feasibility of the intervention can be investigated by exploring its acceptability to those in receipt of the intervention, those delivering it and the service providers (Campbell et al., 2000). Mixed methods design is recommended at this stage to understand and explore any potential constraints and complications (Craig et al., 2008a).

2.2.3 Evaluation Phase

Definitive clinical trials are carried out to measure the effectiveness of the developed complex interventions. Guidance suggests that choosing the correct methodological approach is of paramount importance, however, randomisation is recommended to protect for recruitment bias (Craig et al., 2008b). Randomised controlled trials are recommended as the most robust measures of efficacy for use in this phase (Campbell et al., 2000). However, there will be times when alternative methodologies are more appropriate such as stepped wedge designs where interventions are phased in and control groups come from those on the waiting list (Hemming et al., 2015).

2.2.4 Implementation Phase

Once definitive trials have been conducted, there is a need to disseminate and share the findings of the research and evaluate the effectiveness within routine clinical practice. This phase relates to the post research trial outputs, such as supporting the implementation of effective interventions into routine clinical practice and also in assessing the longer term outcomes and impact (Campbell et al., 2000).

2.2.5 Unexpected Research Outcomes

In research, outcomes often emerge that are unexpected or in conflict with the hypothesis. This can lead to confusion and a search for evidence to provide a rational for such outcomes. Further analysis is often required to explore the application of the intervention, the intervention development and the design of the trial. The MRC framework provides a model to reduce this occurring by the following of systematic phases, however unexpected outcomes can still arise. The MRC framework provides opportunities for regular review and reflection within the phases. This provides scope to make early refinements to studies and to carryout reiterations or discontinue research in a timely manner if unexpected outcomes, acceptability or feasibility issues arise (Campbell et al., 2007).

2.2.6 Limitations of the MRC Framework

Despite the acknowledged influence and strengths of the MRC framework it has limitations (Hardeman et al., 2005). It has been criticised for being open to the interpretation of the researcher using it, which can result in a lack of consistency in its application to practice (De Silva et al., 2014). There is limited guidance outlining how data gathered is synthesised, and there is a lack of detail of how to develop complex interventions, instead the focus appears to be on outlining the structured phases (Moore et al., 2015). A broad definition of complex interventions is provided within the framework that could be further refined (Hawe et al., 2004). Refinement could lead to further explanation of groupings of the different more specific complex interventions. This may be useful as this could lead to additional guidance outlining and refining best practice in the development

of specific complex interventions such as 'psychological interventions'. More specific complimentary guidance has been developed in the areas of surgical (McCulloch et al., 2009) and trials of group interventions (Hoddinott et al., 2010), but there has been no specific guidance for mental health interventions. However the broader definition of complex interventions currently in place allows for innovation and creativity without the added constraints of an overly detailed and field specific guidance.

Whilst the MRC framework has been hugely influential and been used in various research studies as an underpinning model (Mairs et al., 2016; Lovell et al., 2008; Corry et al., 2013) there remains a lack of evidence to support whether it has actually improved or assisted the development of more acceptable and feasible complex interventions in routine clinical practice. It should be noted however that the main intention of the original framework was to provide good practice guidance to researchers (Craig and Petticrew, 2013). Nevertheless, no new evidence or evaluations specific to the effectiveness of this framework have been reported (Craig et al., 2013a).

2.2.7 Rationale for using the Framework

The MRC framework strongly advocates the need for preparatory work being undertaken prior to larger scale clinical trials (MRC, 2000; Craig et al., 2008a; 2008b; 2013). The framework is frequently used to support the development of complex interventions (Craig and Petticrew, 2013) and is widely used in health service research (Corry et al., 2013). Using the framework has the potential to improve the generalisability of research outputs and have a greater influence on policy and practice (Bonnell et al., 2006). Furthermore it allows for the refinement and fine tuning of interventions via the structured developmental phases (Craig et al., 2008a).

Overlooking the earlier phases in the development of a complex intervention and not establishing a strong foundation could result in many problems that can impact upon credibility and transferability. The risk of which however can be reduced if careful and methodical planning that this framework encourages is followed. In order to progress onto larger scale clinical trials it is recommended that the

development, feasibility and piloting preparatory stages are complete. Hence providing justification for the complex intervention having a 'worthwhile effect' (Craig et al., 2013a). Preparatory research sets the foundations for future research, practice and the future implementation of evidence-based recommendations (Hoddinott, 2015). Complex intervention should be developed that have the potential to be embedded into clinical practice (Richards and Hallberg, 2015).

When the literature heralds many unanswered questions the use of qualitative research is recommended to address this deficit (MRC, 2000; Craig et al., 2008a; Ritchie et al., 2014). Qualitative research can assist in the development of new acceptable and feasible interventions. Completing a thorough exploration of the developmental phase and preparatory work can provide results and valuable insights that guide the development of complex interventions, hence establishing if further research and evaluation is justifiable and required (Campbell et al., 2007; Richards and Hallberg, 2015).

Using the MRC framework to guide preparatory work enables this to be achieved by fully understanding the context, the problem, identification and optimisation of any potential solutions or interventions, the implementation and the evaluation.

2.3 Methodological Approaches

Within this section 'epistemology' the theory of what we know (Pope and Mays, 1995) and 'ontology' the study of how we interpret the social world (Ritchie et al., 2014) and 'philosophical paradigms' will be discussed. An overview of quantitative and qualitative research methodologies will also be discussed.

2.3.1 Positivism, Post Positivism and Interpretivism Paradigms

Prior to the development of the philosophical stances in research being defined, research was referred to as 'logical reasoning' and based on assumptions of how the world or phenomenon is received, witnessed and understood (Trochim, 2000). Epistemology is the philosophy of knowledge hence underpins what we know (Pope and Mays, 1995). Ontology is the study of what is known about the social

world and how this is interpreted, whilst 'methodology' is specific to the understanding of how and what we do (Ritchie et al., 2014). There are many different philosophical paradigms 'schools of thought' in research, however, the three most influential approaches are: Positivism, post positivism and constructivism / interpretivism (Trochim, 2000).

Positivism is concerned with the understanding of knowledge and is focused on the interpretation of what can be directly seen or observed (Trochim, 2000). Positivism uses a deductive reasoning approach meaning that the information sought and gathered is predetermined or led by hypothesis testing (Pope and Mays, 1995). In the middle of the 20th century there was a significant and important shift in research philosophy with the advent of 'post-positivism'. Post positivism is a refinement to the positivism stance and is underpinned by the view that nothing can be certain instead all theory can be challenged. It is the process of reflection, challenging and critique that the post positivist stance argued increases credibility of research findings, as nothing is absolute and it is argued that total objectivity which is associated with positivism should be contested (Trochim, 2000; Ritchie et al., 2014).

The 'interpretivism' stance was developed in opposition to the positivism stance and was inspired by early writing of 'Immanuel Kant' (Gregor and Timmermann, 2012) and 'Wihhelm Dilthey' (Parry, 1997). Interpretivism is focused upon reflection, the interpretation of the social world and lived experiences of both participant and researchers understanding of a given phenomenon. Whilst lived experience of participants who hold the knowledge of enquiry is of paramount importance so too is the ability of the researcher to be reflective and to attempt to adopt a neutral stance in interpretation of the data (Ritchie et al., 2014). Hence, it is important for the researcher to recognise the challenges that present by displaying transparency in analysis and reporting of any data (Taylor and Francis, 2013). Research is often described as falling into one of the two dichotomous classification's, 'qualitative' and 'quantitative' research (Table 2).

[Intentional Space]

Table 2 – Dichotomy of Qualitative and Quantitative Classifications

	Qualitative	Quantitative
Methods	Observation / Interviews	Experimental / Surveys
Research question	What? How? Why?	How much? How many?
Reasoning approach	Inductive (Bottom up)	Deductive (Top down)
Sampling	Theoretical	Statistical
Outcome measures	Interpretation / Meaning	Standardised
Strengths	Validity	Questionnaires
Aims of the method	Trustworthiness	Reliability / Consistency
		Verification

Table adapted from Pope and Mays (1995); Paley and Lilford (2011).

Positivism and post positivism are commonly associated with quantitative research. Conversely, qualitative research methods fall within the 'interpretivism' paradigm and are viewed as opposite to positivism in that the focus is upon the social world and the interpretation of phenomenon (Ritchie et al, 2014). Qualitative research largely uses an inductive reasoning approach. Deductive reasoning is led by hypothesis testing (top down), conversely inductive reasoning is led by observation which then progresses to a hypothesis (bottom up) (Pope and Mays, 1995).

Research provides the opportunity to find out new knowledge using systematic, robust and rigorous approaches that enables the gathering of data and data analysis to answer questions and provide new knowledge (Parahoo, 1997). Over the past century research has significantly evolved, during this time pioneering researchers have developed a multitude of specific research methodologies and approaches.

In order to provide high quality, effective and efficient clinical services, research is of great importance. A sound foundation for practice is based on the research evidence base informing practice. Conversely, without practice in mind, research would also lack foundation or direction (Cormack, 2000). Often research is focused on testing the effectiveness and efficiency of complex interventions in

healthcare without firstly conducting the preparatory ground work in research (Campbell et al., 2007).

2.3.2 Quantitative Research

Quantitative research is concerned with the 'how much, how many' questions and is often focused on effectiveness and efficiency of interventions (Ritchie et al., 2014; Parahoo, 1997) however has also been described as being interested in 'cause and effect' (Cormack, 2000). Within quantitative research there are various study designs that can be used including, randomised controlled trials, feasibility pilot studies, quasi-experiments (Parahoo, 1997). Given that this current study is not concerned with cause and effect or quantification, but instead is an enquiry of a social phenomenon and understanding of people and their experiences, quantitative approaches were discounted and are not described in any depth.

2.3.3 Qualitative Research

Qualitative research is concerned with the detail, process and understanding of a phenomenon (Green and Thorogood, 2014; Hoepfl, 1997). Qualitative research has the ability to bring about change via the discovery of new knowledge (Taylor and Francis, 2013). It can often be identified by the research question that a particular study is trying to answer with the 'What, How, Why' questions, which are fundamental to qualitative research instead of the 'how much or how many' questions (Ritchie et al., 2014).

2.3.4 Mixed Methods

Qualitative and quantitative research approaches can be used independently of each other or complimentary to each other which is often referred to as taking a 'mixed methods approach' (Taylor and Francis, 2013). Health service researchers are described as being more concerned with using the methods best placed to answer a question rather than being constrained to one of either a polarised qualitative or quantitative paradigm (Bowling, 2002). The choice of research methodology should be decided upon once the research questions are defined (Punch, 2014).

Whilst a mixed method approach could have been adopted, with the use of a quantitative survey (for example) to determine the effectiveness of the interventions currently being provided to this patient group, in the IAPT service. This was discounted as it was felt that the focus of this study should be on gaining a thorough insight to enhance the understanding of people who present with comorbid traits of personality disorder and that a qualitative focus would be the most suitable approach. Within the given timeframe of this research, it was felt that doing mixed methods would have been unachievable.

2.3.5 Qualitative Methodological Approaches

An overview of three considered qualitative approaches: Ethnography, Phenomenology and Grounded Theory, will be provided followed by an overview and justification of methods selected.

2.3.5.1 Ethnography

Ethnography emerged from the field of anthropology 'the study of mankind' and its roots were set in the immersed study of cultures in their naturalistic settings (Taylor and Francis, 2013). This type of qualitative research is conducted in natural environments and settings of the area of interest and uses observational processes, allowing the participants to share in their own ways, information that will inform the area of interest by sharing their experiences and viewpoints (Cormack, 2000). Ethnographic observation is often referred to and requires the researcher to use a range of observational methods to understand a particular phenomenon which could include interviews, visual observations, photographs, drawn pictures. It requires the researcher to immerse oneself into the field of enquiry hence providing an insider's viewpoint (Silverman, 2011).

2.3.5.2 Phenomenology

Phenomenology is a philosophical stance that was introduced by Husserl (1970). Phenomenology is explained as the study of the views, perceptions and experiences of individuals or groups within a specific phenomenon (Stevens et al, 1993). It is particularly concerned with the lived experiences and of the subjective

perspectives of participants in an attempt to gain greater insight and understand the meaning of their experiences to inform future practices (Harper and Thompson, 2012; Green and Thorogood, 2014). Phenomenology has a subjective focus however does not take into account other external sources of knowledge or deductive influences that could impact upon the research findings or analysis (Taylor and Francis, 2013).

2.3.5.3 Grounded Theory

Grounded theory was developed following the joint work of Glaser and Strauss (1967). Grounded theory does not fit within a specific epidemiological paradigm, but instead cuts across positivism, post positivism and constructivism / interpretivism (Harper and Thompson, 2012).

Strauss and Corbin (1998, page 12) describe grounded theory as being "derived from data, systematically gathered and analysed through the research process". A method of constant comparative analysis is used in grounded theory which systematically allows for the emergence of inductive themes grounded within the data and a critical / thorough cross theme analysis approach is taken to develop meaning and understanding of the data collected (Green and Thorogood, 2014). It is argued that when theory is generated grounded within the data that this provides a more realistic view of the phenomenon (Strauss and Corbin, 1998).

The grounded theory approach was not felt to be appropriate to this research whilst inclusive of inductive themes (those that emerge as a consequence of the research) the proposed research was initially shaped by what was already known (deductive themes) and identified as deficits in this area, that required further exploration that were not grounded in the data that emerged. The lack of flexibility in grounded theory therefore has meant that this approach was too constraining for use in this research (Green and Thorogood, 2014).

2.3.5.4 Health Service Research - Justification of the Chosen Approach

The traditional qualitative approaches described above were considered but on their own they lack the flexibility required to pragmatically explore clinical practices and treatment experiences. Also flexibility was required to gain a comprehensive understanding amongst the treatment providers (IAPT Healthcare Professionals) and treatment receivers (Patient Participants) that this research required. Quantitative methods were discounted as the scoping study results determined a need for further understanding and depth of insight being required from within the workforce and those who use the service.

A health service research approach was therefore selected as most appropriate for this research. Health service research provides opportunities to further develop knowledge and understanding of clinical practices and how they are experienced by those that use the service (Hughes, 2008). These insights can then be used to develop new approaches to healthcare provision and can at the clinical trial stages provide evidence of effectiveness (Parahoo, 1997). Bowling (2002) describes health service research as focusing on:

- · What is being provided
- How well it works
- How efficient is it
- Is it meeting the needs of the given population.

Health service research does not solely focus on the effectiveness and efficiency of an intervention as in more traditional clinical research approaches. Instead a more pragmatic, flexible and comprehensive approach to research is adopted. This includes the need to understand patient perspectives, the level of needs they present with and their perceptions of the service and its ability to meet these needs. Health service research aims to be more broadly inclusive of psychological, social, physical and economic factors (Bowling, 2002). Health service research approach allows for the pragmatic bringing together of different techniques required to answer research aims and objectives without the constraints of a particular theory (Ritchie et al., 2014).

Taking a health research approach has meant that this research has not been constrained by a traditional qualitative approach. Instead a more pragmatic and flexible approach has been used to answer the research questions, aim and objectives.

"Quality in research practice has more to do with choosing the right research tool for the task rather than with methods that are confined to specific traditions"

Ritchie et al., (2014 page 22)

The different qualitative approaches when explored collectively do however provide a useful function to the researcher. They enabled what has been described as an 'intellectual muscle building exercise' that guided and provided insight into different methodological approaches, hence reducing the risk of errors in design and increasing the quality of the research proposed (Seale, 1999).

2.4 Research Design

This health service research study is made up of a scoping study literature review, two inter-related qualitative studies and synthesis (Figure 1).

- 1. Scoping study literature review
- 2. Qualitative interviews with IAPT health professional participants
- 3. Qualitative Interviews with patient participants
- 4. Synthesis of the findings and development of a complex intervention treatment guidance / recommendations for practice for those who present with personality disorder traits in primary care IAPT services.

The research is underpinned by the MRC framework for complex interventions (MRC, 2000; Craig et al., 2008a) and is focused on the development of a complex intervention for people who present with personality disorder traits in primary care IAPT services. Taking this stance provided the necessary preparatory investigations to inform knowledge and understanding of the experience of people with personality disorder in primary care IAPT services, hence shaping the development of recommendations for practice. The methodological approaches for each study are justified below and the working methods for each study are detailed in Chapters 3 and 4.

2.4.1 The Literature Review

Conducting a literature review is the fundamental and essential starting point of any research project (Stevens et al., 1993; Parahoo, 1997). A literature review enables the researcher to identify work already completed. It also assists in identifying gaps and deficits in the literature, hence ensuring that future research is not just a replication of previous work (Polgar and Thomas, 2013; Ritchie et al., 2014).

The literature review phase enabled the researcher to become familiar with challenges they may encounter and develop a familiarity with the field knowledge and in clarifying the rationales underpinning their research (Ritchie et al., 2014). There are several types of literature reviews, including traditional narrative, systematic, meta-analysis, meta-synthesis and scoping study reviews.

2.4.1.1 Traditional Narrative Review

Traditional and narrative literature reviews are described as less rigorous in design due to the lack of systematic structure, which allows for the replication of findings. This type of review is often described as a simplistic method that focusses upon reviewing a body of literature to provide thorough broad background knowledge (Cronin et al., 2008).

2.4.1.2 Systematic Reviews

Conversely systematic reviews are often described as the most robust and thorough due to their replicable and rigorous design. Systematic reviews are focused upon one particular area of research and look to critically appraise and synthesis the literature with a specific focus on effectiveness. The key characteristics of a systematic review should include:

- Pre-defined question and objectives
- Clear and explicit inclusion and exclusion criteria
- Clearly defined search strategy and methodology
- Systematic appraisal with assessment of validity, reliability and bias

Systematic synthesis with key findings reported

(Higgins and Green, 2011).

Systematic reviews are generally conducted with the main focus being on synthesising the results of best evidenced clinical trials, mainly RCT's in a specific field of interest (Cronin et al., 2008). Systematic reviews have, however, also been criticised for being too focused, reductionist and excluding of other important and informative literature (Polgar and Thomas, 2013). Tools have been developed to guide and support conduct in performing systematic reviews with Moher et al (2009) developing the 'Preferred Reporting Items for Systematic Reviews and Meta-Analyses' (PRISMA) statement, checklist and flow chart.

2.4.1.3 Meta-analysis / Meta-synthesis

Meta-analysis and meta-synthesis are not literature reviews however they do provide a collective analysis, synthesis of data and the drawing of conclusions from a series of inter-related studies using statistical methods (Cronin et al., 2008; Uman, 2011). Meta-analysis are used in quantitative research studies and are focused on statistical analysis (Uman, 2011) and meta-synthesis provides the same level of depth but are focused on qualitative research studies (Noblit and Hare, 1988). Meta-synthesis is however not without its critics, as many feel pooling together and collectively interpreting results from different qualitative studies dilutes and weakens the original detailed study findings (Walsh and Downe, 2005).

2.4.1.4 Scoping Study

Scoping study literature reviews are particularly useful in the identification and synthesis of a broader range of methodological approaches in the literature, particularly in under researched areas where a limited supportive literature is available (Arksey and O'Malley, 2005). Scoping studies are less concerned with the quality and depth of the literature instead the focus is on identification of wide ranging results via a mapping out process that provides a comprehensive and overall update on the existing literature (Levac et al., 2010; Arksey and O'Malley, 2005).

Five key stages have been identified in conducting a scoping study:

Stage one – Identify the initial research question

Stage two - Identify relevant studies

Stage three – Study Selection

Stage four – Charting

Stage five – Collate summarise and report the results.

One of the major strengths of scoping studies can be seen in the structured replicable framework which has similarities with those outlined in systematic reviews. Conducting a scoping study ensures that systematic methods are employed and reported (Arksey and O'Malley, 2005).

Scoping studies have been criticised for lacking rigour due to the broad scanning nature of the methodology and lack of detail in the procedure (Davis et al., 2009). This has led to other researchers who have used the model to explore opportunities to further enhance and improve the consistency in the use of scoping studies by providing enhanced detail to the stages outlined (Levac et al., 2010). Levac et al (2010) critiques their experiences of using the model as proposed by Arksey and O'Malley (2005) and provide further recommendations to enhance the stages of the scoping study design and further increase its rigour. Assessing the quality of the literature and employing additional reviewers during the screening process are two of the additional recommendations that will strengthen the findings of scoping studies (Levac et al., 2010).

For the purpose of this research a scoping study literature review was determined as the most appropriate approach due to the dearth of available literature in relation to personality disorder and its occurrence and treatment in primary care IAPT services. Other methods of review were discounted due to the paucity in literature available in this field of enquiry. They also provided less opportunity to explore a range of different literature sources and review of differing methodologies that a scoping study supports. Whilst narrative reviews were considered, their lack of structure and systematic methods would have weakened the robustness of any findings (Byrne, 2016). Employing a scoping study literature review allows for greater flexibility in the gathering of a broader field of literature

from mixed methodological approaches. This increased the opportunity to scope out and to identify relevant and insightful literature and information. A scoping literature review offered the opportunity for a broad scanning review of mixed literature using replicable and systematic methods by following the stages as outlined by Arksey and O'Malley (2005) and the enhanced detail of the each step as outlined by Levac et al (2010).

2.4.2 Justification of Methods used in the Qualitative Studies 2 and 3

This section will explore and review the available methods of data collection, sampling, recruitment, data analysis. A justification of the chosen methods for studies 2 and 3 will be provided.

2.4.3 Data Collection

Data collection is the process of gathering information (data) that enables the answering of the research questions in qualitative research. Two types of data collection in qualitative research are commonly described 'naturally occurring data' and 'research generated data' (Pope and Mays, 1995). Naturally occurring data is data that is not directly linked to the research, but instead is naturally present and available such as literature and policy. Conversely, research generated data is implicitly generated from within the research process and collected following interactions between researcher and participant (Ritchie et al., 2014).

There are a variety of data collection methods that could have been used to support the qualitative studies. The most commonly used include:

- Observation/ethnography
- Focus Groups
- Interviews (Silverman, 2011).

2.4.3.1 Observational Data Collection

Observational data collection methods provide an observational view and insight into the lives of others, however are fraught with limitations that are argued to

impact on the rigour of such approaches with the over reliance of researcher interpretation being highlighted as a key weakness (Taylor and Francis, 2013; Silverman, 2011).

The gathering of observational or ethnographic data in one to one IAPT treatment sessions to understand the interaction between the therapists and patients in this particular research was determined to be unethical due to the potential negative impact in may have had upon the treatment process in routine clinical practice. It also would not have allowed for the depth of knowledge required from the participants to answer the research questions. Observational data collection methods were therefore discounted as they were felt to be overly intrusive. Ethnographic data collection generally focusses upon cultural learning, with cultural behaviors, ways of life and speech being observed to develop new insights (Taylor and Francis, 2013).

2.4.3.2 Focus Group Data Collection

Focus groups are groups set up by a researcher to generate discussion around a particular phenomenon and are a useful approach when exploring the experiences of others. Focus groups allow for a shared understanding, generation of discussion not necessarily led by the researcher and can be useful in bringing in the experiences of participants who would not engage in a more formal 1-1 type interview (Kitzinger, 1995).

In this research the use of focus groups was rejected, as there was a concern that participants would potentially feel uncomfortable discussing their needs and experiences in a group. Further focus groups were discounted as it was important that all participants have an equal opportunity to be heard in depth and with sensitivity. Given the high prevalence of patients who present with avoidant personality disorder traits who are likely to have difficulty with social interaction (Moran et al., 2000), this could have had a potential negative impact and hindered recruitment, if focus groups had been utilised.

Focus groups were considered with staff groups for effective resource management that would have less impact on the service by capturing staff all together. However, it was also felt that this could hinder openness of experiences as mixing IAPT health care professionals of varying abilities may have provided reduced depth of knowledge through fear of repercussions or being judged for their views in this sensitive area of enquiry. It has been argued that participants of focus groups can be prone to conforming to the popular opinions being shared and some are constrained by the dynamics of a group setting to share conflicting ideas (Ritchie et al., 2014) hence why focus groups were not used.

2.4.3.3 Individual Interview Data Collection

Individual interviews are usually carried out face to face but can also include telephone interviews and online methods including video calls are becoming increasingly used. Interviews can follow unstructured, in-depth and semi structured approaches. Individual interviews provide participants with opportunity to share personal experiences and insights in a safe environment (Harper and Thompson, 2012). In-depth approaches provide a mixture of structure and freedom to explore and probe for deeper understanding and meaning from participant responses (Ritchie et al., 2014).

Topic guides provide a structure to ensure that individual in-depth interviews are focused on answering the research questions and enables the researcher to probe for a greater understanding of complex themes allowing for flexibility and the opportunity for the participants to bring in inductive themes and data that may not have been known (Ritchie et al., 2014). Too much information in semi-structured interviews can be seen as counterproductive as it is argued that can close down the participants from providing detail of their lived experiences (Taylor and Francis, 2013).

A critique of individual interviews can be directed towards the relationship between the interviewer and interviewee as often the only time the pair meet is during the research interview, therefore minimal opportunity to develop rapport and trust is afforded. This could have implications for the content of the data shared as participants may be guarded with the information they share or lack confidence to share information openly particularly sensitive information (Green and Thorogood, 2014).

Individual in-depth Interviews were selected for use within this research. Taking the in-depth stance allowed the researcher to delve deep into the participant's understanding of complex social and personal experiences in a safe environment whilst ensuring a focus is maintained within the allotted interview schedule (DiCicco-Bloom and Crabtree, 2006).

2.4.4 Recording of Data

Audio recording of interviews are used in qualitative interviews as they allow the researcher to be focused upon the interview and participant without the added distraction of note taking. This also ensures accurate accounts are held that can be reviewed for depth of understanding and can be transcribed verbatim to enable thorough and robust analysis. Field notes for post interview reflections can additionally provide the researcher with useful insights, reminders and record observational information such as body language of interviewee or researcher own emotions, that may not be recordable or identifiable when listening back to the audio recordings or reviewing transcriptions (Ritchie et al., 2014).

2.4.5 Sampling

Sampling is concerned with the focused identification and recruitment of the most appropriate sample of participants to inform the field of enquiry (Ritchie et al., 2014). The focus should be upon identifying a sample of participants from the research population that are selected based on characteristic that will inform the research (Curtis and Drennan, 2013). The sampling aim in qualitative research is to identify a sample with enough diversity from within the study population to draw reasonably accurate conclusions and insights that are generalisable back to the specific study population (Marshall, 1996; Gale et al., 2013). There are many sampling strategies used in qualitative research (Table 3).

[Intentional Space]

Table 3 – Qualitative Sampling Strategies

Sampling Strategy	Brief Description
Purposive Sampling	The most commonly used approach to sampling in qualitative research and is also known as 'criterion-based sampling'. The sample is chosen and identified based on the participants meeting specific characteristics which are informed by the study aims and objectives and known gaps in understanding. A limitation of this sampling method is that recruitment is driven by researcher subjectivity.
Theoretical Sampling	An initial sample is identified, analysed and then based on the results another sample is identified until saturation is reached. This strategy is used within grounded theory and whilst it has some benefits due to its flexibility this approach also has limitations as it requires unlimited time frames and resources.
Snowballing	This strategy recruits from within the study, with participants who have already taken part in the research suggesting other people who may meet the criteria for involvement in the study. This can be a particularly useful approach in engaging hard to reach populations (for example people who are homeless). A major limitation of this approach is that participants and researcher have direct influence on the recruitment of the sample, which could influence on the diversity of participants who take part.
Convenience	This strategy is viewed as the weakest strategy. Participants are recruited opportunistically and on the spot, again it can be useful in identification of hard to reach populations however this strategy lacks rigour and weakens the validity of any findings.

Adapted from Ritchie et al (2014).

The sampling strategy chosen for this research was 'purposive sampling'. The rationale for selecting this approach was based on the need to identify a defined population of patients with traits of personality disorder who were undergoing psychological therapies in IAPT services and the IAPT healthcare professionals working in the service. Inclusion and exclusion criteria were set up to determine those characteristics. The identification of a homogenous sample using purposive sampling is driven by the authors known knowledge in the field of enquiry and also the research gaps identified via the scoping study literature review. Therefore taking a criterion-based sampling approach enabled the recruitment of the specific

population best placed to inform and answer the research questions (Green and Thorogood, 2014). A range of between 12 and 50 participants is suggested as being sufficient to reach saturation in most qualitative research studies (Ritchie et al., 2014).

2.4.6 Recruitment

Recruitment in qualitative research can take various forms including recruiting from already known networks, liaising with recruitment agencies or advertising. Another strategy for recruitment and the one used within this research is recruitment for a specific area of interest, for example a hospital clinic or specific team of clinicians (Green and Thorogood, 2014). The mode of recruitment can also vary from emails, presentations, websites, advertisements and letters. Opportunities to ask for further information should be made available for potential participants, which ideally should include direct contact with the research team prior to involvement in the study (Ritchie et al., 2014).

Research recruitment is not without its challenges, ensuring participants are not out of pocket for time, travel and loss of earnings is important to consider. Participants in research should be valued in their contribution, hence providing reimbursement is one way of recognising the value of their involvement but it can also provide an incentive to engage in the research process (Green and Thorogood, 2014).

2.4.7 Data Analysis Methods

There are many different types of data analysis including approaches that are clearly but not exclusively linked to the methodological qualitative approaches taken such as ethnographic accounts, grounded theory and interpretative phenomenological analysis (Curtis and Drennan, 2013). Ethnographic accounts follow a descriptive analysis that report in depth on the observations of their lived experiences. Grounded theory analysis focused on moving between inductive and deductive themes and theory until saturation has been reached. Interpretative phenomenological analysis is focused upon the experiences of the participants to develop an understanding of their experiences (Ritchie et al., 2014).

Thematic and framework analysis approaches were considered to be appropriate in answering the research objectives in this study. Whilst various analysis methods can be used it is argued that researchers should ensure that the data collected is not considered in isolation and instead it is suggested that researchers should draw upon and understand the area of enquiry more broadly in order to understand the data more accurately (Green and Thorogood, 2014).

2.4.7.1 Thematic Analysis

Thematic analysis is not aligned to any specific qualitative methodological approach which makes this approach highly accessible and popular in the analysis of qualitative research (Ritchie et al., 2014). Thematic analysis is focused on reviewing the themes of the participants more generally, which are identified as patterns in the data but it lacks any clear systematic structure to its process (Peters, 2010). Thematic analysis is concerned with providing an overview of the full data rather than reporting the most frequently encountered themes that emerge (Harper and Thompson, 2012).

Whilst providing an approach for the identification of emerging themes and insights, a limitation of this approach is its lack of transparency in the process that reduces utility to do further secondary analysis (Ritchie et al., 2014).

Furthermore it is argued that thematic analysis findings are often subjective to the researcher and are at risk of being reported out of context from the data set in which they have been taken from. There is a lack of auditability using this method, which reduces impact and trustworthiness of any reported findings (Smith and Firth, 2011). The lack of systematic approaches have led to this approach being overlooked in favour of a framework approach. It was felt that the lack of structure could impact negatively on the rigour of findings and make the management of vast quantities of data more challenging to analyse.

2.4.7.2 Framework Analysis

Framework analysis is increasingly the method of choice in qualitative health services research (Gale et al., 2013). Framework analysis provides a method of systematically organising a vast field of data into a manageable matrix that in turn

enables a comprehensive and systematic analysis to take place (Ritchie et al., 2014). Arguably, thematic analysis has lots of cross over with framework, however, the main difference can be identified in the systematic organisation of the collected data and analytical methods employed (Smith and Firth, 2011). Framework analysis provides a transparent and systematic approach which increases the rigour and credibility of outcomes reported and enables the opportunity for repeated analysis to be performed (Ritchie et al., 2014; Smith and Firth, 2011).

The framework analysis approach follows a systematic 7 stage process:

Stage 1 – Transcription

Stage 2 – Familiarisation

Stage 3 – Coding

Stage 4 – Developing the analytic Framework

Stage 5 – Applying the framework

Stage 6 – Charting the data into the framework matrix

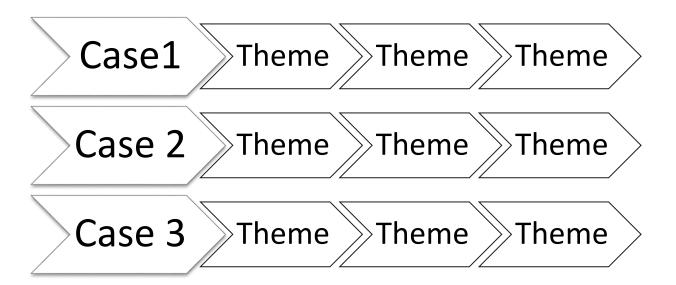
Stage 7 – Interpreting the data.

(Gale et al., 2013).

Framework analysis was developed in the 1980s for the National Centre of Social Research. Using this approach requires support that is led by an experienced qualitative researcher (Ritchie and Lewis, 2003). The amount of training and education relating to the systematic stages of this approach are seen as a potential barrier to its use (Gale et al., 2013). However, it is seen as a useful approach for novice researchers to be guided through due to its systematic and structured stage (Smith and Firth, 2011).

The framework matrix is defined by the rows which refer to the individual cases (in this research the individual interviewed participants) and the columns, which set out the coded themes (Figure 3). This allows the researcher to perform 'within case analysis' so that specific themes can be viewed without losing the context of the individual participants raw data and also to look collectively at themes from across the participant population whole dataset, which is referred to as 'cross-case analysis' (Ritchie et al., 2014).

Figure 3 – Case and Theme Based Analytical Approach



Framework analysis also allows for the inclusion of deductive themes, which shape the initial framework and the emergence of inductive themes that come from the emerging research data that is being collected (Gale et al., 2013).

The framework approach provides a clear structure to work within, but there is a risk that the following of a systematic process becomes the focus ahead of the interpretation of data that informs the outcomes. Researchers therefore need to ensure that during the process, reflexivity and the allowing of inductive themes to emerge is not lost in the process of inputting data into a matrix set up based on deductive themes. The matrix is required to develop throughout the data management and analysis stage, not to be a rigid inflexible tool (Ritchie et al., 2014).

The systematic processes framework employs ensures that the process is transparent and replicable hence strengthening the rigour and credibility of any outcomes (Smith and Firth, 2011). Framework analysis has been chosen as the most suitable and appropriate data analysis method to support this research.

2.4.8 Saturation

Saturation is a term that is used to describe the point at which no new or emerging data of interest in line with the phenomenon is reached and hence data collection stopped (Mason, 2010). Sample size in qualitative research is often determined by saturation being reached. Frequency of reported ideas is important in measuring saturation, but so too are the outliers whom often share rich information that can bring about important insights previously not considered (Morse, 1995). Throughout the data collection phase, analysis of whether saturation is being reached should be considered and discussed within the research team until a consensus is reached. Determination of saturation could be criticised as being subjectively driven and open to manipulation, it is disputed that saturation is often not reached, this being due to funding, time restrictions and premature decisions on saturation being reached prior to the coding completion of the complete dataset (Mason, 2010).

2.5 Rigour in Qualitative Research

Rigour in qualitative research will determine the strength of the research and the credibility of any reported outcomes (Anderson, 2010). Rigour in qualitative research is often challenged due to the interpretive methods of analysis taken (Mays and Pope, 1995). The key concepts of measuring rigour in qualitative research are trustworthiness, credibility, conformability, transferability, dependability, and auditability (Critical Appraisal Skills Programme (CASP), 2014; Spencer et al., 2003). Qualitative researchers often report what they have done without providing the necessary depth or understanding hence impacting upon the rigour that can be attributed to their findings (Ryan Nicholls and Will, 2009). The key concepts used to measure rigour are described below.

2.5.1 Trustworthiness

The measurement of validity and reliability in qualitative research is measured by a focus being placed upon trustworthiness (Shenton, 2004). Validity and reliability is often perceived to be of particular importance to quantitative research however it is argued by Golafshani (2003) that these factors are important for the credibility of

any research. Trustworthiness can be established via clear reporting of potential researcher bias in any outputs and interpretation of research findings. This risk of researcher bias can be further minimised and reliability improved by working closely with a research team who can check for consistency, support reflexivity and guide open reporting of such hence increasing the trustworthiness of finding (Silverman, 2011).

2.5.2 Credibility

Credibility or 'truth value' in qualitative research is measured via the reporting process of the presenting variables directly involved in the study i.e. the participants. A good additional measure of credibility can be seen when participants view the results and are able to relate to them and acknowledge their own contributions. Credibility is fundamental to the accuracy of any reported results (Houghton et al., 2013). Validity of findings can be demonstrated by making reference and sharing of raw data and fragments of recorded datasets, such as the framework matrix examples that have been used to support the analysis of the research. This can be further supported if participants are revisited and the interpretation of results revised with them and refined appropriately (Harper and Thompson, 2012).

2.5.3 Conformability

Conformability is the process in which the researcher adopts a neutral stance in the conducting and interpretation of the research, without being drawn into subjective or objective perceptions. This is a challenging process as to be totally neutral without objectivity is difficult as predjudices, experiences, interests, motivations and values will be present (Shenton, 2004). It is contested that no researcher is able to identify absolute truths from qualitative research (Mays and Pope, 1995). However attempts to remain as neutral as is practically possible can be supported by the frequent use of reflexivity (discussed in section 2.6).

2.5.4 Transferability

Transferability relates to the ability of applying and transferring the resulting findings of the study to other external groups within the researched area. Ensuring a sample of participants that is deemed representative of those who can inform the phenomenon will aid transferability. Sampling methods need to be appropriate to ensure the correct population are identified and recruited. Achieving transferability in practice however can be difficult to achieve, often the small sample sizes of qualitative research and the localised nature of this research means that geographical constraints may impact on transferability. Openness in reporting of limitations is therefore important (Shenton, 2004).

2.5.5 Dependability

Replication using the same methods within different but similar areas could be beneficial to determining transferability and is referred to as dependability (Shenton, 2004). In order for dependability to be determined researchers are required to provide detailed and accurate accounts of the methods undertaken to achieve their results in a way that provides sufficient information that another researcher could repeat the study.

2.5.6 Auditability

Auditability is the provision of clear replicable systematic trail that enables another researcher to follow the same process and reach the same or similar conclusions (Ryan-Nicholls and Will, 2009). An example of auditability could include the sharing and accessibility of research field notes to compliment interview transcripts, or could be seen in the provision of verbatim quotes that are supportive of the themes being reported (Beck, 1993). Systematic conduct of the research and its analysis will increase rigour. Interpretation of participant perceptions due to researcher bias is were rigour could be challenged particular if weak unsystematic structures are in place (Ritchie et al., 2014).

2.6 Reflexivity

The aim of reflexivity in qualitative research is to ensure that researchers remain as neutral as reasonably possible in the conduct of the study, this is also described as 'empathic neutrality' (Ritchie et al., 2014). It is acknowledged that neutrality is unrealistic to achieve fully as researchers will have their own unique experiences, biases, and knowledge base (Harper and Thompson, 2012). Nevertheless, the role of reflexivity is to reduce these risks and potential sources of bias by being transparent and reflective regarding the impact the researchers can have upon the research process and its outcomes (Taylor and Francis, 2013). Explicit reflection should run throughout every stage of the research process, whether that be in the design of the questions, the development of the topic guides, the field work or the analysis and reporting of outcomes (Ritchie et al., 2014).

Reflexivity is often described in two distinct ways. The first being concerned with the impact of researchers own history or background and the influences and bias this can present, this is often referred to as 'personal reflexivity'. Personal reflexivity is important with frequent self-reflection being required in an attempt to reduce researcher bias (Harper and Thompson, 2012). Approaches taken to address this will be detailed in chapter 4 which focused on working methods of studies 2 and 3.

The second is based on assumptions and the impact of assumptions on the research during the early phases of research design, data collection and its analysis (Harper and Thompson, 2012). Reflexivity has become a measure of standard and rigour in qualitative research as it allows for improved quality particularly when it has been conducted with the inclusion of research group involvement this is referred to as team reflexivity (Barry et al., 1999).

2.6.1 Team Reflexivity

Working within the scope of a team can improve the validity and reliability of the research findings with team reflexivity being one of the most influential components. Conceptual thinking is more advanced due to the joining together of

people with different experiences and knowledge, particularly in the coding and analysis phase of the research (Barry et al., 1999). There are however challenges to team reflexivity due to the different opinions and viewpoints that require consideration which can mean that reaching a common consensus is more time consuming (Barry et al., 1999).

Whilst this study did not employ a research team in the truest sense, a teamwork approach was intrinsic to the research process. The main core of this team being the author and his academic supervisors however an expanded team approach was also embraced with the research advisory group and the extended research supervisory group.

Within this research the author has identified benefits in ensuring a team approach and collaborations have supported not just in the analysis phases but have been present from the outset, in the research design, data collection and analysis phases.

The use of team reflexivity in this study has guided, encouraged and challenged the researchers own reflexivity and the continual need to explore the impact of one's own involvement in the research, on the participants and the analysis. Going from a knowledgeable expert in the clinical field to an inquisitive researcher has presented its own unique challenges. Developing an open and honest approach has been encouraged throughout and has ensured that researcher reflexivity has been a common theme throughout the research process.

2.7 Patient and Public Involvement

Patient and Public Involvement (PPI) in research is of paramount importance, historically patients were the subjects of research not partners rather than involved in research (Harper and Thompson, 2012). Patient and public involvement in research has over the past decade become increasingly important (DOH, 1999a; DOH, 1999b). The establishment of organisation's, such as 'Involve' have been crucial in developing guidance and advice on involving patients and public in research (Hayes et al., 2012).

Whilst the benefits of PPI are commonly reported in the research community there is limited evidence to support its actual impact (Faulkner, 2015). There are many hurdles to overcome when involving patients in research including the provision of resources to support effective involvement, such as funding and additional training requirements (Telford and Faulkner, 2004).

A longitudinal study involving patients in research has been carried out and it is suggested that involvement has increased over the years, and is increasingly encouraged as a key research component by different funding bodies. The National Institute of Health Research is named as most supportive of patient involvement. It is also claimed that involvement of patients throughout the research process is influential in the success of the study (Ennis and Wykes, 2013). Engaging with patient and public involvement ensures that the research and the data available is of a better standard and implementable in routine practice (Craig et al., 2008a).

Involvement of service users as participants in research or as someone to check over a questionnaire is inappropriately insufficient to be described as patient and public involvement. Instead it is advocated that patients with lived experience should be involved at all stages of the research process to guide and contribute to its implementation and also to have a voice in deciding what researched is funded (Telford and Faulkner, 2004; Ennis and Wykes, 2013). Patient and public involvement, engagement in research can take many forms however there is shift away from patient and public involvement purely to provide a consultation role for researchers as it did initially. Patient and public involvement roles have become much more influential in the research process with both collaborative and coproduced research involvement and service user led research being increasingly supported (Harper and Thompson, 2012).

2.8 Ethical Conduct in Research

Ethical conduct is interlinked with research governance (Appendix 27). Ethical conduct is something that should be considered throughout the research process and its primary aim is to cause no harm, protect participants and ensure fair treatment (Faulkner, 2015; Orb et al., 2000). The declaration of Helsinki was the

first international document to outline the ethical guidance for conducting research with human participants in 1964 but has since be updated on several occasions (World Medical Association, 2013). Ethics is guided by four ethical principles, autonomy, non-maleficence, beneficence and justice (Beauchamp and Childress, 1979).

2.8.1 Autonomy

Autonomy relates to the rights of participants to be involved in research but to have the autonomy to remain in control of their involvement. The use of informed consent, accurate and factual information sharing and non-coercive approaches to involvement in research are supportive of this principle (Orb et al., 2000). Participants should be provided with clear and accurate information about the research at each contact point to ensure that informed consent is sought (Harper and Thompson, 2012). The right also for participants to change their minds about consent at any point without being judged is fundamental to their involvement (Orb et al., 2000).

2.8.2 Non maleficence

Non maleficence is a key principle to all research conduct and relates to causing no harm and adherence to rigid and considered ethical principles that will reduce any potential for harm to involved participants (Ashcroft et al., 2007).

2.9.3 Beneficence

Beneficence is an extension of non-maleficence however is more concerned with the need to 'do good'. The involvement of participants in healthcare research whether it is in quantitative research that involves a clinical trial or qualitative research where participants are exposed to and involved in research interviews for example, has the potential to cause adverse effects. The consideration of beneficence here is useful as it allows the focus of research to explore and investigate the risks against the benefits of involvement of research participants and the secondary potential impact for the greater good on the wider population. Beneficence however can also mean that an over cautious response in which

researchers view participants as overly fragile may mean that the participants autonomy for involvement in research is compromised as they are excluded through fear of a potential but unlikely adverse effect (Orb et al., 2000).

2.8.4 Justice

Justice relates to the rights of participants to be treated fairly and that groups that are described as vulnerable are protected and treated equally. Justice also protects against practices of exploitation or abuse (Ashcroft et al., 2007).

Ethics should be a key feature of all research throughout the research process, not only focused on design and development but also considered during data collection and analysis. The researcher and researcher team should use reflexivity to ensure their own biases are not influencing the research but instead ethical conduct remains at the heart of the research (Green and Thorogood, 2014). The ethical process, ethical conflicts or special ethical considerations specific to this study are described in depth in Chapter 4.

2.9 Summary

Taking a health service research approach was the most appropriate methodology to take. Health service research is driven by being able to address the research aims and objectives without being constrained by a specific traditional methodology (Silverman, 2011). The choice of taking a health service research position and being pragmatic in approach has ensured that the best and most appropriate method has been employed to address the research aims and objectives. Considerations of various methodological approaches have been considered and rationales provided for the methodological choices taken that have enabled high standards of rigour in the conducting of the research.

Chapter 3

Literature Review

3.1 Study 1 - Scoping Study Literature Review

This chapter will provide an overview of the scoping study literature review and the results. The reporting of results will be discussed by dividing the scoping study into four objectives: policy, treatment, treatment experience and needs, each will then independently be reported.

This literature review was conducted using a scoping study methodology (Arksey and O'Malley, 2005; Levac et al., 2010) and was completed in 2014. The results of the review shaped the direction of the research and the subsequent qualitative studies (Study 2 and Study 3). The scoping study methodology was selected due to a dearth of literature available in this specific field of enquiry. A scoping study methodology enabled a broad scan of literature that supported the identification of key literature (Arksey and O'Malley, 2005). Scoping studies enable the identification of a wide range of literature using differing methodological designs. This increased the opportunity for identifying the most relevant and insightful information that could guide this research. The review adopted the recommendations described by Levac et al (2010) to enhance the design of scoping studies and increased its rigour by applying the recommendations for critical appraisal of the literature. The inclusion of additional reviewers from the supervisory team was also employed to verify the results.

One of the main strengths of a scoping study methodology is seen in the structured replicable framework, which has similarities with those outlined in systematic reviews. Five key stages were recommended in conducting the scoping study:

Stage one – Identify the initial research question

Stage two – Identify relevant studies

Stage three – Study Selection

Stage four - Charting

Stage five – Collate summarise and report the results.

(Arksey and O'Malley, 2005).

3.2 The Research Question, Aim and Objectives

A core overarching literature review question was developed in order to establish what literature in the specific field of interest had already been conducted and to establish findings that informed the research proposed.

What are the needs and treatment experiences of people with personality disorder traits in primary care?

Overall Aim

To carry-out a broad scan of the literature and to critically examine the literature currently available in this area of interest.

Four key objectives provided a structured framework for identifying, reporting and appraising the literature.

Objective 1 – To determine what recommendations have been outlined in national policy relating to personality disorder in primary care

Objective 2 – To determine what psychological treatment / interventions have been developed in primary care

Objective 3 – To determine what are the treatment experiences of people with personality disorder in primary care

Objective 4 – To determine what are the needs of people with personality disorder in primary care

A narrative review methodology was used to report objective 1 and the results of this review will be detailed separately from the other three objectives. Literature pertaining to objective 1 was selected by the author based on knowledge, contact with other experts in the field and via attendance at conference. This ensured that the relevant literature was identified hence a different scoping method was used for identifying the policy literature.

3.3 Personality Disorder – Policy Results

Objective 1 – To determine what recommendations have been outlined in national policy relating to personality disorder in primary care

Prior to 2003 limited policy literature was available regarding the care and treatment of personality disorder (Sampson et al., 2006). Personality disorder was seen as a condition that was incurable, highly stigmatised and excluded from many services (NIMHE, 2003a). There was a lack of clarity of who, where and how, care and support should be provided (DOH, 2009). People with personality disorder were misunderstood by a range of services they came into contact with when seeking support, including health and criminal justice services (Tyrer et al., 2015). Little training or education was provided to professionals to understand and improve their knowledge of personality disorder (NIMHE, 2003b). This led to a pervasive and entrenched stigma, with the belief that people with personality disorder could not be helped and would be a drain on services taking up significant resources. Subsequently this led to a multitude of services rejecting people with personality disorder and excluding them from service care and support (NIMHE, 2003a; NIMHE, 2003b).

Personality disorder, no longer a diagnosis for exclusion (NIMHE, 2003a)

A key document published by the National Institute for Mental Health in England (NIHME) 'Personality Disorder: No Longer a Diagnosis for Exclusion' (NIMHE, 2003a) was important in reforming care and service provision for personality disorder. This document provided guidance on what needed to change within services with a particular focus on specialist secondary mental health services and accessibility to clinical care and treatment. Whilst welcomed, this guidance focused on specialist secondary mental health service responses but largely

overlooked the occurrence of personality disorder and its impact on the wider system including primary care.

This document however was transformational in improving the service provision of personality disorder. The key drivers outlined, included recommendations for general adult mental health services, forensic settings and educational proposals. In relation to the general adult mental health services it was advised that specialist multi-disciplinary approach to care and treatment was adopted for people with personality disorder who present with high levels of distress and complexity and in areas where prevalence was high that specialist day services were developed. Forensic service provision was also recommended as requiring enhancements to support the identification of personality disordered offenders and the development of specialist forensic personality disorder services across the country to improve the treatment and management of personality disordered offenders. Educationally a deficit in skills and knowledge of working with this patient group is noted across services and a strategy to enhance this for both the existing and future workforce is recommended. All key drivers noted above were set alongside a pump-priming investment from the department of health.

As part of this policy, patients were interviewed via a focus group to ensure the service user voice was considered. The need for early intervention prior to crisis and the requirement for services to become proactive instead of reactive were emphasised. Choice of evidence based treatments and early interventions for people between the ages of 15-25 years with emerging personality disorder difficulties were highlighted. The focus group identified that effective treatment during the earlier phase of the condition could potentially prevent the disabling escalation of personality disorder symptoms later on.

Breaking the cycles of rejection: the personality disorder capabilities framework (NIMHE, 2003b)

In the same year NIMHE (2003b) produced an accompanying document that addressed the need for greater education and awareness of personality disorder with the development of a training capabilities framework. This training initiative was key in identifying the need to raise awareness and skills development across

a wide range of agencies. This policy was influential and as a result of this a nationally developed training course called the 'Knowledge and Understanding Framework' (KUF) was and continues to be widely delivered across the UK. The KUF has been evaluated on three occasions, once with multi-agency staff (Lamph et al., 2014) and two occasions with secondary service staff (Davies et al., 2014; Ebrahim et al., 2015). All evaluations report improvements on staff understanding, attitudes and capabilities post training, however all also report a decline in effect at follow up.

National Institute for Health and Clinical Excellence (NICE, 2009a; 2009b)

Whilst the evidence base for the treatment of personality disorder is growing, NICE guidance has only been developed for two of the ten different types of personality disorder. This could be attributed to BPD and anti-social personality disorder being the most prevalent types of personality disorders to be identified in health and criminal justice services and often seen as most needy and complex (Lamph, 2011).

The NICE guidance for BPD (NICE, 2009a) focuses on those individuals with most complexity and risk. It recommended that long term treatment should be provided for at least one year. Primary care treatments were not recommended due to a lack of evidence based trials of low intensity interventions and lack of evidence for effective short term treatments with this patient group. However there was a suggestion that there could be benefit from shortened long term treatment approach. Additionally the NICE Guidance for anti-social personality disorder (NICE, 2009b) outlines preventative measures and early intervention but little advice was provided regarding evidence based psychological interventions.

Recognising Complexity; Commissioner guidance for personality disorder services (DOH, 2009)

This document provided commissioner guidance for establishing services for people with personality disorder across primary care, secondary care and forensic pathways. It was identified that the highest levels of unmet need and prevalence are seen outside of specialist secondary mental health services and present within

the primary care system. A range of psychological interventions and therapies for personality disorder was recommended at different stages of the health care system (DOH, 2009).

Improving access to psychological therapies implementation plan: national guidelines for regional delivery (DOH, 2008).

No reference was made to personality disorder specifically although the gate keeping role is discussed as is the need for IAPT services to signpost and make appropriate referrals that support timely interventions (DOH, 2008).

Talking therapies: A four-year plan of action (DOH, 2011)

Three years after the original IAPT plan (DOH, 2008) personality disorder in primary care was recognised (DOH, 2011). One of the key challenges outlined was the need to develop innovative evidence based interventions for people with personality disorder in a stepped care pathway. Any development of novel ways of working with this patient group was deemed to be of great benefit to GPs who support large numbers of people with personality disorder co-morbidity, due to the lack of primary care based treatments available. Whilst recognised as an area requiring attention, no clear guidance on what to do with the patient group was shared (DOH, 2011).

In conclusion, the increased interest in personality disorder via the identified policy documents over the past 14 years has provided opportunities to be innovative and reform service responses for people who have personality disorder related difficulties. However, a criticism of the policies outlined could be aimed at the missed opportunities to address earlier interventions or prevent people transitioning to higher level and more expensive services. Attention has focused on treatments directed at those with highest risk and complexity and this is understandable given such a prolonged period of exclusion (NICE, 2009a). A clear disparity between the NICE guidance for BPD / anti-social personality disorder was identified when compared to other guidance, for example Anxiety (NICE, 2007) and Depression (NICE, 2009c) both recommend and implement the use of a cost effective stepped care approach, something that is not addressed

within the personality disorder guidance. The lack of attention for those with less severe or co-morbid personality disorder in primary care continues to be overlooked. A need has been clearly identified to address this gap, however, minimal advice, guidance or research has been provided at this point to address the service deficits.

3.4 Review of Treatments, Treatment Experiences and Needs

The outlined scoping study literature review methodology within this section was used to answer and report on the results of the remaining objectives 2-4.

Objective 2 – To determine what psychological treatment / interventions have been developed in primary care

Objective 3 – To determine what are the treatment experiences of people with personality disorder in primary care

Objective 4 – To determine what are the needs of people with personality disorder in primary care?

In order to identify the necessary evidence, a broad search was undertaken. Three different scoping review facets 'personality disorder', 'primary health care' and 'treatment experience' were identified as broad search terms. More specific scanning search terms that were relevant to each of the search facets were then identified (Table 4). Medical Subject Headings (MeSH) terms were used in searching for literature as they captured results using common medical umbrella terms in place of several related terms that could be used in titles and abstracts. This ensured that search strategies were reliable, inclusive and less likely to miss out key literature (Doig and Simpson, 2003).

Boolean operators (and /or) were used to maximise the identification of literature. In each of the scoping review facet areas (Table 4) all searches terms were conducted with (or) to ensure that a wide range of publications were initially gathered. In order to draw on only the most relevant literature the final search combined the results of all three identified scoping review facets by conducting the

search with boolean operator (And). The results from each search area were then merged using (And) to condense and refine the search results.

The following Databases were searched; Ovid Medline (1946-2014), Psychinfo (1806-2014), Embase (1980-2014), Health and Psychosocial Instruments (1985-2014), AMED (1985-2014), Global Health (1973-2014), Social Policy and Practice, EMB Review Cochrane Controlled Trials, EMB Cochrane Systematic Reviews / CINAHL Plus.

<u>Table 4 – Search Terms</u> (*Indicates recognised MeSH Terms)

Personality Disorder	Primary Health Care	Treatment Experience
Personality Disorder*	Primary Health Care*	Treatment Experience
Borderline Personality Disorder*	General Practice*	Satisfaction
Antisocial Personality Disorder*	General Practitioners (GP's)*	Dissatisfaction
Paranoid Personality Disorder*	Improving Access to Psychological Therapies	Patient Satisfaction*
Histrionic Personality Disorder*	(IAPT)	Quality
Obsessive Compulsive Personality Disorder*	Psychological Interventions	Recovery
Narcissistic Personality Disorder	Psychosocial Interventions	Non-Completion
Schizoid Personality Disorder*	Psycho-somatic presentations	Impact
Schizotypal Personality Disorder*	Primary Care Psychological Therapies	44-51 (or)
Dependant Personality Disorder*	Stepped Care Model	
Anxious Personality Disorder	Counselling*	
Avoidant Personality Disorder	Mental Health Graduate Workers	
Emotionally Unstable Personality Disorder	Cognitive Therapy*	
Impulsive Behaviour*	Practice Nurses	
Adaption psychological*	Poor Attenders	
Social Adjustment*	Early Intervention*	
Emotional Regulation	Timely Interventions	
Interpersonal Relations*	27-41 (or)	
Self Injurious Behaviour*		
Problem Solving*		
Careless coping style		
Social Difficulties		
Affective Difficulties		
Emotional Distress		
Anger Management		
1-25 (or)		

3.4.1 Inclusion / Exclusion Criteria

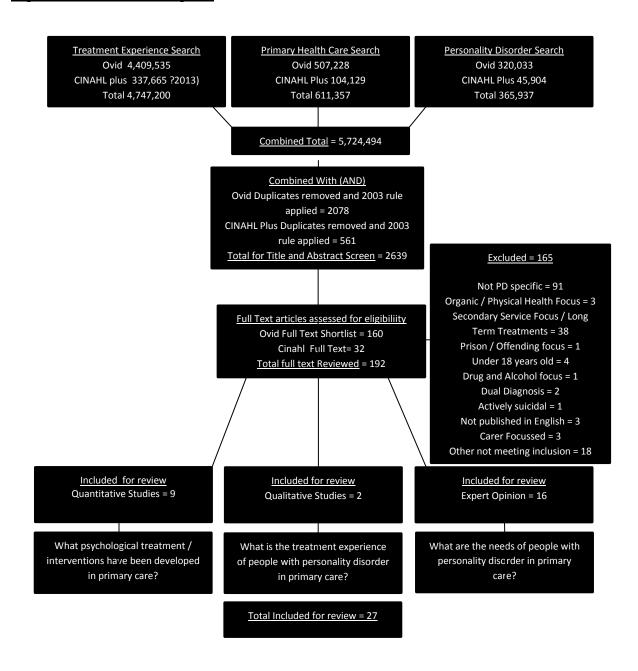
The inclusion / exclusion criteria (Table 5) were applied to support the screening of relevant studies. All titles and abstracts following the merged search were screened using the criteria. Literature before 2003 was excluded due the change in approach for personality disorder as outlined by the seminal NIMHE policy document (2003a).

Table 5 – Inclusion / Exclusion criteria

Inclusion Criteria	Exclusion Criteria
Adults aged 18+	Prison / Offenders Secure Setting
Diagnosed PD	Specialist Secondary Mental Health
Undiagnosed PD (Personality	Care
Disorder or traits as a focus)	Secure hospital Settings
Western Society	Long Term Treatments (In excess of
Only English language papers	30 sessions or 12 months duration)
Offenders who are not classed as	Under 18 years
prisoners or forensic mental health	Over 65 years
service patients	Drugs and Alcohol Dependency
All methodological designs	Organic Conditions / Physical Health
	focussed
	Dual Diagnosis (ie, Psychosis)
	Literature before 2003.
	Actively suicidal
	Learning Disability
	Focus on carers
	Dissertations and Grey Literature

A search strategy flow chart adapted from the PRISMA diagram (Moher et al., 2009) shows the numbers of hits identified and the study selection processes (Figure 4). In total 5,724,494 hits were made when combining the 3 scoping review facets using 'Or'. However, once 'and' was applied and duplicates removed and the rule to exclude papers prior to 2003 was applied, the number reduced to 2639. Papers were then screened at title and abstract for inclusion using the criteria as set out in table 5. One hundred and ninety two papers received a full text review. Excluded papers are reported consistent with the exclusion criteria and are accounted for and grouped within the Prisma Diagram (Figure 4). A hand search of literature from reference lists and the included policy literature were also undertaken.

Figure 4 – PRISMA Diagram



A framework for charting and reporting the findings from the literature review was set up in an excel spread sheet. A series of tabs relating to each objective supported the charting process (Appendix 3). All included studies (that were not policy related) were shortlisted for review with some brief methodological data, key findings and limitations extracted. Each paper was then catagorised with relevance to answering one of the three remaining objectives.

3.4.2 Charting Methods

3.4.2.1 Charting Method for the Treatment and Interventions Objectives

Papers relating to objective 2 'To determine what psychological treatment / interventions have been developed in primary care' were all quantitative studies. Therefore the Effective Public Health Practice Project Quantitative Critical Appraisal Tool (EPHPP) (Thomas et al., 2004) was selected to guide the data extraction and critical appraisal. One of the strengths of the EPHPP is its utility for providing a clear and systematic process for data extraction that allows for a quality rating assessment of each identified component. The components reviewed in the EPHPP are; selection bias, study design, confounders, blinding, data collection methods, withdrawals and drop outs, intervention integrity and analysis. A rating dictionary accompanies the tool and guides the reviewer to extract and rate the relevant data outlined in the studies (Thomas et al., 2004). The component ratings can be collated to report the overall rating of a study in a clear and systematic reporting method determining an global study rating of 'weak, moderate or strong'.

This tool is not without its limitations. It became apparent that some of the areas for rating required a subjective opinion that could lack consistency and reliability even when the guidance and rating dictionary was referred too. The author independently reviewed the titles and abstracts but sought clarification and advice when necessary from the academic supervisory team.

3.4.2.2 Charting Method for the Treatment Experience Objective

Only two papers that used the same sample and data were identified that were specific to objective 3 'To determine what are the treatment experiences of people with personality disorder in primary care' both of which were qualitative papers. The Critical Appraisal Skills Programme (CASP) qualitative appraisal tool (CASP, 2014) was the most appropriate to guide an in depth data extraction and critical analysis. This tool was chosen due to the clear and systematic process that guides the extraction of data from published qualitative work hence guiding the

researcher thorough the critical appraisal process. This tool is easy to use and of beneficial for the novice researcher (Noyes et al., 2011).

Other qualitative papers were identified during the search but did not meet the inclusion criteria mainly as they were set I specialist secondary mental health services.

3.4.2.3 Charting Method for the Needs Objective

The needs section relating to objective 4 'To determine what are the needs of people with personality disorder in primary care' provided the largest number of papers, 16 in total, but methodologically the weakest literature, as all were expert opinion based (Burrow and Walker, 2012). There was limited advice available within the literature on how to best appraise expert opinion papers. However the following framework developed by Burrows and Walker (2012) provided a series of useful questions to review expert opinion papers. Use of this tool enabled a reliable and replicable process that could be discussed and consensus reached with the academic supervisory team in the review of the selected papers.

<u>Table 6 – Appraisal of Expert Opinion Papers</u>

Review Questions

Is the author an expert?

Is the opinion published within a credible source?

Is the opinion evidence based?

Are the authors personal statements clearly presented as such?

Is the opinion in response to a practical concern?

What are the findings?

Does the author provide arguments for and against the position?

Does the author identify limitations?

3.5 Reporting the Results

The key findings and results are collated, summarised and reported. The included literature was divided and reported in line with the relevance to answering objectives 2-4. Each area was reported independently, the results were then

looked at collectively to answer the overarching research objective and to guide the direction of qualitative studies 2 and 3.

3.6 Treatment of Personality Disorder in Primary Care - Results

Objective 2 - To determine what treatment / interventions have been developed in primary care

Nine studies were identified that provided psychological treatments for personality disorder related difficulties in primary care settings (Table 7). Of these seven were randomised controlled trials (RCT's), (Muran et al., 2005; 2009; Maddux et al., 2009; Joyce et al., 2007; Emmelkamp et al., 2006; Berger et al., 2004; Neacsiu et al., 2014) one cohort study (Craigie et al., 2007) and one observational case study (Rees and Pritchard, 2013).

Of the nine papers, four originated in USA, two from Australia, and one each from New Zealand, Holland and Austria, none were from the UK (Table 7). International differences in service composition made it difficult to determine whether the interventions were consistent with those provided in primary or secondary care services equivalents in the UK. Therefore a limitation of the data may be that trials included may have included some participants that are not representative of the UK based patient group this research is focused upon.

The included studies were differentiated by two distinct areas of focus; the first being personality disorder specific treatments delivered to a primary care patient population (Muran et al., 2005; 2009; Emmelkamp et al., 2006; Neasciu et al., 2014; Rees and Pritchard, 2013). The second focused on common mental health disorders like depression and anxiety but included the impact of co-morbidity of personality related difficulties on treatment outcomes (Craigie et al., 2009; Maddux et al., 2009; Joyce et al., 2007; Berger et al., 2004).

In the studies that focused on co-morbidity, the incidence of personality disorder is described as a secondary component to depression or anxiety. However, it could be argued that personality disorder is the underlying condition that causes symptoms of depression and anxiety.

A common limitation of all of the studies was that they were focussed on specific types of personality disorder and not personality disorder difficulties more generally with the exception of Neasciu et al (2014). There was also a clear lack of ethnic diversity in the participants selected and excessive use of assessment outcome data in all but one study (Maddux et al., 2009). The above limitations impact on the generalisability of findings to this patient group in UK IAPT services.

<u>Table 7 – An overview of included personality disorder treatment studies</u>

PD Specific Trea	tments			
Authors	Participants	Intervention	Outcome measures	Design
Muran et al., 2005	N= 128 Personality disorder	Brief Relational Therapy (N=41)	Symptom Checklist-90-Revised, Global	Three arm RCT
(USA)	Cluster C focused.		Severity Index, Target Complaints,	
		Cognitive Behavioural Therapy (N=46)	Global Assessment Scale, Inventory of	
	60 men		Interpersonal Problems, Wisconsin	
	68 women	Short Term Dynamic Therapy (N=41)	Personality Inventory.	
	Aged 21-65 years.			
Muran et al., 2009	As above (Same Sample)	As Above	PSQ includes the work and alliance	Three arm RCT
(USA)			inventory, session evaluation	
			questionnaire	Mixed method
				some
				qualitative data
				collected in
				PSQ
Emmelkamp et al.,	N = 62 Avoidant Personality	Brief Dynamic Therapy (N=23)	PDBQ, Avoidant personality sub-scale,	3 Arm RCT
2006	Disorder Focused		LWASQ, SPAI, The Avoidance Scale.	
(Holland)		Cognitive Behavioural Therapy (N=21)		
	Aged 24-61			
		Waiting List Control (N=18)		
	30 males			
	32 females			

Rees and Pritchard,	N = 2 Avoidant Personality	Cognitive Behavioural Therapy (N=2)	Strength of belief, personalised	Observational
2013	Disorder Focused		statements not tested for reliability,	Case Study
(Australia)			DSM-IV Depression Anxiety and Stress	
	1 Male aged 49		Scale-21, Quality of Life Enjoyment and	
	1 Female aged 51		Satisfaction Questionnaire, Brief fear of	
			negative evaluation scale, The working	
			alliance inventory	
Neacsiu et al., 2014	N= 48 Trans-diagnostic emotion	Dialectic Behavioural Therapy Skills	DERS, DBT-WCCL, PHQ, OASIS, B-	Pilot RCT
(USA)	dysregulation focused	Training (N=24)	THI, ASI-SR, CEIS	
	13 males / 29 females	Activities based support group (N=24)		
	>18 years old			
Co-Morbidity Focuse	ed			1
Craigie et al., 2007	N = 115 Anxiety or Depression,	Group Cognitive Behavioural Therapy	Comparisons were made in relation to	Cohort Study
(Australia)	screened also for PD co-		personality disorder co-morbidity	
	morbidity	Groups mixed but co-morbidity measured as	The Mini International Neuropsychiatric,	
		(No PD, N=31)	Interview, DSM-IV, MCMI-III, BDI-II,	
	82 female / 33 male	Simple PD, N=50)	CCL, Q-LES-Q	
		Complex PD, N=34)		
Maddux et al.,2009	N= 681 Depression and	Nefazodone (N=226)	SCID-I, SCID II,HRSD	Three arm RCT
(USA)	predominately cluster C PD			
	445 females /236 males			
	1	85	1	1

		Cognitive Behavioural Analysis System of		
		Psychotherapy designed for treatment of		
		depression (N=228)		
		Or combined treatments (N=227)		
Joyce et al., 2007	N =167 Depression with	Interpersonal Psychotherapy (N=87)	SCID-I, MADRS, SCID-PQ, TCI	RCT
(New Zealand)	secondary interest of PD co-	4 removed		
	morbidity			
		Cognitive Behavioural Therapy (N=80)		
	122 female / 45 males	6 removed from initial study.		
Berger et al., 2004	N = 73 Panic disorder or anxiety	Paroxetine only (N=38)	Panic Attack Diary, Likert Scale, CGI,	RCT
(Austria)	and co-morbid PD.	Paroxetine+ Group Cognitive Interpersonal	The Sheehan Disability Scale.	
		Therapy (N=35)		
	48 female / 25 males			
	l	<u>I</u>	1	1

Assessment tools - Personality Disorder Belief Questioniarre (PDBQ), Avoidant personality sub-scale, Lehrer Woolfolk Anxiety Symptoms Questionairre (LWASQ), and social phobia sub scale of the social phobia anxiety inventory (SPAI), Post session questionnaire (PSQ), Difficulties in emotional regulation scale (DERS), DBT ways of coping checklist (DBT-WCCL), Patient health questionnaire (PHQ), Overall anxiety severity and impairment scale (OASIS), Brief History Interview (B-THI), Addiction Severity Index self report form (ASI-SR), Credibility and Expectancy of Improvement Scales (CEIS), The Millon Clinical Multiaxial Inventory-III (MCMI-III) screening, The Becks Depression Inventory –II (BDI-II), The Cognitive Checklist (CCL), The Quality of Life Enjoyment and Satisfaction Questionnairre (Q-LES-Q), The Structured Clinical Interview (SCID-I) The Structured Clinical Interview (SCID II) for personality disorder screening, Hamilton Rating Scale for Depression (HRSD), The Structured Clinical Interview for personality disorders questionnaire (SCID-PQ), The Temperament and Character Inventory (TCI), The Clinical Global Impression Scale (CGI)

3.6.1 Participants

In total 1,276 participants were included in this section of the review. The studies that were focussed on personality disorder treatments included 240 participants (Muran et al., 2005; 2009; Emmelkamp et al., 2006; Neasciu et al., 2014; Rees and Pritchard., 2013). In all 1,036 were included in the studies that focussed upon the treatment of co-morbidity, three focussing on co-morbidity of personality disorder in depression (Craigie et al., 2007; Maddux et al., 2009; Joyce et al., 2007) and one with a focus on comorbidity in anxiety (Berger et al., 2004).

A majority of the papers with a specific focus on personal disorder recruited mainly people with Cluster C personality disorders, with the exception of Neasciu et al (2014) who recruited (N= 48) participants with mixed emotional dysregulation disorders.

Participants were recruited from single clinic populations and most used clear randomisation processes with the exception of Rees and Pritchard (2013) which was an observational case study and only included 2 participants. All studies excluded borderline personality disorder. The reason for this could be attributed to the review being primary care specific. Two of the studies excluded Cluster A and B personality disorder, as it was felt that patients from Cluster A and B required longer term treatments based on available evidence (Muran et al., 2005; Muran et al., 2009).

3.6.2 Interventions

A variety of different interventions were described in the studies (Table 8). Most commonly included was cognitive behavioural therapy (CBT N=769) (Muran et al., 2005; Muran et al., 2009; Emmelkamp et al., 2006; Rees and Pritchard, 2013; Craigie et al., 2007; Maddux et al., 2009; Joyce et al., 2007). A variety of other interventions were used including brief relational therapy (BRT) (N=41), Short term dynamic therapy (STDT) (N=41) (Muran et al., 2005), Brief psychodynamic therapy (BDT) (N=23) and waiting list control group (WLC) (N=18) (Emmelkamp et al., 2006). Only the Neacsiu et al (2014) study explored the use of newer generation personality disordered treatments, within this study they evaluated the

impact of a dialectic behavioural therapy skills training (DBT-ST) (N=24) compared against an activities based support group (ASG) (N=24)

Two of the included studies provided a secondary analysis of previous trials. Maddux et al (2009) provided a secondary analysis of an earlier RCT in which cognitive behavioural therapy was compared against pharmaceutical treatment with Nefazadone or combined cognitive behavioural therapy and Nefazadone treatment for depression (Keller et al., 2000). Joyce et al (2007) also provided a secondary analysis from an earlier depression focused RCT which compared cognitive behavioural therapy against interpersonal psychological therapy (IPT) for depression (Luty et al., 2007).

Craigie et al (2007) explored the outcome of cognitive behavioural therapy when personality disorder and depression complexity presented. Only one study explored the co-morbid impact of personality disorder on panic disorders and anxiety cognitive behavioural therapy group treatments (Berger et al., 2004). Rees and Pritchard (2013) provided an observational case study that explored the effectiveness of cognitive therapy for avoidant personality disorder in two clinical case studies. However the design of this research whilst providing interesting preliminary information was weak. An overview of the interventions provided and outcome measure frequency follow ups are outlined in table 8.

<u>Table 8 – Table of Interventions</u>

	Table of Interventions				
Authors	Interventions	Session Duration and Frequency	Outcome measure frequency and follow up periods		
Muran et al., 2005	Brief Relational Therapy (BRT),	30 fixed sessions one session per	Patient Questionnaires - Pre Measure SCID, Self reports at pre-		
		week.	treatment, Termination and 6 month follow up.		
	Cognitive Behavioural Therapy (CBT),		Brief Questionnaires complete every session		
			Therapist Questionnaires - complete at 3 rd session and		
	Short Term Dynamic Therapy (STDT),		termination.		
Muran et al., 2009	As Above	30 fixed sessions one session per	As above plus post session questionnaire after every session for		
		week.	the first 6 weeks only (PSQ) both patients and therapist		
			independently complete.		
Emmelkamp et al.,	Brief Dynamic Therapy (BDT)	45 minute sessions 20 session over	Pre measure SCID II, self-report at pre-treatment, post treatment		
2006		6 month period	and at 6 month follow up.		
	Cognitive Behavioural Therapy (CBT)				
	Waiting List control (WLC)				
Rees and Pritchard,	Cognitive Behavioural Therapy (CBT),	12 weekly, 50 minutes sessions	Pre-treatment, post treatment and 6 week follow up		
2013					
Neacsiu et al., 2014	Dialectic Behavioural Therapy (Skills	Each group lasted 16 sessions +	Pre-treatment, 2 months, post treatment and 2 month follow up.		
	Training) (DBT-ST)	included 30 individual introductory			
		meetings.			
	Activities based support group (ASG)				

Craigie et al., 2007	Group Cognitive Behavioural Therapy	10 weekly 2 hour sessions and a	Pre-treatment, post treatment and 1 month follow up.
	(CBT)	one month follow up session	
Maddux et al.,2009	Nefazodone Prescription	12 weeks treatment	Pre and post treatment using SCID-II
	Cognitive Behavioural Analysis System		Depression was rated at each clinical visit using Hamilton Rating
	of Psychotherapy		Scale for Depression (HRSD)
	Or combined treatments		
Joyce et al., 2007	Interpersonal Psychotherapy (IPT)	16 weeks of therapy 8-19, 50	Pre and 6 weeks and post therapy
		minute weekly sessions then an	
	Cognitive Behavioural Therapy (CBT)	additional 3-8 monthly maintenance	
		sessions spread over 6 months	
		(minimum of 8 sessions to complete	
		the treatment)	
Berger et al., 2004	Paroxetine prescription	Paroxetine 24 Weeks	Assessments at 1,2,4,6,8,10,16,20,24 weeks
	Combined Paroxetine+ Group		
	Cognitive Interpersonal Therapy Group	Combined 20 weekly sessions with	
		2 sessions either side of group	
		treatment	

Within the identified studies there is a strong focus on using cognitive behavioural interventions and psycho-dynamic interventions in providing personality disorder specific treatments to this patient group in primary care and particularly those who present with Cluster C personality disorders. Only one study utilised an adaption of the newer generation personality disorder treatments that being 'dialectic behavioural therapy –skills training' (Neacsiu et al., 2014). Dialectic behavioural therapy currently has the best evidence base for BPD treatment and replication of studies within the literature (Stoffers et al., 2012).

Cognitive behavioural therapy is the most commonly used intervention (Table 8) however there is a wide range of different control and comparative treatments, treatment durations and differences in frequency of treatment are reported. Furthermore a wide variety of differing outcome measures were used making comparability difficult. Follow up also lacked any consistency, only six of the studies described follow up periods which ranged from one to six months. The confounding differences therefore make any collective interpretation of the treatment outcomes and their results unattainable.

3.6.3 Treatment of Personality Disorder in Primary Care - Findings

Cognitive behavioural therapy appears to hold some potential utility for having a positive effect on this patient group. Two studies report cognitive behavioural therapy as having superior treatment effectiveness than other treatments. One study compared cognitive behavioural therapy against brief relational therapy (BRT) and short term dynamic therapy (STDT), this study focussed on the treatment of Cluster C personality disorders (Muran et al., 2005). Muran et al (2009) used the same sample to report the impact of therapeutic alliance and repairing of therapeutic relationships following therapeutic ruptures and found that less severe ruptures and better resolutions improved engagement and session quality for patients. Less ruptures were reported to occur in the cognitive behavioural therapy group when compared against the brief relational therapy and short term dynamic therapy groups. Furthermore patients were less likely to self-report ruptures than therapists (Muran et al., 2009).

Cognitive behavioural therapy was also more effective than interpersonal psychotherapy (IPT) as outlined in the Maddux et al (2009) trial which focussed on the treatment of chronic depression alongside co-morbid personality disorder.

Cognitive behavioural therapy however was reported to have comparable effectiveness to brief psycho-dynamic psychotherapy (BDT) and the waiting list control group in the treatment of avoidant personality disorder (Emmelkamp et al., 2006). The brief psycho-dynamic psychotherapy intervention group however showed similar effect to the waiting list control. Durability of effect was measured at 6 month follow up and a significant difference was reported in 4 of the 7 measures employed. Only 9% of participants who received cognitive behavioral therapy still met the criteria for avoidant personality disorder, compared to 36% of participants in the BDT group at the follow up stage (Emmelkamp et al., 2006).

Providing group cognitive behavioural therapy displayed superior effectiveness on outcomes when compared against an interpersonal psychotherapy group (IPT). Increased complexity was reported in the cognitive behavioural therapy group however even with the added complexity this group still showed greater effectiveness than the IPT group. No personality disorder specific outcome measures were employed in this trial but the cognitive behavioural therapy group was shown to help this patient group with their symptoms of depression (Joyce et al., 2007). However in another study that included CBT group therapy as the intervention personality disorder outcome measures were used and CBT group therapy was shown to have minimal impact upon personality disorder symptoms. However those identified with less severity of personality disorder did respond more positively than those with higher levels of severity (Craigie et al., 2007). A group component was also employed by Berger et al (2004) however this intervention was described as 'group interpersonal therapy' and the focus of the intervention was on panic disorder and anxiety, however this therapy did not improve outcomes but it is reported that those with personality disorder comorbidity require a longer duration of treatment. Rees and Pritchard (2013) used an observational case study methodology (N=2) however the low numbers and methodologically weak design make any findings unusable.

3.6.4 Quality Appraisal

Utilising the EPHPP provided a global quality rating for each study (Table 9). Of the nine studies three were determined to be 'Weak' (Craigie et al., 2009; Rees and Pritchard 2013; Berger et al., 2004) four 'Moderate' (Muran et al., 2005; 2009; Emmelkamp et al., 2006; Maddux et al., 2009) and two 'Strong' (Neasciu et al., 2014; Joyce et al., 2007).

Table 9 – Summary of overall quality appraisal ratings using the EPHPP

			(COMPONENT RAT	INGS		
Study Refence (Author, Date)	a) SELECTION BIAS	B) STUDY DESIGN	C) CONFOUNDERS	D) BLINDING	E) DATA COLLECTION METHODS	F) WITHDRAWALS AND DROP OUTS	G) GLOBAL RATING (SEE SCORING SHEET)
Muran et al., 2005	2 MODERATE	1 STRONG	3 WEAK	2 MODERATE	1 STRONG	2 MODERATE	2 MODERATE
Muran et al., 2009	2 MODERATE	1 STRONG	3 WEAK	2 MODERATE	1 STRONG	2 MODERATE	2 MODERATE
Maddux et al., 2009; Keller et al., 2000	1 STRONG	1 STRONG	3 WEAK	2 MODERATE	1 STRONG	2 MODERATE	2 MODERATE
Craigie et al., 2007	2 MODERATE	2 MODERATE	3 WEAK	3 WEAK	1 STRONG	2 MODERATE	3 WEAK
Joyce et al., 2007; Luty et al., 2007	2 MODERATE	1 STRONG	2 MODERATE	2 MODERATE	1 STRONG	2 MODERATE	1 STRONG
Emmelkamp et al., 2006	2 MODERATE	1 STRONG	3 WEAK	2 MODERATE	1 STRONG	2 MODERATE	2 MODERATE
Rees and Pritchard., 2013	3 WEAK	2 MODERATE	3 WEAK	3 WEAK	1 STRONG	1 STRONG	3 WEAK
Berger et al., 2004	2 MODERATE	1 STRONG	3 WEAK	3 WEAK	1 STRONG	2 MODERATE	3 WEAK
Neacsiu et al., 2014	1 STRONG	1 STRONG	1 STRONG	2 MODERATE	1 STRONG	1 STRONG	1 STRONG

3.6.5 Critique

All results should be treated with caution and no firm conclusions can be reached. No studies included described power or power calculations and the mixed designs were largely weak to moderate with the exception of two (Joyce et al., 2007; Neacsiu et al., 2014). The diverse differences amongst the studies made them incomparable. Differing outcomes, interventions, settings and focus on different diagnosis were all identified confounders effecting further analysis of this data collectively difficult to achieve. Additionally follow up periods were different and the longest was a 6 month follow up period therefore durability of effect is difficult to report.

One of the studies (Maddux et al., 2009) was funded by the pharmaceutical company that provided the medication used in the trial. This conflict of interest was declared however this could have increased bias of reported effect. Another study (Neacsiu et al., 2014) reported having a control group that was comparable in time and attention to the intervention group however the duration of sessions was double that of the control group. Therefore the beneficial effect reported may have been due to the extra time and skills training the intervention group received as the comparison interventions were not balanced in duration.

3.6.6 Treatment Results Conclusion

Only seven RCTs (N=1226) were identified, one was a pilot study (N=48), one cohort study (N=115) and one observational case study (N=2). All were moderate in size with the exception of Maddux et al (2009) that had 681 participants. The variety of studies and their confounders made drawing conclusions and making comparisons unattainable. The confounders included the different treatments, outcome measures and diagnosis. The settings were also variable and no UK based trials were identified or no IAPT specific trials were identified. Hence the literature available for treatment in primary care populations is very weak. Some of the studies described statistically significant findings however none of those reported were powered. No firm conclusions can therefore be reached hence this body of evidence and its applicability to IAPT and co-morbid personality disorder treatment needs to be treated with caution.

Overall the results suggest that cognitive behavioural therapy, manualised treatments and coping skills development as in the dialectic behavioural therapy skills training study, lend themselves better to time limited interventions than interventions of relational or psychodynamic underpinnings for this patient group. Only one study that trialed an intervention taken from the personality disorder evidence based treatments was identified and used DBT interventions (Neacsiu et al., 2014). This paper scored the joint highest in its appraisal using the EPHPP and also appeared most relevant to the author's area of interest. Furthermore it was methodological robust in it design, however it was only a small scale pilot RCT.

3.7 Treatment Experience - Results

This review focused on objective 3 'To determine what are the treatment experiences of people with personality disorder in primary care. The CASP qualitative appraisal tool (CASP, 2014) was used to guide the reporting of this section. There is a lack of research in understanding the treatment experiences of people with personality disorder in primary care. No research to date has been focused on psychological treatment specific to personality disorder in primary care IAPT services, hence a paucity of literature relating to treatment experience was identified.

Only 2 qualitative papers (Gilbert et al., 2012; 2013) were identified from the search that explored the experiences of people with personality disorder traits at a primary care level, but these experiences were not specific to primary care treatment experiences (Table 10). Both publications used the same sample and were conducted in the 'Icebreaker Service, Plymouth UK. The Icebreaker Service provided a street level NHS primary care service for people who presented as at risk of personality disorder between the ages of 16-25. A majority of the participants were over 18 and therefore these papers were included in the review.

Table 10 – Qualitative Papers Overview

Gilbert et al., 2012; 2013	
Recruitment /	Self-selecting sample (N=27)
Participants	
Methodology	Qualitative – twin track approach described
Research Aim	Exploration of chaotic life styles / traumatic
	relationships (Gilbert et al., 2012)
	Exploration of crisis situations (Gilbert et al., 2013)
Data Collection	Individual semi structured interviews
	Recorded and transcribed verbatim
Data Analysis	Thematic analysis appears to be the chosen data
	analysis approach this was performed by two
	independent analysts (Gilbert et al., 2012) and three
	in Gilbert et al (2013)

Both papers make reference to the lack of published research available in understanding people with personality disorder traits or those 'at risk of personality disorder'. The same data set was used for both papers with different areas of analysis and participants in both studies are identical. The sample was self-selecting. A total of 70 participants were invited to participate however only 27 took part. 20% did not respond to the invite after dropping out of the service. Originally the researchers set out to interview 20 participants and planned to carry out additional interviews with family members and friends using a snowballing recruitment strategy. However during the course of the research it became apparent that participants were not forthcoming in identifying any family members or friends to be interviewed and therefore this was removed. In light of this the researchers increased the numbers of patient participants to be interviewed hence reached (N=27). Recruitment to the study was closed once saturation was reached and no new themes were emerging.

Gilbert et al (2013) described using a "twin track approach" with a good rationale provided for this choice of method which is consistent with the study aims. As both papers are interested in understanding the experiences of individuals at risk of personality disorder, the methods employed were appropriate. Gilbert et al

(2012) however failed to provide any substantive detail on the qualitative methodology used although it would appear a thematic analysis approach was employed to analyse the data.

Gilbert et al (2012) explored the accounts of young people at risk of personality disorder in relation to chaotic lifestyles and traumatic relationships they may have experienced prior to intervention and since referral into the service. Gilbert et al (2013) explored crisis situations in the young people 'at risk of personality disorder' in an attempt to understand and develop new insights into these difficulties to inform future treatments and interventions for this patient group. Individual semi structured interviews were carried out to gather this data. The researchers demonstrated how they adopted an empathic approach to the research interviews due to the potentially distressing content that could emerge. A clear account of the patient being at the heart of the study is provided in Gilbert et al (2013) with their emotional wellbeing, sensitivity and a clear protocol for supporting their distress presented.

Data was analysed using the ATLAS.ti software. Conventions for coding and developing themes were carried out by two independent and experienced researchers (Gilbert et al., 2012). It is unclear if the same researchers carried out the interviews. It is unclear in the Gilbert et al (2013) paper who conducted the analysis however 3 analysts are mentioned hence improving the credibility of the findings by having more than one analyst in both papers. During the data analysis of Gilbert et al (2012) the different responses of individuals were discussed with potential explanations introduced. Interviewers were independent from the service. Ethical approval is briefly described.

3.7.1 Critique

The papers reviewed are taken from the same sample to provide different analysis of the data provided. However the information regarding recruitment processes and saturation processes were not fully outlined in the papers when viewed independently. In order to gain a comprehensive overview of these research and the methods, employed in both papers need to be reviewed together. Participants were not included in the formulation of the research questions however during the

interviews were invited to add any information they thought may be relevant to share based on their experiences.

Follow up interviews were planned 1 year after the original interviews however participants declined as they had moved on or where too busy. Gilbert et al (2012) argued that the sample is representative of the 'at risk' population however the self-selecting sample and exclusion of people who either left the service early or escalated due to risk and severity could been seen as an unbalanced sample. This sample therefore is unlikely to be fully representative of the patient group as those who dropped out, refused or were excluded due to secondary care referrals may have different difficulties and views than those outlined in the papers.

Originally the researchers set out to interview 20 patients and a selection of carers or friends. Due to an inability to recruit carers or friends a decision was made to increase the numbers of patient participants. It is then reported that saturation was reached at (N=27) however had the cap of 20 been reached and the study stopped as originally proposed, it could be assumed that saturation would not have been reached and the only reason it was reached is due to the lack of success in recruiting carers. The numbers originally proposed should not have been influenced by the removal of the family / friend interviews, saturation should have been the point to close recruitment, as without saturation the rigour of the findings would have been weakened (Ritchie et al., 2014).

3.7.2 Results

The main outcomes reported provide a good insight into the need for a greater understanding of people with traits of personality disorder in primary care and in particular younger people via an early intervention model. An economic viability argument is provided in the Gilbert et al (2012) study, who stated that early support, problem solving and guidance may assist in reducing the likelihood of behaviours, risks and escalation of service use. One of the greatest challenges identified however is in the need to develop a supportive structure for people post service involvement in mainstream society (Gilbert et al., 2012). Gilbert et al (2013) also make reference to the need for ongoing support mechanisms and an apparent reliance on support services. Participants are described as having

problems in developing stable and secure relationships outside of support services. It is suggested that interventions aimed at reducing crisis may enable more effective coping and less chaotic life styles.

Both papers provided new insight into an under-researched area and more knowledge is required regarding the experiences of people who have traits of personality disorder or undiagnosed personality disorder in primary care services. There is a consistency in the results of this research with other published papers and policy documents regarding the need to understand and provide interventions in a timely manner to people with personality disorder at a primary care level. New areas for research and enquiry are suggested with an emphasis on social support outside of services and pro-active strategies of timely support to people at risk of personality disorder.

In conclusion whilst some interesting findings have emerged from the studies, they do not tell us anything about the treatment experiences of people with personality disorder in receipt of primary care IAPT services or primary care based treatments. The results do however provide an insight into the patient group and some of their difficulties and recommend the need for further research and the need for treatments for this patient group at a primary care level.

3.8 Needs - Results

Within this section of the results for objective 4 '*To determine what are the needs of people with personality disorder in primary care,* shall be explored. A dedicated and specific exploration of needs in people who presented with personality disorder at a primary care level is presented.

Although 16 papers were included, there were only a two papers that solely focused on the needs of the patient group at a primary care level (Paris, 2013; Byng and Gask, 2009). All other studies were included due to them describing personality disorder needs in relation to its co-morbidity with other disorders such as anxiety and depression or were narrative reviews of personality disorder treatments in secondary care that included within them needs to be addressed at a primary care level. A selection of the papers offered advice that informed and

addressed the general needs of people with personality disorder. All identified papers were expert opinion. No papers included the perspectives of the patient group or their lived experiences.

The identified expert opinion papers were appraised using a tool as described earlier by Burrows and Walker (2012). The questions set out for appraising the evidence are utilised to synthesis and report the findings. Using the tool by Burrow and Walker (2012) it should be noted that this tool is not without its limitations and although attempts to provide guidance are described within the paper accompanying the tool, answering questions can lack reliability as subjective bias, influence and level of reviewers knowledge can all impact on the answering of questions.

Question 1

Is the author an expert?

Directly reading the papers does not always provide clarity on the level of expertise the authors possess. Therefore the following process was developed and applied (see table 11). A physical internet search of each of the authors took place to view their areas of interest, previous research and publications in order to apply the coding as described below.

Table 11 - Author expertise table

Level of expertise	Author Reference
1 = Expert writer in the	Zanarini (2008)
personality disorder field	Sansone and Sansone (2008)
	Paris (2013)
	Moran and Crawford (2013)
	Tyrer and Duggan (2007)
	Livesley (2005)
	Newton-Howes (2008)
	Haywood and Moran (2007)
2 = Professor, academic or	Schindler et al (2013)
mental health clinical specialist	Latas and Milvanovic (2014)
	Macmanus and Fahy (2008)
	Grant et al (2014)
	Byng and Gask (2009)
	Trull et al (2003)
	Dixon-Gordon et al (2011)
3 = Other or unknown	Berk and Rhodes (2005)

Eight papers scored a 1 as they were from expert writers and academics in the personality disorder field, seven papers scored a 2 being from clinical expertise or academic backgrounds in mental health. One paper received a score of 3, a search to establish the background of the authors Berk and Rhodes (2005) was unsuccessful, hence was rated as unknown.

Question 2

Is the opinion published in a credible source?

Once again the rating method described for this question lacked any reliability instead Burrow and Walker (2012) described the expertise of editors of books as a measure of publication credibility, with no reference to guide journal articles credibility. A decision was therefore made to measure this on impact factor given all papers included where journal publications. Impact factors however are related to the specific journals not a specific paper or article but are used as a measure of impact based on the frequency of citations. Whilst impact factors are important in measuring the quality and credibility of a journal the score, it does not reflect the quality of an individual paper and therefore should not be used as a stand-alone analysis of quality (Polit and Northam, 2011).

Questions 3,4,5

Is the opinion evidence based? Are the authors personal statements clearly presented as such? Is the opinion in response to a practical concern?

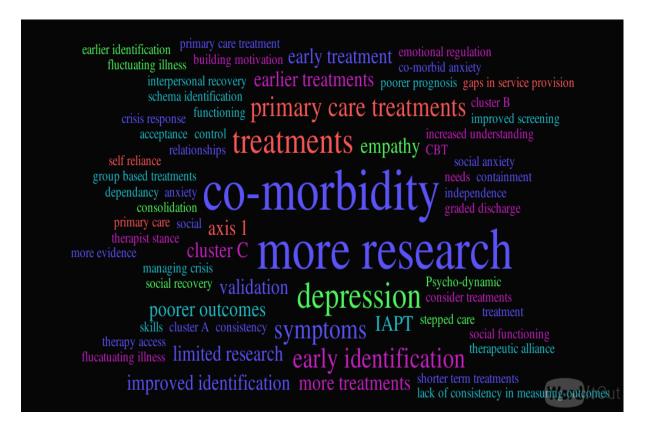
All papers identified were evidence based and supported by clear references throughout, clearly presented and in response to practical and reasonable concerns.

Question 6

What are the findings?

Figure 5, provides a visual representation of findings in the form of a word cloud, highlighting the most common needs identified during this review. Those more prominent and larger font size represent needs that have been more frequently mentioned, with the smaller font mentioned less frequently. In order to develop the word cloud the author hand picked out the key identified needs from each paper in relation to personality disorder presentations in primary care services.

Figure 5 – Patient Need's Word Cloud



The emerging needs from the literature are featured above with co-morbidity being the most frequently mentioned. This was closely followed by the need for better identification of personality disorder in primary care in order to provide more effective and timely interventions. Shorter term treatments and specific personality disorder focused approaches presented throughout the review however as already suggested more evidence based approaches and treatments are required. Within the needs review clear guidance and recommendations are frequently made however as can be seen from the treatment section of this literature review although needs are clearly identified by experts in the field little has been done to adequately address these concerns.

There is common acknowledgement that personality disorder co-morbidity complicates treatment and effects outcomes in the treatment of Axis 1 conditions such as anxiety and depression (Berk and Rhodes, 2005; Schindler et al, 2013; Latas and Milvanovic, 2014; Macmanus and Fahy, 2008; Newton-Howes, 2008; Haywood and Moran, 2007; Dixon-Gordon, 2011). This is important as IAPT services in the UK are directed to provide treatment to Axis 1 conditions (DOH, 2008).

Another common theme that emerged was the identification of key responses and treatments components that should be considered when providing care to those with personality disorder, including the need to develop good therapeutic alliance, enhance emotional regulation skills, manage crisis, validation, containment and consistency (Zanarini, 2008; Paris, 2013; Livesley, 2005; Berk and Rhodes, 2005). Outside of therapy efforts should be made to guide patients to develop an improved self-reliance, maintain social activities were possible, such as work and education and work on their interpersonal relationships, all of which should positively impact on their social functioning (Zanarini, 2008; Paris, 2013; Berk and Rhodes, 2005). Formats of treatments and key responses are suggested within the needs literature (Livesley, 2005; Zanarini, 2008; Berk and Rhodes, 2005; Haywood and Moran, 2008) including group therapy approaches (Moran and Crawford, 2013).

Questions 7,8

Does the author provide arguments for and against the position? Does the author identify limitations?

Assessment of the expert opinion biases were achieved by exploring the balance of their arguments and any identification of limitations or conflicts of interest. Generally these are mixed with some experts providing a balanced narrative (Zanarini, 2008; Paris, 2013; Moran and Crawford, 2013; Grant et al., 2014; Newton-Howes, 2008). Whilst others are very focused on sharing the intended key message with little diversion or mention of limitations or cautionary advice (Schindler et al., 2013; Sansone and Sansone, 2008; Latas and Milvanovic 2014; Livesley, 2005; Byng and Gask, 2009; Trull et al., 2003; Tyrer and Duggan, 2007; Berk and Rhodes 2005; Haywood and Moran, 2008 Dixon-Gordon, 2011).

3.9 Literature Review Summary

3.9.1 Strengths

A strength of this literature review is the justified choice of methodology, as the scoping study literature review captured a wide range of literature and scoped out the available evidence from a dearth of literature available in this specific area of enquiry. The adopted enhancements as suggested by Levac et al (2010) enabled a more thorough and rigourous approach that strengthened this review and its findings. The reporting of the literature within 4 different key objectives is a strength, as presenting and analysing the literature in this way enabled the effective use of critical appraisal tools to support the reporting of results.

The quantitative section of the review, which explored the treatment of personality disorder within primary care, provided further evidence of the lack of specific approaches to treating or identifying this patient group. The sections relating to treatment experiences and needs highlighted a further lack of available evidence. Personality disorder in primary care is reported to go undetected therefore the dearth in literature in this specific area is expected.

3.9.2 Limitations

A limitation of this review is that the author was independently responsible for the reviewing of titles and abstracts, whilst clarification and advice was sought from academic supervisors when the author felt a second opinion was required on the papers that were less clearly meeting inclusion or exclusion, this review could have been strengthened with a more consistent team approach to the selection of papers included and the analysis of them throughout.

The treatment of personality disorder section of this review contained several quantitative studies that either reported secondary analysis of data from original studies or explored the impact of co-morbid personality disorder as a reason for a negative treatment effect in trials. Only one study included the newer evidence based psychological therapies outlined in the NICE (2009a) guidelines.

The studies included that explored the treatment experiences at best provide a general insight into people at risk of personality disorder but do not provide any detail of the treatment experience. Instead their focus is on insights into living with the difficulties and retrospective experiences of life experiences that may have contributed towards their difficulties.

A limitation of the needs section of the review is in its weakened body of evidence as only expert opinion papers are identified. No qualitative papers were identified that explored the patient perspectives of needs. There is a lack of any qualitative research exploring the views and opinions of those using the primary care services with personality disorder and related difficulties.

3.9.3 Literature Review Key Findings

In summary when combined the findings of this review are unsubstantiated and strongly highlight the need for further research. A need for earlier identification of personality disorder and a greater understanding of the patient group's needs and treatment experiences in IAPT is required. The lack of any identifiable evidence based treatment further supports the rationale to pursue the next stage of this research. Carrying out interviews with IAPT healthcare professionals and patients

in primary care with personality disorder traits will establish what would an acceptable and feasible intervention in IAPT might look like and provides the necessary and thorough exploration required to provide the preparatory evidence to support the development of future IAPT treatments.

The key findings from this review highlights the lack of existing knowledge of personality disorder populations in primary care and a lack of evidence based interventions relating to the treatment of this patient group. This review is the first review of its kind exploring personality disorder treatments in primary care services. The key findings from each of the 4 objectives outlined at the start of this chapter are provided below:

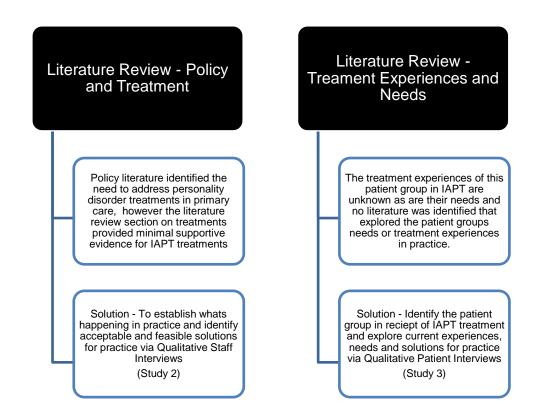
- Objective 1, Policy Identifies a need to provide innovative interventions for people with personality disorder using a stepped care model that includes treatment in IAPT services.
- Objective 2, Treatment There is a dearth of literature available that
 provides evidence based treatment for this patient group in primary care
 IAPT services. No UK studies have been identified leading to the
 assumption that this is still not being addressed within UK IAPT services.
- Objective 3, Treatment Experience No specific papers have been identified that report treatment experiences of the patient group in receipt of an IAPT intervention.
- Objective 4, Needs Only expert opinions have been provided within the literature to date regarding this patient group needs, no patient research to date has been published that has explored this patient groups perspective on their needs.

This scoping study has via a thorough mapping out of the available literature provided the insight to answer the original overarching research question that was described at the beginning of this chapter.

What are the needs and treatment experiences of people with personality disorder traits in primary care?

Collectively the findings provide a clear and comprehensive insight that we do not currently know what the needs and treatment experiences of people with personality disorder traits in primary care are. This therefore provides the necessary evidence and supportive rationale for the qualitative studies 2 and 3 that followed. Figure 6 displays how different parts of the literature review have supported the rationale for the following studies and were they are interconnected.

Figure 6 - Linked Components of the Literature Review to the Qualitative Studies



Chapter 4

Working Research Methods

4.1 Working Research Methods

This chapter provides an overview of the working research methods employed during this thesis. Methodology and methods differ in research as methodology is focused on the specific research approaches taken and their justification, whilst the working research methods are focused on the procedures that were applied (Kothari and Garg, 2009). The working research methods for both qualitative studies 2 and 3 are outlined in this chapter.

4.1.1 Study 2 IAPT Healthcare Professional Interviews - Objective

Qualitative interviews with IAPT healthcare professionals to explore the views and experiences of therapists working within IAPT services with this patient group.

4.1.2 Study 3 Patient Participant Interviews – Objective

Qualitative interviews with patients to explore and understand their needs and treatment experiences within IAPT services.

4.2 Selection Criteria (Study 2 IAPT Healthcare Professionals Interviews)

Studies 2 and 3 had defined and different selection criteria to ensure that a diverse sample of participants were identified to inform and answer the research objectives. The inclusion/exclusion criteria, for Study 2 is outlined below;

Inclusion criteria

 Frontline clinical staff and/or involved in the clinical leadership or direct line management of IAPT services. This included both trained and trainee psychological wellbeing practitioners (PWP's) and high intensity cognitive behavioural therapist, clinical psychologists, clinical leaders and IAPT clinical service managers.

Exclusion criteria

 Staff working outside of IAPT or the 5 Boroughs Partnership NHS Foundation Trust.

4.3 Recruitment (Study 2 IAPT Healthcare Professionals Interviews)

Recruitment commenced on 23/06/15. IAPT Healthcare professional interviews were conducted between 30/06/15 and 4/12/15 and recruitment closed on 12/01/16. A purposive sample was used to recruit participants working in IAPT as frontline psychological therapists at both Step 2 and Step 3 and members of the clinical leadership team and managerial team that held direct line management for the IAPT service. A process for recruitment following 3 stages was adhered to in line with the research protocol.

Stage 1 - A strategy was put in place to raise the profile of the research amongst the IAPT workforce. Attendance at two IAPT staff meetings and at both a Step 2 and a Step 3 specific 'continued professional development meetings' were attended to provide an overview of the research and to begin the recruitment process by generating interest from potential IAPT healthcare professional participants. Recruitment Flyers (Appendix 4) approved by Ethics (Rec Reference: 15/NS/0043: IRAS Project ID: 173408, Appendix 5) were developed to promote recruitment. They were displayed in staff rooms and offices. The flyers were also distributed to all the potential participants working within the IAPT service via email and handed out at team meetings. Every member of the IAPT workforce (N=52) was sent a recruitment flyer via email and could register their interest in person, via phone or email.

Stage 2 – Two contingency plans were put in place to support the recruitment of IAPT healthcare professionals in case target recruitment was not achieved. The first was a reminder system that was sent via email to remind all potential participants of the opportunity for involvement in this study. The second was to

open up the opportunity to other IAPT services within the 5 Boroughs Partnership NHS Foundation Trusts. As target recruitment was achieved neither plan was implemented.

Stage 3 – Potential participants who had registered interest were provided with an information sheet (Appendix 6). Interview dates were then agreed (at least 24 hours had to have passed since receiving the information sheet and the interview). This allowed participants to reflect on the information sheet and provided them with the option to withdraw from involvement prior to the interview. Written consent was obtained prior to the interviews taking place (Appendix 7). A brief information gathering form (Appendix 8) was completed prior to each interview but only once written consent had been provided.

Early in the recruitment phase it was noted that Step 2 IAPT healthcare professionals were harder to recruit than Step 3 IAPT healthcare professionals and it became apparent this was due to a feeling that they had little to offer as many were relatively inexperienced and felt they had minimal knowledge of personality disorder. This was effectively addressed following attendance at a Step 2 meeting to discuss and alleviate these concerns highlighting the need to gain a diverse ample of staff with varying levels of knowledge to participate in this research.

4.4 Selection Criteria (Study 3 Patient Participant Interviews)

The inclusion/exclusion criteria, for Study 3 is detailed below;

Inclusion Criteria

- Scored 3 or more on the Standardised Assessment of Personality –
 Abbreviated Scale (SAPAS) Screening tool (Moran et al., 2003).
- Received a minimum of one IAPT treatment session
- Six weeks had passed since commencement of their first treatment session
- Had received their last treatment session within the last 12 months
- Were able to provide informed consent
- English speaking (due to a lack of resources to fund interpreters)
- Aged 18 and over

To be considered for involvement in the study each participant had to have completed at least one treatment session in IAPT in order for them to be able to reflect on their treatment experiences and required to be at least six weeks into the treatment timeframe before interviews could take place. Ensuring a six week timeframe had passed since commencement of therapy allowed adequate exposure to treatments in IAPT so that participants could comment on recent treatment experiences. The one session rule was adopted to ensure that those who dropped out of treatment prematurely were able to contribute to the research and provide valuable insights into why they may have dropped out.

Exclusion Criteria

Participants were excluded if they;

- Had any significant language barriers that would require a translator (due to financial constraints).
- Were identified as having significant literature problems that would markedly impact on their ability to engage or had a diagnosed learning disability or organic impairment that could impact on the interview process and capacity to consent.
- Were identified as being substance misuse dependant or in an acute phase of mental illness such as florid psychosis or actively suicidal.

Of note is the first two exclusion points which are likely to have been already screened out at the IAPT screening. Participants in severe mental health crisis or substance misuse dependency as outlined in the third point were excluded as it felt that it would be unethical to expose patients to research interviews who are in an acute phase of severe mental crisis or dependent on substances.

4.5 Recruitment (Study 3 Patient Participant Interviews)

Study 3 recruitment commenced on the 23/06/15. Patient interviews were conducted between 28/07/15 and 19/01/16 and recruitment closed on 12/01/16. Potential patient participants were recruited from the 5 Boroughs Partnership NHS Foundation Trusts, Wigan and Leigh IAPT service. Recruitment focussed on all

new IAPT referrals, those currently in receipt of a Step 2 or Step 3 treatment and those discharged from IAPT treatment in past 12 months. The administrators of the IAPT service and therapist were advised of the recruitment procedures as detailed in the research protocol (Appendix 9) and were given a point of contact for any clarification required. Regular contact was maintained with the administration team and therapists and made regular face to face visits to the team offices to ensure adherence to the protocol was undertaken.

As with the IAPT healthcare professionals a process for recruitment in line with the stages set out in the research protocol were adhered too.

Stage 1 - A patient recruitment flyer (Appendix 10) and a cover letter, that provided an introduction to the research was given to potential participants (Appendix 11). Initially they were provided to all new IAPT referrals at the point of their first treatment session via their therapist.

Flyers and cover letters were provided to all those currently in active treatment however it is unlikely all were distributed. Other methods of recruitment included the displaying of flyers in IAPT patient waiting areas.

Stage 2 - The same information was also provided to those actively in receipt of treatment at Step 2 or Step 3. Therapists were tasked with sharing the recruitment flyers and cover letters with all patients on their active caseloads. It became apparent in the first few weeks that a minority of therapists were only sharing this information with the patients they felt met the criteria for involvement into the study, based on their clinical perceptions. Therapist self-screening however could have proven problematic as it became apparent that they were only selecting those with obvious traits of personality disorder and their perceptions would have been an unreliable method of participant recruitment due to mixed levels of personality disorder knowledge within the workforce. Challenges with requesting the support of clinicians to recruit patient participants is common and can be attributed to a variety of factors including; self-screening, not having allocated time to support recruitment and in protecting patients from being the disappointment of rejection as unsuitable participants (Adams et al., 2015). In an attempt to reduce the risk of this occurring the researcher offered clarification via attendance at team

meetings, being visible within the IAPT clinics and via email contacts. It was stipulated that all new patients and all those currently in active treatment should have equal opportunity for involvement in the research and that any decisions made on screening into the study would be made following adherence to the research protocol and the participants meeting the defined inclusion criteria.

Stage 3 – A contingency plan was developed if recruitment failed. This involved forwarding the recruitment flyers and cover letter being sent to patients who had been discharged from the IAPT service within the past 12 months. Twelve months was set as a limit to ensure that only patients with recent experiences of treatment could retrospectively share their experiences. To make this more manageable and to reduce the risk of over exposing the research unnecessarily or turning away potential participants, the sharing of recruitment flyers and covering letters was staggered. A three month timeframe was set for each stage of this plan, starting with those most recently discharged prior to the recruitment strategy going live.

Due to insufficient participants and hence saturation not being reached the above contingency plan was used within the patient recruitment process. A list of patients across both the Wigan and Leigh sites were identified who had been most recently discharged from the first three month timeframe. To avoid over recruitment, flyers were distributed to the Leigh area only which resulted in target recruitment being reached.

Stage 4 – A further contingency plan that mirrors that outlined in the IAPT healthcare professional recruitment strategy, was put in place to mitigate against failure to recruit (which included the expansion of patient participant recruitment across all the 5 Boroughs Partnership NHS Foundation Trusts other local IAPT services) but was not utilised as target recruitment was achieved.

4.5.1 Patient Participant Screening Process

Once a potential patient participant had expressed interest either via email, telephone contact or via their IAPT therapist all participants were screened via telephone to ensure they met the inclusion. A brief script was read out (Appendix 12) to gain explicit verbal consent before commencing the SAPAS (Moran et al.,

2003). The SAPAS is not a diagnostic tool but it has during a preliminary validation been tested in its accuracy to identify personality disorder with a score of 3 out of 8 possible questions being indicative of a DSM IV (APA, 2000) diagnosable personality disorder in 90% of cases. Furthermore it has been deemed feasible for usage in routine clinical practice for the identification of people with personality disorder (Moran et al., 2003). More recently the SAPAS has been selected for use in other studies to support the identification of personality disorder in a naturalistic research protocol that aims to explore the prediction of outcomes in IAPT service in the UK (Grant et al., 2014) and a recent study looked at the impact of co-morbid personality disorder on those in receipt of IAPT treatment with anxiety and depression (Goddard et al., 2015).

A basic information gathering tool was also completed (Appendix 13). If at any point anything arose that would exclude the participant from the study, the screening would be sensitively terminated and all personal information collected was immediately destroyed. The patient being screened was advised of this during the screening process. If the potential participant met the inclusion criteria they were sent out more details of the study in a mode of their preference (post or email). The information included a cover letter (Appendix 14), participant information sheet (Appendix 15) and consent form (Appendix 16). Consent forms were sent out for information purposes at the same point as the participant information sheets for participant information. The above received a favourable opinion by Ethics (Rec Reference: 15/NS/0043: IRAS Project ID: 173408 Appendix 5) and Trust Governance.

Most participants (except 2 who requested postal) wanted the research materials sent to them via email. All participants were offered the option of attending an informal meeting to gain further clarification or information, but none were requested.

Participants who were sent the research information but had not made contact after a week had passed to either 'withdraw or arrange an interview' were recontacted by the researcher to establish if they still wished to take part in the research. This outreach approach was adopted as a high percentage of this patient group are known to have avoidant traits (Moran et al., 2000) and therefore

may feel it difficult to bring themselves to make further contact. This process ensured that all had equal opportunity to engage and become active participants in the research. Great sensitivity however was taken not to coerce involvement but instead a neutral and enquiring stance was taken. Potential participants who did not wish to take part were not required to explain why they wished to withdraw. Those who expressed interest in being actively involved were given a date / venue and the interview was scheduled. Participants who consented were offered an interview date within 12 weeks taking into account the need for 6 weeks to have passed within their IAPT treatment timeframe.

4.6 Consent

Prior to any interviews commencing, the process of the interview and research was explained. Written consent (Appendix 16) was completed face to face with the participant on the day of interview, providing them with opportunity to seek further clarifications.

Consent was revisited at each stage of interaction between the researcher and the participants in order to ensure they were aware of this being a voluntary involvement and one in which they could disengage from without reason, at any point. The participants were also advised that they could request for data already gathered to be destroyed.

4.7 Data Collection Process

All interviews were digitally recorded on an encrypted device. A reflective diary and field notes were also kept to capture emergent themes from the interviews, and to improve the rigour and conduct of future interviews. Each participant was given a unique identification code. A participant coding system was used to ensure the anonymity of participants. All data was recorded and stored within the NVivo programme.

[Intentional Space]

4.8 Data Analysis Process

Framework analysis was used for both studies 2 and 3. A series of systematic stages were used to guide the analysis process (Gale et al., 2013):

Stage 1 – Transcription

Stage 2 – Familiarisation

Stage 3 – Coding

Stage 4 – Developing the analytic framework

Stage 5 – Applying the framework

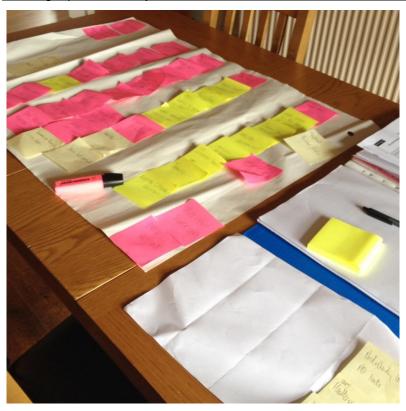
Stage 6 – Charting the data into the framework matrix

Stage 7 – Interpreting the data

Interviews were transcribed verbatim by a university approved transcription service. However two interviews from each study were self-transcribed using the NVivo transcription tool. This ensured that the author was immersed in the data and supported plans to make any necessary alterations to topic guides in the early stages of the research. Early interviews indicated that discussing needs with the patient group was highly emotive and this meant that it was difficult to sufficiently explore in depth other areas of the topic guide such as treatment experience and next steps. As a result of this and after discussion with the research supervisors the structure of the patient interview topic guide was amended and re-organised to discuss needs at a later point in the interview. Of the four self-transcribed interviews, three were selected at random and one was selected due to the sensitive nature of the interview.

All completed transcripts were read and listened too to ensure that the content of the transcript matched the audio recording and to further immerse the author into the data before formally beginning the process of analysis. During this process notes were made and inductive key codes emerging from the data were highlighted on post it notes. Post it notes were organised into groupings which informed the initial themes for inclusion in the framework matrix (Photograph 1).

Photograph 1 – Early Post-it Note Familiarisation Process



An indexing process was used and a flowchart outlining the process undertaken in the IAPT healthcare professional study can be viewed in Appendix 17, this was mirrored in the patient interview analysis. This process allowed inductive themes to shape the framework matrix but also protected against any significant omissions. This process allowed for testing the compatibility of the coding against the emerging framework themes.

A finalised framework matrix that included both deductive and inductive themes was then set up electronically using NVivo. Written field notes were collected post interview and were added to NVivo to record non-verbal responses, clarify points of interests and to record any analytic content identified at interview. Several meetings took place with the supervisory team to discuss the coding areas that would be used for the framework matrix and coding of data from the original transcripts ensuring that codes were appropriate and of interest to answer the research questions. Coding of the original data set into the NVivo framework matrix was performed once indexing and agreement was reached for the initial framework matrix themes. This method continued and the analytic framework evolved and adapted with flexibility particularly when the inductive data offering

new or unexpected data emerged. Interviews that were already coded were revisited every time a new theme emerged to identify if any similarities could be elicited, that may have been previously overlooked.

NVivo is an electronic software package which does not perform the analysis but is an effective electronic data management tool (Gale et al., 2013). The audio recordings, verbatim transcripts, written field notes and the agreed framework matrix were all stored together using the NVivo software. The NVivo software allows for data to be coded into the framework matrix via a copy and paste process that can also be linked back to its original place within the verbatim transcript. This allows for further analysis of context, as the coded content in the framework matrix can be linked directly back to the raw verbatim data. This is particularly useful within research teams to support agreement being reached on coding and this process was used with the researcher's academic supervisors on several occasions.

The original transcripts were coded into the framework matrix using the following identification key; direct quotes (Red text), summarised comments (Black text) and key areas of interest (Blue text) Green text was used to identify any coded material that had been included within the finalised analysis reports, that were taken from the original framework. A sample of the matrices are included in Appendix 18 (NVivo/Excel Framework Matrix – Healthcare Professional) and Appendix 19 (NVivo/ Excel Framework Matrix – Patient Participants). The author was responsible for coding all transcripts but they were also discussed during academic supervision.

4.9 Data Analysis Rigour

Within qualitative research the reliability of the analysed data can be criticised if a lone researcher identifies the themes independently. Dissimilar to quantitative research where inter-rater reliability is often described, qualitative research acknowledges that different researchers will identify different themes and interpretations of the data. The themes were developed by the researcher and were then discussed and refined with the support of the supervisory team. A

consensus was reached and themes validated which strengthened the findings of this research (Ritchie et al., 2014).

Data was then taken from the framework matrix, further analysis and refinement of the themes was achieved that ensured reporting of results was clear, accurate and succinct. Researcher interpretation was removed from initial results to ensure that the participant's views were reported and consistent with the raw data, in an attempt to reduce researcher bias. A consensus amongst the supervisory team for the key reporting areas was discussed. Team reflexivity during the data analysis phase played an important role in ensuring that the reported areas were accurate and balanced in line with the original data set.

4.10 Patient and Public Involvement (PPI)

Patient and public involvement has been a major influence from inception to completion of the study. The research idea was initially developed during the time working in personality disorder services between 2010-2013 as the strategic lead for the development and implementation of a nationally recognised multi-agency personality disorder strategy (Lamph and Hickey, 2012). Significant patient and carer involvement was central to this strategy and the proposed research was influenced by patient and public involvement feedback that highlighted gaps in service provision and understanding.

A consistent message from patients and carers during the early development phases emerged including their frustration that difficulties were allowed to escalate and that more timely interventions had not been made available earlier. These messages were consistent with those reported by patients in national policy documents were patients had shared the following statements to describe their experiences;

"I didn't access much of the mental health service (They wouldn't let me!) but I used up hundreds of thousands of pounds of other budgets such as housing, social service and substance misuse" (DOH 2009 page 9)

"Had I been helped when younger I would not have got this bad" (NIMHE 2003 Page 21).

Hence these were further explored by engaging with patient groups to present and establish additional feedback on the research proposals. This enabled a deeper understanding and insights that shaped the research proposal.

Furthermore working alongside multi-agency healthcare professionals highlighted the prevalence of people with traits of personality disorder presenting in primary care. Frustrations were consistently reported amongst multi-agency workers and that there were gaps in treatment provision and a lack of treatment options made available for this patient group particularly those who did not meet the criteria for secondary mental health services. A lack of diagnosis, complexity and low risk would commonly be reported as barriers to accessing evidence based interventions in secondary mental health services.

Time was also spent discussing ideas with frontline IAPT healthcare professionals and managers in the early development stages, they described regularly supporting people with undiagnosed personality disorder traits but without any focussed personality disorder specific skills or effective treatments to offer people who present with the added complexity of personality disorder traits. Likewise GP's reported the same frustrations at the lack of available treatments and referral pathways for their patients who do not meet secondary mental health service criteria but do have personality disorder related difficulties. 'Heart-sink patients' was a term regularly encountered when working with GPs to describe this group in their general practices (Butler and Evans, 1999). An apparent need for developing evidence based interventions and direction in primary care services was identified and needs of the workforce highlighted, that led to the further development of the original research proposal and the application for NIHR funding.

4.10.1 Research Advisory Group

A research advisory group (RAG) was established to ensure patient and public involvement remained at the heart of this research once funding had been awarded. A group of six Experts by Experience (EBE's) who had lived experience

of personality disorder were recruited from the 5 Boroughs Partnership NHS Foundation Trusts Involvement Scheme. The main role of the group was to support the design and development of the research materials, implementation and dissemination. The research advisory group included people who met the following selection criteria;

- Diagnosed personality disorder (any type)
- Psychological treatment experience.
- Proven Track record of EBE participation
- Describe themselves in a phase of recovery

This was developed to ensure that those contributing were well placed to enhance the study based on their lived experiences. On reflection engaging people with lived experience and a confirmed diagnosis meant that those involved had already reached the level of secondary service treatment. Therefore it could be argued that they are a different group to those who this research is focused upon or at least at a different stage in their difficulties. The decision to engage those with diagnosed personality disorder was driven by the joint working collaborations that had already been developed in the early planning of this research proposal meaning that the research advisory group could make quicker progress under the time constraints of the funded research programme. It would have proven very difficult to have identified people in IAPT primary care based treatment without diagnosis to support such a study without the knowledge and understanding of personality disorder traits and the sensitivities surrounding this diagnosis. Involvement of primary care undiagnosed patients was therefore deemed to be impractical.

Benefits were seen in engaging people with confirmed diagnosis and lived experience as they are familiar with the terminology of personality disorder and the identified traits. They were able to talk retrospectively of their experiences and what could have been improved earlier on in their treatments. They were sensitive towards the label of personality disorder particularly in a largely undiagnosed population, most of whom are likely to be presenting with common mental health disorders such as depression and anxiety but additionally present with co-morbid traits of personality disorder. It was also acknowledged that the IAPT patient

group may never receive a formal diagnosis of personality disorder. There were two phases to the research advisory groups involvement; phase one being focused on the research development and phase two more focused on the reporting and dissemination of the research.

4.10.1.1 Phase 1

The Research Advisory Group met on three occasions (each meeting lasting two hours) in year one to guide the early development of the proposed research and support the development of the research materials. A further four meetings were held with the research advisory group at the beginning of year two to finalise and refine the research resources. All research materials were developed in collaboration with the research advisory group, to ensure that the materials were sensitively written, accessible and user friendly. The final meeting in year 2 was dedicated to the ethical sensitivities of the study. The meetings involved discussion about the use of labels and diagnostic language in this research. The involvement and feedback of the group in this process ensured that great consideration was placed on reducing patient participant's distress by using sensitive language, less clinical jargon and reducing labelling by using more descriptive language in place of diagnostic labels.

The main focus of each of the meetings in phase one are displayed below (Table 12) however there was some overlap and most sessions started with a review of the previous meeting outputs or review of the developed materials. Additionally communication and contributions via email and phone took place during the development of materials.

[Intentional Space]

Table 12 - Phase One Research Advisory Meeting Overview

Meeting	Overview of Content			
Meeting 1	Overview and discussion of the proposed research protocol			
Meeting 2	Development of the participant recruitment flyers			
Meeting 3	The recruitment flyers (Appendix 4 and 10) were developed to ensure that the recruitment statements corresponded with the 'Standardised Assessment of Personality – Abbreviated Scale' (SAPAS) (Moran et al, 2003) that was employed as the screening tool for recruitment of patient participants in Study 3. The flyers were developed to ensure that the recruitment statements corresponded with the standardised assessment of personality – abbreviated scale (SAPAS) that will be used as a screening tool to recruit appropriate patients in Study 3			
Meeting 4				
	Development of consent forms (Appendix 7 and 16) and refinement of participation information sheets (Appendix 6 and 15)			
Meeting 5				
Mosting 6	Development of topic guide (Study 2) (Appendix 20)			
Meeting 6 Meeting 7	Development of topic guide (Study 3) (Appendix 21)			
Exploration and discussion of ethical sensitivities				

4.10.1.2 Phase 2

In the final year, nine research advisory group meetings (Table 13) were held to support the development of the recommendations being proposed and also to encourage the patient and public involvement in the analysis, reporting and dissemination of the research findings.

[Intentional Space]

Table 13 - Phase Two Research Advisory Meeting Overview

Meeting	Overview of Content			
Meeting 1	Research Progress update - Phase 2 next steps			
Meeting 2	Initial video discussion and conference poster idea			
Meeting 3	1 st draft collaboratively developing a research poster			
Meeting 4	Collaboratively developed conference poster presentation / video ideas brainstorming session			
Meeting 5	Recording of video and consent to publicise it and the research advisory group instructions for presenting the poster presentation			
Meeting 6	Conference feedback, video impact			
Meeting 7	Patient and public involvement write up for Trust Clinical Research Network North West			
Meeting 8	Next steps – sharing of research results			
Meeting 9	Future dissemination and working together opportunities, sharing results			

In the final year of the research advisory group's involvement, membership changed due to some members being unable to commit to phase 2. The same recruitment criteria was applied to fill the spaces. Six members were involved in the phase 2 of the research advisory group.

Phase 2 largely concentrated on sharing and dissemination of the research advisory group's involvement and experiences. The members of the group were encouraged to share views of how the recommendations could have a wide reaching impact and were invited to put themselves forward to support any future related collaboration's that could further disseminate the findings of this research and any recommendations made.

The research advisory group played a very important role in ensuring that the research was sensitively developed. In light of this a research poster presentation was collaboratively developed outlining this. This was presented at both the 4th International Congress on Borderline Personality Disorder and Allied Disorders

2016 in Vienna, Austria and then more recently shared and disseminated in the same way it had been developed, in collaboration with a member of the research advisory group co-presenting the poster and sharing their insights at the 22nd International Network for Psychiatric Nursing Research Conference (NPNR) 2016 in Nottingham (Appendix 22).

The research advisory group members were encouraged to take a lead during meetings, once direction had been provided to ensure all views and contributions were valued. The final 2 sessions were feedback sessions from the conferences and were also used to discuss future steps and research involvement post PhD.

The involvement of the research advisory group has enhanced this project with support, creativity, challenges and their unique lived experience insights. The involvement of patient and public involvement in this research led to a nomination for a 'North West Coast research and Innovation Awards 2017', were the group were finalists for the award of outstanding contribution to patient and public involvement (PPI). Additionally the research advisory group worked on the development of a video which was shared on public media (Appendix 26).

4.10.2 Extended Research Supervisory Group

Whilst regular meetings occurred with the academic supervisory group, an extended research supervisory group was also established to ensure that all relevant partners in the research and experts from the field provided support and guidance to the shaping, implementation and dissemination of the research. This group included, the author, academic supervisors from the University of Manchester, University of Leeds and Kings College London, a research mentor who is a professor of personality disorder research at the University of Nottingham, the authors clinical supervisor who is a consultant clinical psychologist and the lead clinician in personality disorder in the authors NHS Trust, an IAPT representative from the research site and the research advisory group members.

In practice this group was much more difficult to bring together than originally anticipated due to geographical constraints and the complexity of bringing all the

key stakeholders together on a given date in a specific location. Whilst it is acknowledged that this would have been best practice to hold regular face to face meetings of this mixed stakeholder group, on reflection this also provides an insight into the complexities that can present in engaging various partners.

Hence this this group was virtual. Skype telephone and email communications ensured that viewpoints and expertise was shared on the behalf of different members within the group. Occasionally various members were invited to and attended the academic supervisory meetings.

Drawing on a range of experiences and bringing together the views of all key stakeholders in the research including the research advisory group has reduced likelihood of any misunderstandings, barriers or constraints to the research and enhanced the quality of the research.

4.11 Ethical considerations

Personality disorder is a highly stigmatised mental health disorder. As this research focussed on a previously un-detected population, who are likely to be undiagnosed or sub-threshold for a diagnosis of personality disorder, consideration was required to establish how to identify and recruit participants.

Throughout the study the identification and recruitment of patients in IAPT created challenges. Attaching a label or diagnosis to an unidentified patient population could be viewed as unethical especially given the high levels of stigma commonly associated with personality disorder (Sampson et al., 2006).

Throughout the research constraints and barriers have been met at different stages from different key stakeholders. Unifying the key stakeholders and addressing their concerns collectively required a skilled and considered response to ensure all concerns were explored and addressed whilst not losing the emphasis of the research, its purpose and the potential benefits that could be emerge from such research. Challenges were encountered during the research advisory group meetings and also the IAPT service in which the research was being carried out.

Research and service improvement initiatives can leave some services feeling exposed, vulnerable and open to criticism (Gollop et al., 2004). This was apparent in the early stages of this research. Meetings however took place to discuss concerns raised by the IAPT service to offer reassurance and explore solutions to concerns. The concerns were also shared and explored with the RAG and research steering group committee members. This strengthened the study design and highlighted early ethical concerns that could be addressed pro-actively before seeking ethical approval. The rationale for the research and sharing of the results was highlighted to the service as being of great importance to them regardless of the results being complimentary or critical of service provision.

4.11.1 Breaking Down Barriers Overcoming Constraints

In the early stages of the research, resistance was met from both the IAPT service leadership team and the research advisory group as to how we should approach the recruitment of participants to the study. The IAPT service leadership team opposed the use of the term 'personality disorder traits' from the outset for the recruitment of an undiagnosed population. In an early stakeholder meeting, one of the managers seemed really uncomfortable with this term being used particularly in a primary care IAPT service and instead coined the following description to replace personality disorder traits "people with long standing variables additional to their common mental health disorder that impacts on IAPT treatment outcomes".

In light of the concerns raised about the use of the term 'personality disorder traits' a collaborative approach was taken to ensure that the development of the research materials were considerate and sensitively communicated. Following several meetings with service leaders and the research advisory group we were able to reach an agreement on how this would be best addressed.

Whilst these meetings were held separately the perspectives from each group were represented and shared by the author. At an IAPT service level it was felt to use the term 'personality disorder traits' with patients who were not in receipt of personality disorder evidence based treatments nor had the diagnosis may cause unnecessary harm and distress. The concerns raised provided an important insight into the service and the challenges of identifying this patient group.

Some resistance was initially met from the research advisory group who felt that not describing the term 'personality disorder traits' in the research with patients was adding to personality disorder stigma. The members described how they were still trying to break down and fears of the label and worried that the service were 'brushing an important issue under the carpet'. Whilst the research advisory group initially found this frustrating, interestingly the group also started to consider the impact this could have on IAPT patients. Some members actually started to challenge other group members by reflecting, how they would have felt prediagnosis when they were presenting to primary care services being labelled with personality disorder traits. One research advisory group member said "had someone mentioned personality disorder to me in the early stages of my difficulties in primary care, it could have meant I was more likely to disengage and this could have therefore delayed my treatment".

After much discussion and consideration, it was agreed that whilst 'personality disorder traits' is an acceptable term to use within the IAPT healthcare professional research materials, that a more descriptive and sensitive approach towards the patient participants would be more engaging, sensitive and less jargonistic. This also ensured the research was not unfairly or unnecessary adding further labels to people who may already be at a sensitive point in their lives due to their engagement with IAPT services.

[Intentional Space]

Figure 7 - Concern; Language and Sensitivities



It was agreed that using the term 'personality disorder traits' with the patient participants could be misleading, labeling and unnecessarily stigmatising, especially when they may never go on to reach a confirmed diagnosis. Most of the literature surrounding personality disorder relates to 'borderline personality disorder' and is written in the context of severity and long standing difficulties that often require extensive treatment and have substantially negative impact on people's lives and coping (Lieb et al., 2004). As this is a new area of enquiry it could be suggested that whilst it is personality disorder traits this research is interested in, those traits are likely to be presenting co-morbidly to common mental health difficulties like anxiety and depression and with lower risk and complexity. Therefore highlighting a label with patients via the term 'personality disorder traits' could lead to patient self-searching information about personality disorder, which could lead to unnecessary distress and concern as the literature is unlikely to describe those people with personality disorder traits in primary care given the dearth of literature in this area. Therefore great effort was taken to be more descriptive of the traits of personality disorder to aid the recruitment and engagement of this patient group with sensitivity (Figure 7).

A further concern was shared by the IAPT service who expressed fear that interviewing patients about their needs and experiences could lead them to feeling that the treatment IAPT was providing was insufficient and that they should be in

receipt of something else. This concern was addressed by reassuring the service that a non-leading approach and one of enquiry would be taken throughout the research interviews. The IAPT service was advised that the research would not be suggesting that current treatment was not sufficient to the participants but instead the purpose of the research was purely to establish and gain an insight into patient needs and treatment experiences both positive and negative.

During the development of the topic guide for IAPT healthcare professionals a not-knowing stance replicating that of the patient topic guide was employed. This ensured that sensitivity was taken to not suggest they are doing anything wrong but instead to explore their experiences of treating people with personality disorder traits and their needs as IAPT healthcare professionals in supporting this patient group most effectively (Figure 8).

Barriers

Wrong
Treatment

Wrong
Stance

Not Knowing
Interview
Stance

During the very early development of the research idea, regular meetings were held with service managers and they were reassured that their concerns were heard and addressed by sharing the changes we had made. The constraints and challenges were an important and natural evolution of the research. These challenges ensured ethical concerns were raised and dealt with in a thorough systematic and pro-active approach, not reactive.

Avoiding such open discussion and invitation of feedback in the early stages of research design may be seen by novice researchers as less complicating. However this approach was more ethically robust and reduced the likelihood of the challenges and constraints being encountered much later into the research, when rectifying may have proven much more time consuming and difficult. The early open discussion provided a fundamental development process that was embraced. This process ensured that the researcher was able to move into the field work with a level of confidence and assurance. The success of this approach was seen in how supportive the service was, once the field work commenced. This was also displayed in the very smooth recruitment of participant, engagement with the service and the IAPT healthcare professionals and patient participant interviews that followed.

4.12 Rigour

A number of processes were employed to strengthen and increase the rigour of the research. The key concepts of qualitative rigour were given consideration within the working methods of this study. 'Trustworthiness' was displayed in the collaborative working methods and the supervisory teams input that is outlined throughout this chapter. 'Credibility' is addressed in the results chapters were quotes from the raw data are used to support and provide evidence of the themes reported. A further example of credibility is seen in the framework matrix examples (Appendix 18 and 19). 'Transferability' was covered by the sampling strategies outlined and was further displayed in the openness of reporting throughout the thesis. The systematic conduct of the study, the sharing of research documents and the use of framework analysis has ensured that dependability and auditability are addressed. Conformability is supported by the outlined examples of reflexivity and team reflexivity which follow. Additionally an overview of results was provided to all participants and received several replies of respondent validation.

4.13 The Role of Reflexivity

Both studies presented the author with different challenges. The role of reflexivity was important in recognising the challenges that presented whilst conducting the research interviews. These are discussed below.

4.13.1 IAPT Healthcare Professional Interview Reflections (Study 2)

One of the most challenging parts of conducting the research with IAPT healthcare professionals was the differentiating roles of knowledgeable clinician to an inquisitive researcher (Yanos and Ziedonis, 2006). Throughout the research, finding the balance between presenting as a confident researcher without drifting into leading or influencing expert in the field was a constant challenge.

In order to aid recruitment but also to develop a first-hand insight into the demands placed upon IAPT services, the author who is an accredited therapist with British Association for Behavioural and Cognitive Psychotherapist (BABCP) set up a clinical placement one day per week during the 2nd year within the IAPT service in which the research was being conducted.

Whilst the clinical role within the service improved relationships with the IAPT healthcare professionals and enabled a greater understanding of the service, it also required researcher discipline to ensure that the role of researcher was separated from this clinical time. On several occasions IAPT healthcare professionals sought out the author to discuss the service issues pertaining to their clinical work with people with personality disorder traits. Being engaging enough and validating of the concerns without sharing too much information that influence the research data proved to be challenging. This was overcome by providing clear boundaries and explaining explicitly how the author's role in the service as a therapist was not in a personality disorder specialist capacity. Instead those encountering difficulties were advised that the concerns they raised were exactly the type of experiences required to learn more about via the research, hence this led to many opting in to be interviewed. One of the therapists described being interviewed to others in the team as being 'cathartic process' that has enabled him to feel listened too and provided the opportunity to offload experiences and

opinions. Some IAPT healthcare professionals also requested sign posting advice for complex patients. In some circumstances offering advice particularly about secondary care pathways felt appropriate to share and this enabled the more effective engagement of the workforce. Participants were advised that they as a service would receive an update of any findings and recommendations made would be made available to them at the earliest opportunity.

Being integrated into the IAPT service through the clinical work enabled the author to be seen as 'one of them'. Whilst the author had been known to several of the IAPT healthcare professionals from his previous occupational role, it was observed that once this clinical time was set up a change was noticed in the interest and engagement of the team in this research.

Attendance at team meetings and provision of educative sessions to support therapist 'continued professional development' also raised the profile of the research, kept recruitment updates on the team agenda and supported the recruitment of both IAPT healthcare professional and patient participants. It took skill and resistance to refrain from sharing personality disorder specific knowledge, this was constantly reflected upon. Being informative enough that participants know what it is they are getting involved in, without over influencing or skewing any potential responses they may provide during interview was the greatest challenge during recruitment. This dilemma was discussed at length in academic supervision. However awareness of this challenge and ongoing reflexivity ensured that the risks of oversharing information or leading participant responses at interview were reduced.

Being clinically based also enabled a unique insight into the challenges IAPT healthcare professionals face and having the ability to have mutual discussions as colleagues about changes taking place supported the engagement and breaking down barriers with the IAPT workforce. Having an inside knowledge of the system also supported the researcher in the interview process as time was not lost trying to understand the service 'lingo' or wasted on areas or concerns that the author had observed whilst working clinically in the service. Instead interviews were able to be focused specifically upon the aims and objectives of the research.

4.13.2 Patient Participant Interview Reflections (Study 3)

Equally the challenge of separating the researcher role from that of clinician during patient interviews was also encountered. In the early interviews the tension appeared mutually experienced. Patients would often ask questions of the researcher that felt like they were in therapy and the author especially in the early interviews on occasion's fell into the trap of responding in knowledgeable therapist mode and not inquisitive researcher mode. However inside knowledge and recent experience of delivering therapy in the service also assisted the author in patient interviews. For example issues raised relating to the screening process and the routine outcome measures used in the service were something that without the inside knowledge may have taken up more time at interview and meant depth of interview data based on patient need and treatment experience could have been lost.

Patient interviews were not without challenge and a level of clinical skill was beneficial to this research, due to the complexity of this patient group. Several interviews were extremely emotive, some required assessment of risk to self and others. Others were very interpersonally and emotionally challenging. Having expertise and vast clinical experience of working with people with complex mental health difficulties enabled the author when called upon to deal with the interviews in a contained, confident and sensitive manner.

Furthermore the challenges experienced at interview are not likely to be similar to that of the therapist contact with the patient participants in IAPT treatments. Many of the issues brought up by IAPT healthcare professional in Study 2 results (Chapter 5) were experienced during the patient interviews, hence providing further insight into the complexities of working with people with personality disorder traits in primary care mental health services.

Due to a slower than anticipated recruitment of patient participants, the use of a protocol contingency was utilised, that being to contact patients who had been recently discharged. It was however noted in the author's reflective diary that many of the patients engaged in the research post discharge were keen to share how they saw this as an opportunity to discuss unmet needs and would allude to it

helping them somehow make sense of their problems during screening interviews. On several occasions clarity was required to share that the role of the interview was not to provide any additional therapy or answers but instead would be an interview of enquiry in which we wanted to learn more about patient experiences that could support future recommendations for service improvements.

4.14 Project Management

Each year a Gantt chart was used to project manage this research and set key deadlines and objectives (Appendix 23). This ensured that deadlines were met and when they were not that adequate actions were put in place to keep the research progressing to a high standard in line with funding timeframe constraints.

4.15 Research Governance

Research governance was adhered to throughout the study in line with research ethics, university and NHS trust research governance requirements and the study research protocol (Appendix 9).

A study index folder was held within the University of Manchester Research Office. All confidential information was securely stored within the locked filing cabinets however the study index folder with all the relevant research governance documents and approvals was kept within the office with open access upon request. The 'NIHR Good Clinical Practice Certificate' was also complete prior to the commencement of the field work (Appendix 24).

All personal data was securely held on a password protected and encrypted computer. All participants interviewed were given a pseudonym code for identification. For IAPT Healthcare Professional participants they were given a code of HP (Health Professional Participant) and a unique identifying number. For patient participants they were given a code of P (Patient) and a unique identifying number.

4.16 Expenses

IAPT healthcare professional were interviewed during working hours and therefore no expenses were incurred. Out of pocket expenses were paid to the patient participants, to cover travel expenses, time and loss of earnings for their attendance at the research interview. This was provided in the form of an 'One4all' Post Office Voucher at the value of £40. Participants were provided payment once the interview had been brought to a close. Any participant who started the interview received full payment for out of pocket expenses regardless of the point of interview termination.

4.17 Ethical Approval

As the research was conducted on an NHS Site and including NHS patients the Integrated Research Application System (IRAS) was completed capturing all the necessary R&D approvals (Appendix 5).

Ethical approval from the National Research Ethics Services (NRES) and University of Manchester was sought prior to the collection of any data. The study went through proportionate review (NRES Committees North of Scotland) and a favourable opinion was received on 12th May 2015 (Rec Reference: 15/NS/0043: IRAS Project ID: 173408).

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Chapter 5

Study 2 – IAPT Healthcare Professionals Results

5.1 Results

This chapter reports the results of Study 2. Working methods are detailed in Chapter 4.

5.2 Sample

Twenty eight IAPT healthcare professional qualitative interviews were conducted lasting between 51m:49s and 1h:40m:37s (total time 35h:23m:5s, mean interview duration 1h:25m). Characteristics of the sample are described in Table 14, in brief 27 participants described themselves as 'White British' with only 3 using alternative descriptions, 1 'White European', 1 'Mixed' and 1 'Asian'. Most were female (N= 17) and the majority were employed as 'High Intensity Treatment' (HIT) workers at Step 3 (N= 17), 6 as low intensity 'Psychological Wellbeing Practitioners' (PWP) at Step 2 and 3 participants were in leadership roles.

To ensure anonymity of participants, gender and ethnicity have not been reported in Table 14, instead have been described collectively within text.

Participants were recruited from 5 Boroughs Partnership NHS Foundation Trust from the Wigan and Leigh IAPT Service, UK. Those identified as having a 'Core Professional Registration' included participants who were also registered as clinical psychologists, nurses and social workers.

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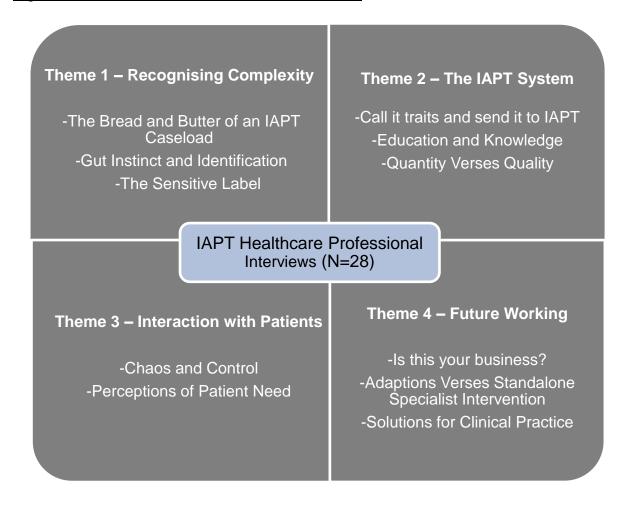
<u>Table 14 – Demographics of Healthcare Professional Participants</u>

Case	Age	Clinical Experience (Yrs)	IAPT Experience (Yrs)	Core Professional Registered	Step or Occupational Role
HP1	26-35	6-10	1-5	Yes	Step 3
HP2	36-45	11-15	6-10	No	Step 3
HP3	26-35	6-10	1-5	Yes	Step 3
HP4	26-35	6-10	6-10	No	Step 3
HP5	36-45	16-20	6-10	Yes	Step 3
HP6	46-55	21+	6-10	Yes	Step 3
HP7	56-65	21+	6-10	Yes	Step 3
HP8	26-35	1-5	1-5	No	Step 3
HP9	26-35	6-10	1-5	No	Step 2
HP10	26-35	6-10	6-10	No	Step 3
HP11	26-35	6-10	6-10	No	Step 3
HP12	36-45	16-20	1-5	Yes	Step 3
HP13	36-45	16-20	1-5	Yes	Step 3
HP15	36-45	11-15	1-5	Yes	Leadership
HP16	46-55	6-10	6-10	No	Step 3
HP17	26-35	1-5	1-5	No	Step 2
HP18	46-55	21+	6-10	Yes	Step 3
HP19	46-55	21+	6-10	Yes	Leadership
HP20	26-35	11-15	6-10	No	Step 3
HP21	26-35	1-5	1-5	No	Step 3
HP22	36-45	11-15	6-10	Yes	Leadership
HP23	18-25	1-5	1-5	No	Step 2
HP24	26-35	6-10	6-10	No	Step 2
HP25	36-45	6-10	6-10	No	Step 2
HP28	18-25	1-5	1-5	No	Step 2
HP29	26-35	1-5	1-5	No	Step 2
HP30	26-35	1-5	1-5	No	Step 2
HP32	36-45	16-20	1-5	Yes	Step 3

5.3 Main Analysis Results

Analysis revealed 4 key themes 1) Recognising Complexity 2) The IAPT system 3) Interaction with Patients and 4) Future Working. Each theme is divided into 2-3 sub themes (Figure 9).

Figure 9 – IAPT Healthcare Professional Themes



5.4 Theme 1 - Recognising Complexity

This theme provided a unique insight into participant experience and understanding of whether or not patients with co-morbid traits of personality disorder are recognised by the IAPT workforce. Processes of identification are described and reported. Identification and the use of the label 'personality disorder traits' and the acceptability of this language within a primary care IAPT service was explored and 3 subthemes emerged: 'The Bread and Butter of an IAPT Caseload', 'Gut Instinct and Identification' and 'The Sensitive Label'.

5.4.1 The Bread and Butter of an IAPT Caseload

This sub theme provided participant perspectives relating to the presence of patients with common mental health disorders and co-morbid personality disorder traits in IAPT services. A large majority of participants acknowledged that this patient group is present in routine IAPT services.

"I think it needs to be acknowledged in IAPT world that these people exist and they will be, I think, your bread and butter of your caseload, you are having these people come in on your caseload. So it needs to be acknowledged in IAPT"

(HP3, Step 3)

"I think in primary care, that people tend to think that personality disorder people don't come through our services, when actually they do all the time. It's not recognised, it's not picked up" (HP6, Step 3)

A minority of participants felt that healthcare professionals 'over complicate' patients difficulties and imply that a specific interest or new focus into a particular difficulty can inadvertently increases the likelihood of identification hence impacting on increased prevalence.

"I think the thing is that you identify things that are commensurate with your training, don't you? So previously we had people coming through as agency PWPs but who had got a large research interest in trauma, and they found trauma everywhere. So sometimes, the more training that you have, the more complicated that you make cases. People can't get more complicated by the virtue of the fact that you've had more training, it's just the fact that you find complaints that other people might not" (HP15, Leadership)

5.4.2 Gut Instinct and Identification

This sub theme revealed whether and how health professionals identified comorbid personality disorder traits. Participants acknowledged that identifying patients with personality disorder traits was difficult, compounded by a lack of dedicated screening tools used in routine IAPT services. The only tool mentioned by a few participants was the Standardised Assessment of Personality – Abbreviated Scale (SAPAS) (Moran et al., 2003) and this was only used to provide evidence to support and justify the transition and escalation of patients to secondary care services. The majority of participants described identification of personality disorder traits as being based on 'gut instinct' or 'clinical hunch'. Over half of the participants described having very limited knowledge of personality disorder traits.

"...somebody else might sit there and go, oh, definite traits, whereas I'm just maybe not aware of it". (HP8, Step 3)

This variation of knowledge of personality disorder traits amongst participants was noticeable however those patients who presented with more severe traits were described as more easily recognised. Difficulties in therapy, a lack of treatment progress, or problems that arise within the therapeutic relationship were often described as indicators for the presence of personality disorder traits. Hence the 'clinical hunch' is described as being commonly used as an inconsistent method of identification. The inconsistency of this method is relative to the mixed experience of knowledge amongst the workforce in IAPT and is further illustrated by the example below:

"I don't think it can be reported accurately because there are people who are practising who don't know what a personality disorder is. So how can they say I've got somebody through with these traits?" (HP12, Step 3)

Participants had mixed views on whether personality disorder traits should be identified in IAPT. Those who opposed identification felt that where traits were identified then no treatment would be offered, thus detection and identification was a futile exercise. For example:

"When you tell somebody that they're diabetic then usually you treat them for diabetes and you monitor them or they get put on medication, otherwise what's the point in putting that label on?" (HP11, Step 3)

Many felt identification would be more acceptable if it meant that they could signpost or access more support to patients. In the absence of this participants felt that it would be unnecessarily adding to stigma.

"There's quite a big stigma against personality disorders, to kind of give them that label" (HP23, Step 2)

Identification was also described as having potential utility if it made the participants more aware of the need to make adaptions or reasonable adjustments to treatment to address the co-morbid difficulties or reduce the impact these problems could have on routine clinical practice. Conversely, several participants were less inclined to be drawn into formally diagnosing personality disorder traits through a fear of opening the flood gates to a whole new patient group.

"I think we've got to be careful we don't label people with this PD. And I think it's best to treat them naturally in the way we do, and not be focused on that. Treat it within the context of everything else we're doing" (HP7, Step 3)

5.4.3 The Sensitive Label

This sub theme relates to the participant experiences and perceptions in relation to sensitivities in the use of language and diagnostic labels in IAPT services.

Most participants felt that the use of diagnostic labels including the term 'personality disorder traits' was acceptable for use with the IAPT workforce, but only if clarity was provided and a common understanding agreed on the meaning of this term, which was described as being insufficient.

Conversely, the participant perception of using the term 'personality disorder traits' directly with patients was met with overwhelming negativity. A clear differential is reported between the terminology that the participants felt was acceptable for use amongst the IAPT workforce, to the terminology that would be acceptable for use with patients. For example:

"With staff, I think that's acceptable. As long as they've all, as I said, have these traits explained to them. So it's not just going from the standard conceptions that they've generated through everyday life" (HP29, Step 2)

Participants felt that a non-labelling approach with patients was preferred, with the use of more descriptive explanations of the presenting problems (or traits):

"I really focus on the problem. I wouldn't go into categorising them into a box. I'd just say it seems to me that you're having these difficulties, so what we'll do is look at interpersonal effects and so on, and discuss tolerance or whatever"

(HP23, Step 2)

Almost all participants felt that personality disorder and personality disorder traits, were negative labels that should not be directly used with patients. These terms were felt to be too personal and related to the core of someone's being. For example, one participant called it an 'offensive label' and another described it as being an 'attack on the person rather than the condition'. Personality disorder is a known diagnostic label however to have personality disorder traits, which is more commonly described in IAPT services, implies that the presentation is below the diagnostic threshold. Hence labelling patients with the term 'personality disorder traits' without a confirmed diagnosis was felt to be unjustified, unethical and unnecessary for use within primary care IAPT clinical practice. It was also described as being counter-productive to the patient's treatment. Most felt that use of diagnostic labels with patients in IAPT services was highly sensitive, stating that even terms like post-traumatic stress disorder, depression and anxiety are often avoided and replaced with descriptive words to describe presenting difficulties.

"That's why we sometimes even avoid using the term depression. We tend to use low mood rather than depression because to some people it might be a bit disempowering to use the term depression. I think it would be the same with PD" (HP17, Step 2)

Several participants described using discreet methods of screening via a series of questions or based on increased knowledge of personality disorder traits to help

them to use a descriptive stance without labelling or attaching unnecessary stigma to the patient.

5.5 Theme 2 – The IAPT System

Participants described how the IAPT system has evolved and changed in recent years with an increased focus on targets, including the need to meet predetermined recovery scores using routine outcome measures and the increasing volume of referrals. Three sub-themes were revealed in this theme, 'Call it traits and send it to IAPT', 'Education and Knowledge' and 'Quantity verses Quality'.

5.5.1 Call it traits and send it to IAPT

Participants discussed the changes in specialist secondary mental health services and how they perceive them as becoming more recovery focussed in recent years and felt this had impacted on a rise in the complexity of clinical presentations in IAPT services, with more patients presenting with co-morbid personality disorder traits.

"There have been big reforms, they had to downsize in secondary services, that might sound controversial. So you find in secondary services that people who have had established treatment plans there, suddenly find themselves discharged, with a revised diagnosis, and we can often because of a lack of resources for them, what else is there? But what the general public generally feed into, which is IAPT" (HP5, Step 2)

Participants felt that specialist secondary care service healthcare professionals (including psychiatrists) are now less inclined to diagnose personality disorder through a fear of the patients not being taken on by the IAPT service and therefore the 'Call it traits and send it to IAPT' theme emerged.

"It wasn't helpful for clients because what was happening in assessment teams was, they were saying, well, don't give them the diagnosis or IAPT won't take

them. And I've heard numerous times, "Call it traits and send it to IAPT" (HP22, Leadership)

Participants also described the difficulties they encountered when referring patients to specialist secondary care mental health services. For some the difficulties in getting referrals accepted have become so profound that they had stopped making referrals. Specialist secondary mental health services were described by participants as having a focus on high risk patients and that they are reluctant to take people back into the service who have been discharged from them. Overall participants felt that there are no other treatment options for this group, so they end up with IAPT.

"I think sometimes it's almost seen as they're trying to deliberately get out of saying that they've got a personality disorder, because they know that otherwise they can't be seen by us. It feels that way sometimes" (HP10, Step 3)

One participant felt like the IAPT service was being manipulated by the use of the terminology 'personality disorder traits' stating the following:

"It's a term that means that you don't meet criteria for us so you can't have our service so you'll have to go to IAPT, and then I think it just becomes a language that's attached around the client. And so the client's struggling around that, what does 'traits of' mean? That's not explained to them" (HP3, Step 2)

The lack of diagnosis or reluctance to diagnose and instead use the term 'traits' in the current system is described as a barrier to meeting patients' needs. Participants were unaware of any available evidence based treatments, services or recommended treatment guidelines for people without diagnosis but presenting with 'personality disorder traits' in primary care. Participants were frustrated that that the needs of these patients were largely unmet. Many of the participants described this patient group as being passed back and forth in what is termed by one participant as "a tennis ball effect" (HP5, Step 3). This was described as having a negative impact on the patient and on the participant's ability to develop the therapeutic relationship, as patients come into therapy with a negative view of services.

"I think it's a dismissive currency at the moment, I think it's...this is going to be quite critical of the mental health assessment team and the position that they're in.

But you get traits of personality disorder, you may as well be given nothing because you don't get anything for it, you just get a step back down to IAPT" (HP3, Step 3)

Most participants make reference to a marked tension between specialist secondary mental health services and primary care service in who should be providing the treatment of the patient group. One participant described it as "a battle between us and them" (HP10, Step 3).

5.5.1.1 The Gap

Just over half of the participants described a 'gap' in service provision for this patient group, and that this gap is occurring at the interface between specialist secondary mental health services and primary care.

"I think the gap in services is people are afraid to give a diagnosis of emotionally unstable or any of the personality disorders, because with that comes the requirement to give them the NICE guideline treatment for it. And we wouldn't accept that for any other disorder, we wouldn't accept that for depression, were we haven't actually formally diagnosed you as clinical depression, so you can go to counselling, you don't need CBT" (HP22, Leadership)

Another participant argued that the IAPT service is already expected to and is filling this gap, however acknowledged it is doing so without specific guidance or training.

"That's a whole new challenge, because you're getting people, that's in the middle. They're in that gap, it's like a vacuum, if you like... And I've come across that a lot in the job, definitely. But I think there's an expectation were it does filter back into IAPT. IAPT seems to be this bubble, this base, this floor of seeing these people, if you like, because nobody knows what to do with them" (HP9, Step 2)

Pathway clarity for this patient group is not defined, one participant described it as being a lottery what intervention the patients receives owing to the diversity of skill mix amongst the IAPT workforce. Another participant suggested that a consensus statement should be developed to provide across service clarity and direction.

"Basically, a consensus statement that says, here's what someone with personality traits should expect from mental health services, both primary and secondary care, and here's what staff working in those services should expect in order to deliver that, here's what the service should expect" (HP22, Leadership)

5.5.2 Education and Knowledge

Half of the participants interviewed had as part of their IAPT continued professional development participated in some locally delivered basic awareness training for personality disorder. However many of the participants who had received this training highlighted a need for on-going refresher training.

"People who've had the training six years ago, there's probably big changes in the way we perceive it and the way we work with it, since then" (HP29, Step 2)

Participants described an on-going need for further knowledge and skills about personality disorder.

"If we are no good at understanding personality disorder, understanding the traits, identifying them, then you know were Lost! Those things need to be in place first you know, in order for us to actually respond we need to be able to do those things initially" (HP1, Step 3)

A majority of participants felt that IAPT requires more than just awareness. Most of the participants were in favour of an increase in skills development that could enable therapists to adapt treatments for this patient group for use alongside the routine evidence based approaches for common mental health difficulties.

"The awareness bit is great and being able to look at characteristics and traits, and know which one falls maybe into which personality disorder diagnosis, but that

doesn't help you in terms of how to tailor things to work with certain traits" (HP30, Step 2)

Participants described the IAPT core curriculum as being protocol focussed to depression and anxiety disorders using NICE guideline evidence based approaches. However the lack of any specific training in understanding the complexity of co-morbid personality disorder was described at both Step 2 and Step 3. A majority of participants felt that personality disorder training should be included in the IAPT core curriculum.

"From a national point of view, first of all, there needs to be something in the training curriculum. There's virtually nothing at the minute in any IAPT training that looks at personality traits. It's the same with LD and stuff, I think with all these conditions, there should be some provision in the training curriculum" (HP22, Leadership)

Whilst treatment skills and knowledge development amongst the participants was clearly supported, several participants also made reference to additional training to help them manage themselves and their own reactions better during difficult therapy sessions.

"It's learning how to manage how I feel when I'm in front of these people. That's what it is for me. Not bothered about time and knowledge, it's about how I manage a person that's boiling in front of me, because that sets me off" (HP9, Step 2)

5.5.3 Quantity Verses Quality

Participants emphasised the increasingly business-like way IAPT services are delivered and deemed to be more focussed on quantity (numbers of patients seen) than quality (impact / patient experience of the intervention). The demands on participants were described as being focussed on an expectation to get patients into recovery as measured by routine outcome assessments and demands for them to provide treatment for as many patients as possible. It is these pressures that were depicted as creating the tension over quantity and quality of

interventions. Whilst participants reported a preference for 'quality' they report feeling constrained by the 'quantity' dilemma and output expectations of the service.

Most participants described a demanding workload within IAPT. Time was reported as a challenge across all steps in IAPT, but was seen as particularly demanding at Step 2 where up to 10 patients per day are seen. Whilst this is acknowledged to be stressful, the importance of protected time for supervision was seen as essential and something that participants felt is adequately provided within this service.

"The major constraints within this service is because it's not really about quality, it's about quantity, it's about prevalence rates, it's about recovery rates, it's about bums on seats. In a nutshell that's IAPT" (HP5, Step 3)

One participant described it as a "conveyer belt" (HP7, Step 3) of patients, where there is a need to get the next one in, due to it being a target driven business. Many participants recognised the importance of measuring recovery, but how it was focussed only on standardised routine outcome measures and failed to take into account patients own subjective views of progress or the objective views on progress from the therapist.

There was a level of frustration from Step 2 therapists particularly from those who had been with the service when they previously were employed as mental health graduate workers with one describing being "stripped off her skills" describing her newer role as a Psychological Well-being Practitioner (PWP) in the following way; "guided self-help is a bit like putting cherries on cakes in a warehouse. It's a bit like in-out, in-out" (HP24, Step 2). This frustration was largely preceded by demands upon time, lack of ability to be flexible and adaptive and high volume caseloads which caused time pressures.

"You've got no time at Step 2, by the time you completed assessments, you get all this stuff out then close them down, because your next person is coming in, so you have got ½ hour" (HP25, Step 2)

Participants agreed that the core business of the IAPT service is to treat common mental health difficulties using NICE recommended interventions and that the service has not got the capacity to become a 'catch all service'.

"From what I know of other IAPT services and IAPT in general it's not really been set up to take that into consideration. It's only mental health problems, these are your protocols, this is what you do, it's all NICE guidance, if it's not NICE guidance we're not interested" (HP11, Step 3)

"They would have to have depression or anxiety. That's a thing that they must have. If they happen to have something else then so be it. As long as they've got that anxiety and depression that's what we're commissioned to do" (HP4, Step 3)

The need to consider the impact of personality disorder traits on the service was strongly supported with one participant suggesting it should be prioritised ahead of and alongside other co-morbidities such as long term physical health conditions.

"There's a lot of demand on the IAPT generally, it's trying to cover everything. It's covering everything. And I think obviously if you're trying to do that, it's going to shrink the focus on these areas that are huge. For me, this should be alongside long term conditions, this should be alongside physical health, if you like. If I was honest with you, I think sometimes we're focusing on things that are below, this should be above it, in my opinion, and it's not" (HP9, Step 2)

Several participants describe a system that is not responsive to people with personality disorder traits. There is a reluctance to describe the service as working directly with personality disorder or traits through fear of the service becoming overwhelmed.

5.6 Theme 3 - Interaction with Patients

This theme developed from participant perceptions of their clinical experiences of working with people with co-morbid personality disorder traits and two sub themes emerged, 'Chaos and Control' and 'Perceptions of Patient Need'.

5.6.1 Chaos and Control

Participants shared case examples to illustrate the complexity of some patients that they had, or were working with, with many being identified as having comorbid personality disorder traits. Participants described the main challenges as being centred on the 'chaos in the room', 'the lack of therapist control over the treatment' and 'the high levels of presenting complexity'. The following factors were highlighted as important in an effective interaction with patients, 'building rapport', 'consistency of the therapist' and 'a good therapeutic relationship'.

"The therapeutic relationship is quite important, because obviously someone who has difficulty maintaining a relationship is going from one therapist to another therapist and it will probably be quite chaotic" (HP8, Step 3)

One participant described the positive impact he had on a patient's recovery by repairing a therapeutic rupture with her. He shared how he went above and beyond his role by contacting the patient via telephone after an emotive and difficult session for both parties. He believed this to have had an important and positive impact on the patient's recovery and continuation with treatment. He also felt it impacted positively on their therapeutic relationship, but acknowledged that this was not his routine practice or routine practice for an IAPT therapist to go above and beyond in this way due to service demands that would normally constrain this.

A majority of participants referred to the challenge of working with this patient group. Those who present with co-morbid personality disorder traits were identified to be on a continuum of severity, with some of the less complex cases responding well to routine IAPT approaches and those with added complexity described as requiring more flexible approaches.

"You see somebody coming in with massive levels of complexity, and then the next person is coming in and it's just a bit of social anxiety, you know, when I walk down the street people are looking at me" (HP25, Step 2)

Participants described a 'loss of control over therapy' and shared examples of patients exerting control over the therapy session due to the multitude of mixed problems and complexity they present with. This meant that they could oscillate from one problem to the next on a weekly basis making adherence to the IAPT model and protocol delivered therapies very challenging to deliver.

"You have to understand the off shoots but also remember that you're working with anxiety at the moment, you've got a specific job to do, you're working in a guided self-help way. But it's about keeping these things in the conversation"

(HP9, Step 2)

The chaos in the room that was described as making it challenging to deliver therapy within a time-limited treatment and reports of frustration were shared due to the lack of readily available evidence based alternatives.

"I suppose it just makes you think that there's only a limited amount you can do and then you just think when that's been done, this person needs more. And it's just about whether there's actually any services out there that could do that and would be able...without them waiting, say, like for a year or so" (HP30, Step 2)

Many of the participants described being overwhelmed and highlighted the challenges they had keeping focussed and on track in therapy sessions. This often led to a negative appraisal of self and own skills.

"Very hard because you feel like you're not doing them any good because you don't know what their needs are and you want to help them. So you feel like you're trying to give this bit, and this bit, and this bit, but then you feel like, what have I actually done" (HP20, Step 3)

This patient group clearly stimulated a multitude of emotional responses in the participants. An inner strength to manage these emotions and a need for the development of the participants own resilience as therapists was described.

"It's learning how to manage how I feel when I'm in front of these people. That's what it is for me. Not bothered about time and knowledge, it's about how I

5.6.2 Perceptions of Patient Need

When discussing the needs of this patient group from the staff perspective, a mixed knowledge response was received ranging from participants displaying a good knowledge of personality disorder and the difficulties the patients are likely to present with and others feeling they have very minimal knowledge.

"For me, it seems to be the case that when people come to a service with a personality disorder, the thing they're seeking treatment for isn't necessarily the personality disorder, they're coming because they're depressed or because they're anxious. The personality disorder might make them vulnerable to becoming depressed and anxious. So are we treating the personality disorder, or treating depression and anxiety? If we're treating depression and anxiety, should we not be treating that in people with personality disorders as well?" (HP15, Leadership)

Participants described difficulties in engaging with this patient group. Participants often described the strict 'did not attend' (DNA) policy with mixed views but many could see both the benefits and constraints of its implementation. Positives views in support of the DNA policy include the effective management of waiting list and cost effectiveness of the service. It is suggested by several participants that the policy improves patient commitment to treatment by encouraging their regular attendance, however negative views highlighted that patients would be lost to treatment if their attendance was poor. In light of this, many participants described a need for greater flexibility for this patient group being required due to the levels of complexity they present with.

There was a mixed and blurred opinion relating to whether the needs of this patient group are being met in IAPT services. Whilst many participants stated that the need to receive an accessible service for anxiety and depression are being met, a large proportion of participants felt that the needs of the patient group are going unmet or only met in the short term due to patients frequently representing.

"It's like putting a plaster over it. It's going to keep falling off, isn't it?"

(HP12, Step 3)

Emotional regulation skills development with patients was described as a need often missed, one participant described how patients require space to access emotions and several others discussed how more work on emotional regulation would be beneficial.

"I think an ability to manage their emotions better, because they usually come into our service because, on a day to day basis, their emotions are causing them all sorts of difficulties in their personal life, with regard to employment, education, leisure activities, and they're perhaps just going from one crisis or problem, to another, and no wonder they're anxious and depressed, which obviously brings them into our world" (HP5, Step 3)

The need for patients to 'emotionally ventilate' / 'offload' was discussed however protocol based treatments were described as not always allowing for this due to the need to get through the protocols and delivered materials, this being a particular challenge at Step 2.

"Somebody comes into the room, their agenda isn't to sit and listen to the therapist, there's a need to talk, a need to access very quickly, oh I have had a difficult week..." (HP9, Step 2)

Participants also reported a patient need in social and relationship difficulties. The intervention of choice currently used to address this need in therapy is frequently described as taking a 'problem solving approach'. One participant described a need for increased external sources of support and longer-term relationships with this patient group, making reference to services that no longer exist.

"I think we need relationships – I think they need long term relationships with professionals. I think they need somebody who might only pop round every four weeks, every five weeks and just check in with them and have a coffee, just knowing that that person is there... I think that's very important for people, that's probably not just with Personality – that's for people with Mental Health issues in

general isn't it. There are no day centres is there, there are no drop in centres, there is nothing any more for this client group where they can just go"

(HP18, Step 3)

Cognitive behavioural therapy is described as the most common treatment approach used in IAPT service is focussed on the 'here and now', but many participants felt that these interventions were not the most effective to meeting patient's needs with longstanding difficulties.

"Not for everyone but some do come in and don't know how they got to this point, sometimes links are clear and you can say have you considered this and this, but sometimes it's not that clear and then you have to say we can spend a long time in the past but CBT is focussed on the present and the here and now, in a way you can find yourself driven by the therapy rather than the person that's sat in front of you, I think when difficulties are longstanding, we probably need to take a little step back from therapy, even if it's just for a session or two, to help the person feel understood" (HP4, Step 3)

Participants commonly shared experiences of this patient group regularly requiring some 'offload' time during therapy. Participants suggested that this allows the patient to move around the focus to their presenting difficulties based on the most upsetting recent experiences on a weekly basis. The participants however whilst acknowledging this need also described needing to be very clear on what it is and is not they are able to offer within the constraints of the service. Participants described how often due to the time limited nature of the treatments it is difficult to cover all aspects of the patients problems within a single course of therapy. This is particularly evident if complexity presents, so it is suggested that this limitation should be shared with the patient to ensure a realistic appraisal can be made of what can and cannot be addressed in IAPT.

"Sometimes these people think that this is more like counselling so it's very important to kind of highlight the kind of work we do so...and a lot of times that then gets resolved because it might just be a misunderstanding but if it's a deeper issue then we do discuss stepping up" (HP17, Step 2)

Many participants were unclear on what the needs of this patient group actually are, instead suggesting that there is a need to understand the needs of this patient group better and for more research in this area.

5.7 Theme 4 – Future Working

This final theme is based on potential solutions and ways forward for IAPT services based on participants views of acceptable and feasible ways to address the needs of this client group and consists of three subthemes, 'Is it your business', 'Adaptions verses Specialist Standalone Interventions' and 'Solutions for Clinical Practice'.

5.7.1 Is it your business?

Participants interviewed were asked to consider and share their views on whether or not they felt that it was an IAPT therapists business to work with patients presenting with co-morbid personality disorder traits. An overwhelming majority held strong opinions that it was 'their business' due to the high prevalence of this patient group presenting to the service.

"Yeah, it has to be because of the amount of people that come through, it's very high volume. You can't ignore these traits. It's about keeping it in the conversation, keeping it in mind and making sure we're meeting these people's needs. We can't just say, well, people who are coming through with personality disorder traits, we can't work with them, it's impossible, it's just the nature of the business" (HP9, Step 2)

How and what they should specifically work on in terms of treatment was however more complex to ascertain. There was a split opinion on what specifically IAPT should be doing in terms of offering interventions. Some participants recognised it as being their business to work specifically with the personality disorder traits as a core problem.

"Well I think I should work with it because that's, you know, the core of the problem really. Anxiety/depression is probably a by-product to this" (HP13, Step 3)

Whilst others determined that it was their business to work with the co-morbidity but only to make reasonable adjustments or adaptions to carry out the anxiety and depression based treatments. Almost half of participants only accepted working with this patient group if anxiety and depression were the explicit focus of intervention.

"I would say if there's a presentation of anxiety or depression then, yeah, that's what I would say this works with. If they've got those traits, it might mean some adaptations to therapy, just as it would with someone who'd got a long term condition, for example. But, yeah, absolutely, the service is there for people with anxiety and depression (HP4, Step 3)

A minority of participants made more reserved judgements about working with personality disorder traits with one participant illustrating this as being trained one way and asked to do a different job without the skill set.

"I don't mind, but it's, kind of, sometimes like saying to a mechanic, do some joinery. It's like saying to a joiner, okay, do a bit of plumbing" (HP25, Step 2)

Whilst participants were not strongly opposed to working specifically with personality disorder or the traits, instead the main barrier appeared to be at an organisational support level, the lack of evidence based interventions and skills deficits.

"I think the limit of my training, currently I'd feel a bit, you know, would I be doing someone a disservice because I don't have the skillset currently to work with?"

(HP32, Step 3)

Three participants felt that personality disorder was not their business in IAPT, interestingly all were from Step 3.

"No, if the person's come in with a personality issue, then they should go to the recovery teams, because they're the experts in dealing with that, I'm not the expert. If somebody comes with an anxiety issue and as it comes out, there are

some relationship issues or personality issues, and if they're pretty straightforward, then I can deal with that, yeah" (HP7, Step 3)

"Personality disorder has never been mentioned to me in interview or in my contract or anything like that. So I would say, no from that point of view. And also no because I've got no skills to help these people" (HP21, Step 3)

5.7.2 Adaptions Verses Standalone Specialist Interventions

Specialist treatment and making adaptions to standard treatment in IAPT were discussed as options for future intervention approaches to address the needs of this patient group. Whilst participants felt that a specialist treatment approach would be beneficial, most of those that did make reference to this also felt in the current climate that this was not a feasible option.

Instead a whole system approach was commonly advocated as the most acceptable and feasible treatment solution. This approach would allow for adapting treatment across IAPT at both steps 2 and 3. However IAPT healthcare professionals would require the skills and knowledge to enable them to make adaptions to their treatments. Furthermore, it was felt that this approach ensures that IAPT core business of treating anxiety and depression remains at the heart of what the service provides but acknowledges the complexity of co-morbid personality disorder traits in designing and adapting interventions.

"With personality disorder client groups, it's about having the knowledge and the skill there, and pulling it out the bag if and when needed. But it would also be nice to get that person into a supportive environment, with somebody with pure interest, and better skills and knowledge than what we've got, who've just trained in that area, who can offer that" (HP6, Step 3)

"I think it would be back to the reasonable adjustments of how you can effectively provide a NICE guideline intervention on anxiety and depression to someone who is presenting with these traits." (HP22, Leadership)

Adaptions to treatment and making reasonable adjustments were both terms used to describe new ways of working with this client group. However both terms described quite different approaches.

5.7.2.1 Adaptions to Treatment

Those who described adaptions to treatment generally focussed on treatment enhancement by adding something new to the treatment. This approach is focussed on working directly with the traits to enhance the potential effectiveness alongside standard IAPT treatment approaches.

"I think if someone's actually diagnosed with personality disorder then maybe they go to somebody who's got that sort of training. But obviously alongside depression and anxiety and whatever else, we're going to get the traits of PD which...don't necessarily need those sorts of therapies, because they're not a full-blown complex traits, but if we had more understanding and more training in that area, we would be able to treat them better at Step 3" (HP21, Step 3)

"Looking at what CBT interventions we utilise and whether there are any ways that we can adapt and make those interventions more helpful, more useful, as I say, as we would do for other populations" (HP11, Step 3)

5.7.2.2 Reasonable Adjustments

Many participants identified that they could only support this patient group as they would any other IAPT patient by following NICE guideline based treatment for common mental health disorders. It is from this viewpoint that the reasonable adjustments approach was suggested. Reasonable adjustments are adaptions that are not focussed directly at treating personality disorder traits. Instead reasonable adjustments are described as approaches employed to navigate around the traits and provide added flexibility, so that standard IAPT NICE guideline based treatments for common mental health disorders can be more effectively delivered.

"The reasonable adjustments all that is, is not letting the traits get in the way of the anxiety and depression treatment, rather than actually doing something about the traits. Like we would make reasonable adjustments for people with a learning disability, it doesn't mean we treat them and improve their learning styles or skills. It basically means we don't let the learning disability get in the way of therapy. We adapt the therapy to cater for their learning disability" (HP22, Leadership)

5.7.2.3 Standalone Specialist Interventions

Standalone or specialist approaches to treatment received very little support from the participants. Those interviewed challenged the feasibility and the IAPT service remit not being specifically focussed on personality disorder appearing the key factors for objection towards this.

"I think you look across the board, I think we can incorporate bits of treatment to make it a bit more tailored, but I don't think that we need the standalone thing, like a separate department for the PDs, for example" (HP17, Step 2)

Those who thought that a standalone approach would be beneficial felt that this should occur alongside but not in replacement of the adaptions and reasonable adjustments that could be applied across the whole IAPT workforce as described above. Another problem raised regarding the provision of a specialist intervention in IAPT related to the remit of IAPT and concerns were raised that if a patient requires a more highly trained therapist then that is what they should receive not a diluted version.

"On the one hand I really want to develop those skills for me professionally but on the other hand... if the person needs a clinical psychologist, why wouldn't... One year's CBT training versus, what is it, five years to become a [Clinical Psychologist]... There's a disconnect there, isn't there? ...if IAPT is all about evidence-based treatment, why wouldn't we be working with evidence-based models for people with personality traits? Why would we be working in a diluted way? Thing with IAPT is it's all evidence based so why come away from that with people with PD?" (HP32, Step 3)

One participant felt that adopting specialist treatments would not be without challenges "introducing a whole new therapy that's probably going to start to get quite messy" (HP4, Step 3). Another felt that some caution should be taken around this, as IAPT is not a specialist service and feared that IAPT has started to take on more and more complexity.

"I'm interested in the evidence based training and methods, but I just feel I'm restraining myself, because I don't want IAPT services, to become also, personality disorder services, 'cause we're taking on, at this moment, we used to take on basic bread and butter, basic anxiety, depression, phobias. Now we're taking on more complex cases, with risk" (HP6, Step 3)

Funding and service constraints in the provision of specialist interventions were also described as being unfeasible.

"The service would never fund someone to be trained in delivering therapy for people with personality traits. So it's more about the other stuff, just the managing it, the interpersonal" (HP12, Step 3)

5.7.3 Solutions for Clinical Practice

Participants commonly felt that IAPT is an appropriate place to provide treatment for depression and anxiety. One participant felt that specialist secondary mental health services had an iatrogenic effect by creating dependency.

"I think it's best placed to deliver it really rather than secondary service where I just think they create dependency on the service anyway" (HP13, Step 3)

This was further supported by another participant who held a strong opinion that primary care IAPT services were better placed than secondary services to provide treatment to this patient group.

"Yes, well, what does a CMHT do? I've worked in them. You might get a home visit once a week. You might see your psychiatrist once every two months, have a little review, how are things going? Okay. On any given day things might be

alright, but if you get them on another day things are shocking. It's again, sitting down and giving them time, making sense of why things keep going wrong, that's more important. CMHT just helping out with tasks isn't going to change things for clients, therapy is more focussed and managed a bit different, CMHT practitioners tend to respond to crisis" (HP12, Step 3)

There was a mixed view of what step is best placed to meet the needs of this patient group however most felt Step 3 would be more effective due to the increased time and flexibility they can use.

"I think probably Step 3 but with adequate training really I think, or a service set up for this client group and, you know, provision.... it's a brief intervention at Step 2.

I suppose at Step 3 you have more sessions and it's more longer term sort of intervention for change and...but then, again, some of these people might respond at Step 2 but I just feel that it's probably more appropriate at Step 3 really"

(HP13, Step 3)

A majority of participants felt that the stepped care model should continue to be used with Step 2 employed as the entry level intervention and that all treatments should start here and be treated using the stepped care approach in the same way as any other patient presenting to the service with common mental health disorders.

"I think it should be the same as anyone else to be honest, so if their anxiety is mild to moderate, they should come through us, because essentially we've still got the same system, we've still got the same skills to adapt and stuff like that. And who are we to say that they can't benefit from Step 2?" (HP29, Step 2)

Suggestions from participants for choice of interventions / therapy for the patient group however provided a variety of views. Formulation driven approaches were described as a potential solution. This is based on the assumption that standard IAPT treatment protocols just treat the disorders and therefore sometimes miss out the individuality of the patient and their presenting difficulties.

"You formulate the person, you don't formulate the disorder, and I think that's what they should do with IAPT, that people have been taught to treat disorders, and they've been given a protocol that looks at a disorder, as if every person that walks in the door with OCD, is a carbon copy of the last one. And it's obviously not the case" (HP15, Leadership)

Some newer third wave CBT approaches such as mindfulness, acceptance and commitment therapy (ACT) and interpersonal psychotherapy (IPT) were described as already being practiced in the service amongst some practitioners. Other specific personality disorder evidence based approaches were also discussed including mentalisation based therapy (MBT), dialectic behavioural therapy (DBT), structured clinical management (SCM) and psychodynamic therapy but these were described largely from limited knowledge perspective and were described based on participant knowledge and treatment interests, creating a very mixed selection of opinions and personal preferences.

Mentalisation based therapy and dialectic behavioural therapy were the most commonly described as having some potential utility for adaption and simplification for use in IAPT services. Below illustrates how one participant used their basic knowledge of mentalisation based therapy and his suggestion of taking a mentalisation stance as an adaption to his treatment approach.

"I would perhaps, based on the very little amount I know about mentalisation, I would try to utilise that a little bit in the approach. I would perhaps look, with the client, in more detail about how they're perceiving other people, other people's actions towards them, how other people might perceive them when they are getting angry, or panicking" (HP5, Step 3)

Dialectic behavioural therapy (DBT) skills were mentioned several times as having potential for making adaptions particularly as self-help resources within Step 2. Dialectic behavioural therapy skills are made up of the following; core mindfulness, interpersonal effectiveness, distress tolerance and emotional regulation. Some participants felt that some of the skills are already being adapted and used in this service but they have not been taught instead are guided via supervision

guidance. This adaption however is delivered with irregularity and was dependent on the supervisor's knowledge of Dialectic behavioural therapy.

"I think that really fits nicely with DBT because it's not about insight based work you know, you don't have to go into depth, it's about like, here's a set of skills lets practice them you know, you go away practice these skills in the context of you know in these situations and you let me know how you get on next week. And I've actually sent round to Step 2 workers either in formal supervision or informally I've sent them some distress tolerance hand-outs and I've said maybe you could sit down with your clients next week and go through some of this stuff... and let me know how you get on, you know... It fits with the guided self-help model, doesn't it? The hands outs are quite nice and exploratory and easy to understand, so yeh personally I think more skills based stuff for the Step 2 and more mentalising work for the Step 3s would be useful" (HP1, Step 3)

Supervisory support and specialist leadership was described as being important addition to any plans for change by having an identified personality disorder lead in the team with the relevant skill knowledge and expertise.

"I think we could honestly cope if we're supported by a lead person in a personality disorder team or specialty, and we could offer that support and education, and treatment, for that client, whilst we're also doing the PTSD work or the anxiety work or whatever, low level" (HP6, Step 3)

The argument for more psychosocial based treatment and support for this patient group was also discussed. One of the participants describes how IAPT services have evolved since its original interception based on the emergence of differing needs of patients who present.

"I don't know whether it's a political thing, financial, I think it's starting to be acknowledged that it started off with that idea of we've got all these people who are depressed and anxious and we need to get them back to work and we need to work with them across the NHS, here's some money and this is what we're going to put together. But actually if you looked at that group of people realistically they'd be the group of people that probably would have traits of personality

disorder as with a lot of people because they're probably struggling economically, socially, relationally, they come from difficult family backgrounds. So actually these people are really struggling and in my opinion people should get a full intervention that's social-psychological, that's how everybody, children and families, should be worked with, but that would never happen, we don't have the resources for that" (HP3, Step 3)

Increasing self-help materials for this patient group were described as being potentially useful particularly for Step 2 practitioners. More choice of resources to address the personality disorder traits such as self-help worksheets that the patients could take away with them were suggested.

"Adapting materials and things that we use, and maybe having a range of materials that we can just go to that would be suitable for working with certain traits" (HP30, Step 2)

Other more subtle changes to treatments and clinical practice suggested by participants included the ability to increase flexibility of approach and time to work with patients with complexity, by extending treatment duration. This was described by participants from both steps of the IAPT service.

"If we're needing to work with traits, and these things might take a bit longer than the six to eight session cut off, then maybe a little bit more flexibility, a little bit more time with some people as well might be helpful" (HP30, Step 2)

However it should be noted that the participants felt that the feasibility of increased time in a service focussed upon improving access was felt unlikely to be supported.

The format of therapy was discussed including group and individual therapy delivery modes. Although many participants could identify the benefits of group based interventions, including the process of learning from the experiences of other patients, the lack of specific focus on the individual patient was discussed with some negativity and therapists generally preferred to deliver individual approaches. Participants did however share how recently group approaches do

appear to be on the increase in this service with new ACT group and wellbeing groups being run.

There was a strong consensus amongst participants that the IAPT core remit for treatment of anxiety and depression should not change, as IAPT is an evidence based service delivering NICE guidelines treatment to people with common mental health disorders. The challenge lies in whether adjustments are focussed on treatment of personality disorder traits specifically or making adjustments so personality disorder traits they do not get in the way of therapy.

"The most realistic is staying within the remit, it's working on the anxiety and depression side isn't it, and challenging that? A bit of training on PD, I think, wouldn't go amiss at all on the traits" (HP29, Step 2)

Chapter 6

Study 3 - Patient Participant Results

6.1 Results

This section reports the results of Study 3 and working methods are detailed in Chapter 4.

6.2 Sample

Twenty two participants were recruited and interviewed from the 5 Boroughs Partnership NHS Foundation Trust, Wigan and Leigh IAPT Service. Thirty-three participants expressed interest in the research. Twenty-four were screened in, eight screened out and one withdrew pre-screening. Only two participants withdrew after being screened in.

Participants were evenly divided between those in receipt of, or recently discharged from Step 2 and Step 3 treatments. Three participants were in the process of being escalated from Step 2 to Step 3 treatment. Participant interviews ranged from between 43m:09s and 1h:46m:13s (total time 28h:31m:31s, mean interview duration 1h:28m). Most participants were female and all except 1 described themselves as 'White British'. Scores on the SAPAS ranged from 4-8 with a mean score of 6 (Table 15).

To protect the anonymity of participants, ethnicity and site of treatment have been omitted from the demographics Table 15 however are reported collectively within the text.

Participants self-identified a range of past and current diagnoses including: Obsessive Compulsive Disorder (OCD), Post Traumatic Stress Disorder (PTSD), Eating Disorder and Personality Disorder (Table 15). Depression and/or Anxiety were most commonly reported. Four participants had not had any diagnosis discussed with them in their current treatment.

<u>Table 15 – Demographics Table of Patient Participants</u>

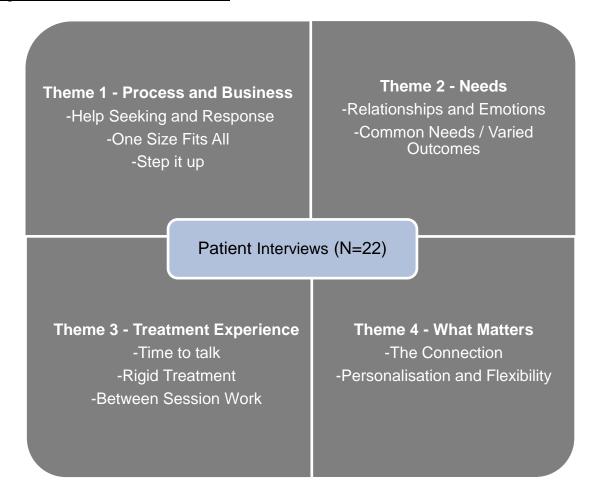
Case	Age	Diagnosis	Gender	Previous Diagnosis	Previous Treatment	SAPAS	Current	Treatment sessions
						Score	Step	
P1	26-35	None or Unsure	Male	Mixed Depression and Anxiety	Lower step in this spell of care none previous	7	Step 3	6-10
P2	26-35	Depression	Male	Personality Disorder	None	6	Step 2	1-6
Р3	26-35	Personality Disorder	Male	Not shared	CBT	4	Step 2	1-6
P4	26-35	None or Unsure	Male	Numerous	Multiple Psychological therapies	6	Step 2	1-6
P5	46-55	Depression/Anxiety	Male	Anxiety	Multiple Psychological therapies	6	between	1-6
							step up	
Р6	26-35	Depression/Anxiety	Female	Depression	Multiple Psychological therapies	6	Step 2	1-6
P7	36-45	None or Unsure	Female	Depression	Multiple Psychological therapies	4	Step 3	1-5
P8	56-65	PTSD	Female	Mixed Depression and Anxiety	Multiple Psychological therapies	5	Step 3	11-15
P9	18-25	Depression	Female	Not shared	None	4	Step 2	1-6
P10	36-45	Multiple diagnosis	Female	Mixed Depression and Anxiety	Multiple Psychological therapies	6	between	6-10
							step up	
P11	46-55	Depression	Male	Not shared	None	5	between	1-6
							step up	
P12	26-35	Depression/Anxiety	Male	Depression	Previous IAPT	4	Step 2	6-10
P13	26-35	Depression	Female	Numerous	Multiple Psychological therapies	8	Step 3	11-15
P14	18-25	OCD	Female	Numerous	Multiple Psychological therapies	6	Step 3	16-20
P16	46-55	Depression	Male	Mixed Depression and Anxiety	Multiple Psychological therapies	4	Step 2	1-6
P17	36-45	None or Unsure	Female	PTSD	CBT	5	Step 2	6-10
P18	46-55	Depression	Female	Depression	None	7	Step 2	1-6
P19	26-35	Depression/Anxiety	Male	Depression	Previous IAPT	8	Step 3	16-20
P20	46-55	PTSD	Female	Depression	CBT	7	Step 3	1-5
P21	18-25	Anxiety	Female	Anxiety	None	6	Step 3	6-10
P22	36-45	Depression/Anxiety	Female	Not shared	Multiple Psychological therapies	8	Step 3	11-15
P23	36-45	Depression/Anxiety	Female	Numerous	Multiple Psychological therapies	5	Step 3	6-10

6.3 Main Analysis Results

Analysis revealed four key themes 1) Process and Business 2) Needs 3)

Treatment Experience 4) What Matters. Each theme was divided into subthemes (Figure 10).

Figure 10 – IAPT Patient Themes



6.4 Theme 1 - Process and Business

This theme focused on the experience of accessing IAPT services and treatment choices made available to patients. This theme was divided into three sub themes: 'Help seeking and response', 'One size fits all' and 'Step it up'.

6.4.1 Help Seeking and Response

Participants described that the process of accessing an IAPT service emerged from a build-up of problems and deterioration in mental health prior to seeking

help. Making the initial contact with a GP or crisis service and asking for help was consistently viewed by participants as difficult. A quarter of participants described how they sought professional help when their difficulties escalated to a point where their difficulties were having a significant and detrimental impact on their lives and functioning.

"I'd been feeling like crap for about four months and then one day it just got too much and I burnt myself with my straighteners. Then that scared me so I went to the doctor" (P9, Step 2)

Just under a quarter of participants described feeling suicidal before they sought access to the service.

"There is no way of sugar coating it, I was suicidal. I was at the point of no return really" (P1, Step 3)

Participants described two different methods of gaining access to IAPT: professional referral or self-referral. Most of the participants self-referred to IAPT, with a majority self-referring following advice from professionals. Many participants described how the self-referral process felt impersonal, as they were handed a leaflet with contact details of the IAPT service. This was accompanied with minimal discussion or guidance from the professional being reported. Participants wanted professionals to make referrals to IAPT on their behalf. A quarter of participants felt that the self-referral process delayed their help seeking. They described how asking for help in the initial contact and the subsequent expectations for them to self-refer was anxiety provoking. This would often result in them delaying their IAPT referral and subsequently delay their access to treatment.

"If I need to ring somebody up it can sometimes take me three days to build myself up to ringing somebody, because I struggle with phones quite badly... And I personally I feel that putting that into the hands of people who struggle dealing with life anyway is... you're setting them up to fail, to a degree... I would have probably been here for therapy a lot sooner had I not known that I was going to have to organise all that myself" (P4, Step 3)

Several participants had received previous IAPT treatments. Those who had self re-referred after previous treatment were reluctant to re-establish contact through a fear of being perceived as failing the previous therapist or themselves.

"I felt awful on... I don't know, when you have anxiety, you worry about other people. So I felt ringing the service up to say, like, oh, I've relapsed, can I make an appointment to see someone, I felt like I'd failed (previous therapist's name). Because he did help me but obviously, because of whatever happened, I'd had a relapse. But I didn't want the service to think that they hadn't helped me, because they did but it was for a short period" (P14, Step 3)

Of those who self-referred a small minority referred to the experience as positive. They felt the self-referral process was empowering as it placed control back in the hands of the patient, hence enabling a build-up of self-confidence and independence.

"Well, in the long run, I mean, obviously at the time when I was feeling vulnerable or down under in a black hole of depression, I would have wanted my doctor to have done it for me, like made the referral or made the phone call to say whatever.

But in the long run, looking back now, I'm proud that I did it myself. I got the leaflet, I was sat at home shaking thinking shall I phone. And then I did make the phone call" (P14, Step 3)

Mixed views were found about waiting times between the phases of referral, triage, treatment and stepping up to more intensive therapy. Just under half of the participants described the timing and access to the service as positive. There was an acceptance amongst a majority of participants that there would be a waiting period before they were seen and many commented that the waiting time was less than they were initially advised. Others however found the waiting time difficult and described a false sense of hope at the triage contact point, where they had expected therapy to immediately commence. Instead they reported the frustration they felt when they were placed back onto a treatment waiting list after the triage assessment.

"I don't even know what I would have wanted. When I was at my bad times, I wouldn't have known, I'd have just wanted something. And I wanted a response. And I think that's the thing, it's the initial response. Because you get your triage, and you think, I'm in. And then you've got that wait again, so it's like, well are they responding to me, actually listening to me? I think just a response, a positive response though, would help" (P12, step 2)

Information provided by the IAPT service and therapists regarding waiting periods was not consistently shared. Some participants reported being told how long they would have to wait for treatment, whilst others described being given very vague information or declined this information completely. When approximate waiting times were shared this was reassuring to the participants, but was met with frustration in those who received no approximate dates for being seen or were declined this information.

"I asked for CBT...I had some CBT assessments, how long's the wait? We're not allowed to tell patients that. We've been told we're not allowed to tell people.

That's not helpful. It's not helpful to not know. And then they spring it upon you, instead of giving you like a vague idea" (P6, Step 2)

The average waiting period for most participants was between 4-6 weeks. This received a mixed review of acceptability, whilst it was felt acceptable to wait for therapy, several participants made reference to a need for interim support, updates and improved communication systems, so they knew they had not been forgotten. Waiting periods for some were particularly difficult and one participant described it as a rejecting experience.

"Well, you feel like basically you've been dumped. You feel like nobody cares, nobody...you're getting to the point where you're that desperate that you've had to go and ask for help which is quite embarrassing and you don't want people to know that you're in this kind of situation but..." (P13, Step 3)

6.4.2 One Size Fits All

Participants felt that treatment choice was not consistently provided leading to a "one size fits all" (P6, Step 2) experience. A lack of choice over the types of therapy offered was highlighted, as were concerns around the prescriptive ways in which therapy was being delivered in IAPT. Participants reported that they were rarely involved in decisions about their treatment. Treatment and intervention choices were described with lots of variability, dependant on which therapist the participant was allocated too.

"I feel like it should be a bit more personalised to what you want yourself... I can understand someone saying, well, we think this is best for you, but I do feel like you should have some input into it as well" (P21, Step 2)

One participant who had two recent episodes of treatment shared how she had only even been offered cognitive behavioural therapy. Even when she asked for something different on her second presentation she was given the same treatment at the same step.

"They probably use the same strategy on the next person, the next person and the next person. It doesn't mean it's going to work on all of us. We're all different individuals" (P18 Step 2)

Participants described therapist predictions of how many sessions they would be offered as unhelpful and impersonal. The number of sessions seemed to be driven by service constraints rather than defined by individual needs.

"It's like putting a price tag on it. It just feels as though you're allocated so much money, once your money's run out there's the door, see you. You're left on your own... It's all to do with politics and things like that I think. And it's not nice. It's very wrong. And I know that it's not the therapists fault, it's the system. I think the system's totally wrong. I think it should be analysed and treated on an individual case instead of on an average ... I mean, who can be average when they've got mental health issues? They can't, can they? And I think that is a very big let down!" (P20, Step 3)

Some participants preferred to know what they were being offered and where they were up to in relation to their treatment however others described this as adding pressure and lacking personalisation to their needs.

"Six sessions, that's it. Not six sessions and then we'll see how you are.Oh, yes, it put me off straightaway, like I was just a piece of meat, really" (P18, Step 2)

One participant described being told how many sessions she would receive as a rejecting experience.

"When somebody says to you I can only offer you so many weeks...That immediately just kicks you in the face... I feel as though I get to a certain point and I feel as though I'm just binned. I mean, it's 12, 13 years down the line now and I'm still not resolved, because I'm never allowed to finish the therapy off" (P20, Step 3)

A minority of participants were provided a choice of different treatments. An example of this was one participant who was escalated from Step 2 treatment to a more intensive treatment and was offered a choice of referral to either a dedicated eating disorder service or Step 3 cognitive behavioural therapy.

"It was good because it made me think logically about what's wrong and what I need to deal with. But I've never been sat across from anyone in this situation who's said we've got options for you" (P10, Step 3)

6.4.3 Step It Up

This sub theme relates to the level of treatment (Step 2 or Step 3) that participants received and the appropriateness to them and their presenting problems. Mixed views were provided relating to the level of the therapy they had received. A majority of those receiving a Step 2 treatment or were awaiting an escalation to Step 3 described Step 2 interventions with negativity.

"She'd give me a piece of paper to write things down on every day and other stuff and I thought it was a bit pointless..." (P18, Step 2) Participants often reported how they are expected to go through the steps (levels) of the system even when they felt that a Step 2 treatment was not going to be beneficial. Many felt that an earlier escalation to Step 3 would have been beneficial.

"You've got to start somewhere, but I suppose if after the first couple of sessions you would understand that it's not really going to... In other words, it's not flowing, it's grating, it's going against the grain with me... What's the point? It's just a waste of weeks" (P2, Step 2)

Participants who had received a Step 2 treatment and were waiting for a Step 3 treatment described feeling hopeful that 'stepping up' would provide a more intensive therapy with a different and more highly trained therapist. Choice and discussion in the process of escalating from Step 2 to Step 3 was delivered with mixed levels of detail and information. One participant reported that she wanted more time in therapy to discuss and make links to her past experiences which was not afforded to her at Step 2. When offered an escalation to Step 3, the difference in steps was not properly explained:

"I was under the impression it was just more sessions, that was the impression I got there, you were going up to the next level, which just meant...I think it's a standard set of eight sessions you get, you just get more and I didn't see the point, because it wasn't working for me" (P21, Step 2)

This participant felt misinformed as there was no mention of increased session duration, and she felt that had this been mentioned she would have probably continued with therapy at Step 3 rather than deciding to terminate treatment. Participants who received a Step 3 treatment were more positive due to the increased flexibility and choices of treatment. Those who provided mixed reviews of Step 3 revealed that the therapy was either too difficult without the added component of additional social support alongside therapy or as lacking the depth required to understand a complexity of their problems.

"I'm being left to come up with the things myself, and I think once you've been in the services, okay, you know, over and over again, you find it hard to pinpoint parts because everything's getting mixed in together, and to try and start from scratch and explain what your problems are, when you're a long-term sufferer, it's probably a lot more different than if something had just happened and you're dealing with what's just happened, do you know what I mean" (P4, Step 3)

6.5 Theme 2 - Needs

This theme focused on the needs of the participants in relation to their presenting problems. Participants described how they generally struggled to articulate their own needs but were able to identify the problem areas they wished to address in therapy. This theme was divided into two sub themes: 'Relationships and emotions' and 'Common needs/varied outcomes'

6.5.1 Relationships and Emotions

This subtheme provided an insight into the presenting problems of the participants. Despite a range of diagnoses, almost all participants described problems in forming and maintaining relationships, interpersonal effectiveness and a large majority identified difficulties managing emotions. The relationship difficulties highlighted by participants included a lack of trust of others which appeared to be based on difficult past early life experiences. These are described as leading to the avoidance of social interaction and a fear of forming relationships with others. Attachment and abandonment experiences from childhood were raised by several participants. Participants with these experiences expressed how they would often push away relationships through fear of rejection. This is illustrated in the following example;

"Well, like in relationships, messing relationships up, horribly; walking away from people who care about me; cutting people out of my life... And I'm suspecting now that perhaps I sabotage my relationships as a way of avoiding being let down by people, because if I can push them away first then they can't let me down and hurt me" (P4, Step 3)

Just under half of the participants described themselves as socially withdrawn.

One participant described a fear of others not liking him, which had resulted in him developing a guarded approach to others, as a method of self-protection.

"You see I don't know whether to be myself because if I be myself I risk people genuinely not liking me as a person. If I put the walls up and I am somebody else then I risk never knowing if anybody is going to like me as a person, I risk never making any real friends because they are making friends with someone who doesn't really exist... because I am different at home to how I am in work, so yes I feel like I am trapped, I feel like I am never going to get ahead, because its never me getting ahead and it's the conflict between them two" (P1, Step 3)

A lack of confidence with interpersonal effectiveness and emotional regulation was consistently described, hence making social interactions challenging. One participant described how people like him are often socially withdrawn and rarely encountered other people.

"To be honest, I don't think you come across people like me, because people like me don't want to be come across... Even until recently, the only place you could really approach me would have been at work or in the pub. I mean, in those circumstances...you could have found yourself in big trouble just approaching me in either of those situations" (P11, Step 2)

Other areas of difficulties frequently disclosed were low self-esteem, self-image and confidence issues. These were highlighted in a quarter of the sample and a further quarter felt their problems related to an inability to manage life stressors.

"It's being able to function in day to day life, really. I can't" (P13, Step 3)

Six participants described being suicidal or as having experienced long standing suicidal ideas throughout their lives. Just under half described using the following coping strategies to deal with their emotions: self-injury, alcohol, illicit substance or painkiller abuse.

6.5.2 Common Needs / Varied Outcomes

Needs are unique to the individual and therefore varying views and opinions were shared by the participants. The participants often found it difficult to identify and articulate what their actual needs were. Instead needs were often discussed in the context of presenting difficulties. This sub theme provided an insight into what participants reported as difficulties/needs being assisted in therapy and difficulties/needs that had gone unmet in relation to their treatment.

Whilst some participants were able to describe met needs or difficulties being assisted by their IAPT treatments, rarely was it reported that all their presenting difficulties/needs had been met. Overall exploration of met and unmet needs therefore provided mixed findings. The most reported met needs to emerge from the data was the opportunity to talk, be listened to and the ability to offload. This was reported in just under half of the participants.

"Well, the actual talking to somebody is the biggest thing. Irrespective of what all the techniques have shown, the fact that it's almost unloading the burden and saying this is what's going on in my life, this is why I'm feeling..." (P16, Step 2)

"Pretty much just having that, like I said just having that someone to speak to, just getting all them words out, being able to go back with an empty head and fill it with better thoughts each week, being able to get rid of all of the bad ones"

(P1, Step 3)

Some elements of standardised IAPT cognitive behavioural therapy approaches were described as assisting difficulties and being helpful to the participants including: psycho-education, behavioural and basic cognitive interventions. The most commonly reported unmet need in just a quarter of participants was disclosed as relationship / interpersonal needs. Those reporting this attributed it to a lack of space and time in IAPT to offload. A small number of participants revealed that they had never really understood what was wrong with them with many of them wanting answers for their presenting problems and guidance to understand their problems further.

"Well, that's why I tend to think that there's maybe something medically wrong because my depression has patterns as well, you know what I mean? It's like I can be...I never tend to hold a job down very long, I think 11 months is about the longest that I've ever held a job down... if somebody said to me this is what's wrong with you, I'd be over the moon" (P11, Step 2)

Participants described feeling frustrated when they were unable to use the techniques offered in IAPT.

"I think the focus is, right, here's one technique, have a go at that, how did you get on? Well, not too bad really. Well, here's another technique, here's another technique. So you get to the end of it and say, right, I've got six or seven different techniques I can try here, but I've not really developed the ability to use them"

(P16, Step 2)

The unmet needs reported by several participants when considered collectively have a correlation with other participants, who reported met needs. This is therefore indicative of a consistency in this patient groups reported needs. The areas of need most discussed, regardless of the context in which they are described, are 'relationships' and the 'offloading process'. However, the context in which the identified needs are described by the participants was subject to their unique experiences of IAPT treatment, for example as a 'met need' or 'unmet need'.

6.6 Theme 3 – Treatment Experience

The treatment experiences of participants are discussed in this theme. This theme is divided into three subthemes: 'Time to Talk', 'Rigid Treatment' and 'Between Session Work'.

6.6.1 Time to Talk

Participants had mixed views of their treatment experiences. Participants who had received Step 2 treatments described more negative treatment experiences than

those who had received Step 3. This was based largely on the treatment being unable to get to the root cause of their problems.

"You don't feel engaged by it, because you feel that you're not necessarily being listened to and what your individual issues are, because although there are common Step 2's and common behaviours that people might show, you're an individual at the end of the day and your problems and your reactions and your emotions are not necessarily the same as anybody else's. And I don't think when it's, right, this week we're doing that, next week we're doing that, you feel like you're not fully engaged and you almost feel right, well, let's just go along and get to the end of the therapy"(P16 Step 2)

Time pressures at Step 2 were expressed as reasons for negative appraisal of treatment. Participants revealed how it was difficult to develop a connection with the therapist owing to these pressures.

"I think because it just feels like you're rushed. It's like you've sat down and then got back up to get out. You're not sat down and getting into that zone of the help sort of thing. Really you're getting settled down for 15, 20 minutes, might have kicked into, yeah, I can see where you're coming from, and then it starts getting the ball rolling, and then as soon as the momentum's started it's like right, I'll see you next week" (P2, Step 2)

The treatments at Step 2 were seen by participants as prescriptive and rigid. The following words were used by participants to describe their experience of Step 2 treatment: *rigid*, *'mechanistic*, *scripted*, *shallow*, *robotic*, *going through the motions*, *lack of flexibility*, *here and now* only *focus*'. The context of using such terms are illustrated below:

"People like me with long term mental illness can't solve anything in six sessions...

Well, like I say, it's more person to person than writing things down or the questions they're asking you. I mean, I know they need to know why you're there but I just seem to get the same answers to the questions over and over again. I don't seem to get anything different" (P18, Step 2)

Treatment preferences overall were unique to the interviewed participants. One participant described that therapist approach was an important factor in determining treatment experience. For example:

"I think there's been variable quality to the therapy, depending on who you've seen. I've had sessions with some therapists and you think wow! That was good, they're really insightful. Then others that seem a bit more mechanistic, almost as though they're going through the motions of the therapy rather than fully engaging with it" (P16 Step 2)

Another participant described her experience as being repetitive and identified this as one of the main reasons she dropped out of therapy.

"I didn't feel right with her. It's like all like on the dot. It wasn't like talking. It was like you have to do these strategies and you have to do this and she was talking to me like I wasn't a person... It felt like I was just one of a long line of people, that it was just a job and it didn't...it came over quite robotic like talk. It didn't come over like that they cared or they wanted to be interested in helping you.

There's just one thing I know about all the treatments I've had is they all ask the same questions. So they're going through the same crap over and over and over again" (P18, Step 2)

Some participants reported how negative treatment experiences can become a barrier to future treatment seeking and can in some circumstances make them less likely to seek help from IAPT. One participant described how her therapy experience was focussed around the development of one breathing technique and that this has made her reluctant to come back into the service through a fear of receiving the same ineffective treatment again.

"Like, obviously I'm wary for the future, because I think if I need to go back, would I actually benefit? Or am I just going to go through the whole window thing again"

(P17, Step 2)

However even within the constraints of the system at Step 2, one participant described how her therapist for the first time in 30 years made her feel she had be taken seriously, listened to and guided into a treatment that could help her by stepping her up.

"Yes, even although he'd said numerous times we're not going to leave you this time, I still didn't believe him, because I'd been told I'd get help before and it's never...you know, but he was insistent and he was like, you're not being left this time, there's going to be somebody there for you, so that was like, oh my god. I didn't quite know what to do with it. A simultaneous feeling of fear and relief, obviously because there's a lot of stuff I've got to go through now and talk about, but at the same time relief that actually somebody for the first time is actually taking me seriously and listened and said you need help, we'll get it for you" (P10, Step 2)

Step 2 treatments, were not all described as negative. A small minority described a positive treatment experience. Conversely, the majority of participants who were treated at Step 3 described positive treatment experiences or mixed experiences with only 2 participants describing the treatment experience as negative. Common themes to emerge included the ability and time provided at Step 3 to offload and be listened too. This additional time and depth to therapy was discussed most frequently as the most helpful element of treatment.

"Because just for me it was the time to talk, the time I don't feel rushed, whether the exercises work or not whether she can figure me out or not, it doesn't matter! As I have got it off my chest. For me personally being able to tell someone, just being independent, independent somebody that I can rant at, or that I can say, I can just get it and hear it out loud, it feels like I have got it out of my brain, and just put it down on the floor and I can just walk away from it, I can just leave that behind for that week, I come out feeling like a weight has been lifted" (P1, Step 3)

At Step 3 being understood and the increased flexibility for more sessions was described as important. When flexibility and choice was experienced this led to positive patient feedback.

"I'm not sure whether it's...I don't know, like, two things really. One, it was more than six sessions. Like, some people have a six or ten slot of just therapy, and it's like, right, you've had your sessions, you're out of here. That's how some people feel. Whereas with me, I felt like he wanted to help me understand my depression, anxiety, OCD, and learn...you know what I mean" (P14, Step 3)

Alternative therapies to CBT were rarely discussed. Only 2 participants made specific reference to different approaches, with mindfulness and acceptance and commitment therapy (ACT) being described as the provided treatments. Both however were described within a positive context as being a new approach that the participants had not previously used. Both also discussed the positive impact of the skills and an ability to practice and apply the skills outside of therapy. Negative reviews were not unique to Step 2 treatments, but were also encountered amongst those in receipt of a Step 3 treatment. However, descriptions of Step 3 when negative were not as damning in their description and were minimally reported.

"You do feel like you're part of a manual, I suppose, because they're just telling you what they've been taught, they're not telling you what would help, you know?" (P13, Step 3)

6.6.2 Rigid Treatment

The rigidity of treatment approaches in IAPT were frequently reported by participants as being counter-productive to recovery. This was of particular relevance when participants discussed trying to make sense of how their early life experiences had impacted on their presenting problems. Participants felt that early life experiences were met with a dismissive stance with IAPT services being largely cognitive behavioural therapy led and 'here and now' focussed.

"I think my issue with CBT and, I know, you're completely going against what it actually is, it completely ignores anything from the past, I know it's just changing your way of thinking, but I couldn't come to terms with the things that had caused my low mood and because I wasn't having the opportunity to talk about them properly, I didn't feel like I was able to get past it" (P21, Step 2)

When treatment overlooked the past, participants felt misunderstood and concerned that therapy they were undergoing would lack the capability of reaching their core problems due to the exclusion of past experiences. Participants were frustrated at the lack of opportunity to explore past issues, especially those who had specifically asked to discuss past experiences and the impact of them on their current presenting problems. One participant described feeling disregarded by the IAPT service. She had reached a point where she felt able to share past experiences and felt that this would be crucial to understanding her current difficulties, but her request was dismissed. Her experience of service rigidity relating to this is illustrated below;

"Yeah, I've always pushed everyone out of everything that's happened and, you know, I've never wanted to speak about it as I was younger, and getting older I was ready to and obviously when you go to your GP about stuff like this, the first thing you do is give you that leaflet, but then here, it's just, like I say, it's just focussed on changing things, like, the here and now. So even though I was ready to talk about it... It was, kind of, disregarded" (P21, Step 2)

Only a minority of participants felt able to discuss the past and present within therapy. The rigidity of treatment in IAPT was also recounted by participants who felt constrained by the therapist to always return the focus on just the anxiety or depression, this lack of flexibility in approach to see the wider picture and problems was viewed negatively. Furthermore, reports of social difficulties appear to impact on the problems people present with. Several participants made reference to this and how additional support with these life challenges is often overlooked.

"The combination of mental health problems and financial problems has basically created the prison that I'm stuck in" (P4, Step 3)

One participant who received the maximum number of sessions in a previous course of IAPT treatment at Step 3 described feeling that therapy for her whilst working had always finished prematurely before she had made what she determines a full recovery.

"Yeah, right. So when you're doing all this, it obviously gets a lot worse before it gets better. You're walking up a mountain basically, and you get to a point where you're peaking and you've got to make that step to go over to try and put an end to the issues that you've got, and they never took me to that point" (P20, Step 3)

Participants consistently convey how the rigidity of treatment approaches in IAPT reduced the impact of therapy on their recovery. The rigid experiences of IAPT treatments did not reflect the complexity of the participant's needs or individuality.

6.6.3 Between Session Work

This subtheme provides an insight into the experience of between treatment session work. Between session work was rarely discussed by those receiving a Step 3 therapy. Participants who did discuss its use, generally discussed it within the context of a Step 2 therapy. Those who did discuss between session work provided mixed views on their experiences of it, however most described it as a negative experience. Several participants felt it was a form of going through the motions rather than being a meaningful part of therapy and that it was burdensome. Between therapy work was described to be a systematic process that is not tailor made to the needs of the participant.

"Yes you feel like you are just being judged on a note pad across the room, here we go again I am just waiting for it now, the sheets to start coming out to tell you which module you are on, and you're like I don't need fucking homework I need help, that's the way I feel I feel like it's a systematic process, I think it should be more Tailor made, If they are going to send you with homework it should be more Tailor made rather than printed off the internet, because it just looks like the same thing everyone else has been given, and I am sure other people come in here with anxiety, well I am almost certain they have... it feels robotic" (P3, Step 2)

A pressure on participants to complete between session work was also described. Written exercises in particular were often not complete due to everyday life pressures and family commitments.

"Sometimes it's just doing the relaxing thing, like three times a week or whatever, and you'll end up finding that that week you've had a brush up your backside and you're then running round doing all sorts and you just don't get chance to do it"

(P13, Step 3)

Others described the barriers to completion being based on an inability to see the benefit of its completion as illustrated below;

"Write that thought down. That's just never going to happen, you know what I mean, because between having that thought and finding a bit of paper and a pen, there might have been another ten thoughts gone on... And to be honest, if I start to write it down, you would never stop. It just wouldn't... There's just no end to it"

(P11, Step 2)

The appearance of the materials was also subject to criticism with one participant suggesting they look similar to something that would be given out in school that you would just throw away. This participant described a preference for something more practical and easier to read, suggesting a bullet point list as being more useful. A further criticism was aimed at the appearance and presentation of the out of session worksheets, which he described as looking as if they had been repeatedly photocopied, which made this process feel impersonal.

"Personal preference it would be more like erm it's not got the little black marks before it's been photocopied a three thousand times or its got fold marks because it's been folded at one point and then opened out and photocopied again" (P1, Step 3)

6.7 Theme 4 - What Matters

This theme focuses on the elements of treatment that the participants felt to be most important for consideration in the future provision of treatment. This theme consists of two subthemes: 'The Connection' and 'Personalisation and flexibility'.

6.7.1 The Connection

This subtheme provides an insight into the connection between therapist and participant and the importance which the participants placed upon this. The connection was overwhelming deemed by the participants to be an important element of the treatment and recovery process.

"I think it's having somebody there who knows how to get you over this. Having contact with somebody that you feel safe with, basically, and they can say to you look, I'm here and I'll make you better, we'll work through this together"

(P20, Step 3)

Connection to the therapist is described as something that is formed quickly, one of the participants suggested that you know straight away if you are going to connect or not.

"Yeah, you're talking about very significant things that are going on. You're not going to want to talk to somebody if you don't have a rapport with them... Because if you don't feel that they relate to you, I don't know, you can just tell, can't you? It's weird, it's like when you meet people and you start chatting to people, you can tell with people that straightaway, oh, they don't like me or I don't like them, or do you know? It's that kind of thing and then you think, well, I'm sitting with this person and divulging everything, I'm not sure that I'm quite comfortable with that. Sometimes you don't even know what it is, you just think there's something amiss here and I don't know why. It's a normal thing, it's not the therapist's fault, it's not your fault, it's just everyday life, really" (P13 Step 3)

Several participants described how they quickly formed an opinion of their therapist in their initial therapy sessions. They described the therapist display of genuine interest in their problems as being a key indicator of whether or not they could connect to the therapist.

"To be honest, I can't put my finger on it. I think I just built up a decent rapport with him. But the first time I met him, the first time I saw him, the first appointment I had with him, before I knew it was him that was going to be treating me, he put me at

ease straightaway and he was friendly. He wasn't cold and he wasn't clinical, he was friendly, and he encouraged me to take my time and not be rushed and be honest, and I...It could all have been a wonderful act. I don't think it was. I think he's very genuine but I just thought this person here is listening. He's listening and he gets it and I've come in and said, look, I am not feeling well and he's said we'll help... I think that was the main thing but I think the other, like I sort of said right at the beginning, it was just the fact that he was not like a therapist. Well, he was, he obviously was, but it was like talking to a friend who wasn't a friend" (P10, Step 2)

A combination of unique and individual factors enabled participants to connect effectively. Different participants provided different combinations of factors they felt were important in the connection between therapist and patient. Some common factors that were seen as important included: trust, honesty, humour, personalised treatment, mutual respect, shared interests, compassion, empathy, validation, not feeling judged, interpersonal effectiveness of the therapist. However, no specific combination of factors were consistently provided, instead they were unique to the individual.

Early negative connections with the therapist are described as being difficult to recover from.

"Didn't feel right from the start, felt cold, when you're talking to a person or psychiatrist you want them to talk to you like a person, like, you wanting to understand my life and try and help me to understand my own life... just there's nothing there between me and her, like a connection. You need a connection to work with anybody really and like I say, it was like there was no connection between me and her" (P18, Step 2)

Some discussion also took place about the importance of repairing of the patient and therapist relationship when sessions have not gone smoothly. Being able to openly discuss and reflect on previous difficult sessions rather than ignore them was described as being a useful process.

"To actually acknowledge and not pretend it didn't happen. Maybe just say like, oh, you know...and I'm not saying go over it, the whole of the next session, but

say, I saw that you were upset, what could I have done differently, what did I do that really set you off?" (P6, Step 2)

Although less commonly reported than Step 2 experiences, Step 3 therapist connections were also described as being problematic.

"It's quite cold. You just go in, you get it done, you go out and... I don't know. Sometimes it just feels like you're at school and it's a teacher barking you that you've got to do this and you've got to do that" (P13, Step 3)

Whilst connection with the therapist was clearly reported to be of great importance, there was a fear shared amongst several of the participants that raising any concerns about the working relationship or requesting a change of worker would not be welcomed by the service.

"I mean, again one of the things that (therapist name) has been going on about is that everybody, you don't like everybody you meet, so I tend to behave in a way where I'm trying to make everybody I meet like me, but some people, they might be perfectly nice and reasonable, decent people but you just don't gel. One of my regrets is that I've had a couple of therapists where that has been the case and I very much felt that if I complained about...it's not a complaint, if you say the therapist is...this is not helping me that much, then because you're criticising their service, whereas you've tried..." (P8, Step 3)

One participant described a positive connection with his Step 2 therapist and a negative connection with his Step 3 therapist. Interestingly other participants reported the opposite experiences when they described their connections to working with these specific therapists. Therefore, whilst we can take from this data some common characteristics that enable the therapeutic connection with this patient group and also factors that may hinder connections, there is something within this particular case that points to common interests and personal preferences that cannot be allocated for.

6.7.2 Personalisation and Flexibility

This subtheme shares the participant perspectives of personalisation and flexibility in therapy. A majority of participants described personalisation and a feeling that the therapist knows you, as being of great importance. A need to feel like the therapist knows the participant and that the participant knows the therapist was seen as a crucial to achieving personalised treatment.

"I think they have to show that they're responsive to what you're saying and tailoring what they're doing to..." (P16, Step 2)

Examples of a personalised approach were shared by participants who described the therapist's ability to recall personal facts, such as names or events and making reference to previous sessions as having a powerful impact upon them.

"When I was talking about all these friends and stuff, he remembered all the names of people I was talking to. This made a massive difference, he remembered, it's important to him, it's the little things, Yeah, rather than somebody sit there, get a load of notes out from the week before going, oh right, yeah, we talked about this, we talked about that. I mean, obviously he had his notes in front of him...To me it meant that he'd listened, he'd took it on board and we could pick up from where we were without having to go back over stuff" (P22, Step 3)

Participants reported however that when the process did not feel personal to them, this then created frustration. One participant who had used the service in the past described how in recent years he felt it has become increasingly impersonal and robotic.

"You know you spend half the sessions going over the same things you have already gone over, and it's very frustrating, for me it is, you know and it's like I have already told you about this, even if they just look through the notes 5 minutes before you come in and refresh themselves, so they are not confusing you with their other patients. Which you know, I understand as a human being you are going to make mistakes, but it's just if you go in there and you think this person

doesn't know me at all we are just going through a robotic stage here... Yes you want to feel like you are known, that they know you kind of thing, not just so that they can reel off facts about me, but you feel like you know that person"

(P3 step 2)

Changes in the way therapists are taught was highlighted by one participant who expressed a need for therapists to realise that not every patient will have a textbook in presentation. The rigidity of the system was frequently brought up as not allowing for personalised based treatments. However, when the therapist did attempt to make the experience more personalised, even if this was outside of therapy, this was consistently met with a positive response from participants.

"It's a little thing, he always used to walk me out of the surgery and he'd walk me to the doorway, and he would, right, then you're all right, I'll see you next week, and he would say things like, now I know you've not been feeling so good, if I've had a particularly bad...now I know you've not been feeling so good this week, can you promise me you'll keep yourself safe until next week? You've got my telephone number, you've got the number of the crisis team, you ring them any time. He would look me in the eye, you ring them any time you need them, and you can ring me on my mobile when you need me. I mean, I never did but it was that, you know..." (P10, Step 2)

One participant described her experience of treatment as being holistic and personalised. She shared that her most recent experience of therapy in IAPT was unlike others she has had, which had previously just focussed on just her diagnosed problem. She explained how her most recent experience met her needs by joining up the interacting components of her life. She outlined how her therapist drew her a spider diagram to highlight her core problem and interacting problems including: anxiety, depression, rituals, family and relationships.

"It's taught me to think that all these are linked. They're like little dominoes, they all trigger each other. But if you can have control over, you know what I mean, like with me, I have control over my rituals and I've learnt that it's okay to feel anxious, gradually these feelings reduce, you know what I mean. But they have a knock-on effect" (P14, Step 3)

Participant reports of flexibility in treatment approach was mixed and could not be attributed to a specific step but instead was determined by the individual therapists.

"He was very flexible. Many times I had to cancel due to work - because I do work full time - so I had to cancel, say, two sessions due to work. He was very understanding. No, so I can't really see a fault" (P14, Step 3)

Offloading was described within the context of therapist flexibility and was described by several participants;

"I am not restricted in the session with (therapists name) So I'm able to just say I am doing this this and this and we have to pick just one thing and go for it, I just eject everything that's in my brain all over her and she just kind of goes oh alright that's fine and kind of makes some sense of it, and kind of gives me the behavioural training to put into place and I try different things" (P1, Step 3)

One participant described how the therapist would give her more time if he could on occasions for example, when the next patient due in had cancelled. She was not sure if he should have done this, but described it as having a positive impact on her relationship and treatment with him. She disclosed that if she had sensed the therapist was clock watching this would create a pressure on her experience.

"It's a feeling of pressure. It's a feeling of this person is not listening. They're more interested in meeting the target and getting onto the next client but they're under pressure" (P10, Step 2)

Another participant described the very positive experience of her therapist sticking with her even when she tried to disengage from therapy. In a previous treatment she had finished prematurely and was allowed to at her first request to disengage without the therapist challenging this.

"I don't actually know but it's, like...because many a times, because of my anxiety and that, I used to say, right, how many more sessions now, is that it now, am I better or, like, shall we leave it a month and then just have another session. And he'd be, like, no, we'll carry on just as we are doing weekly sessions" (P14, Step 3)

'Personalisation' and 'Flexibility' appear to be essential elements of an effective treatment approach for this patient group. Experience of this in treatment, however, received very mixed experiences from the participants. Most at Step 3 felt that the treatment was personalised, individual focussed and flexible to their needs whilst a majority at Step 2 felt it was not and instead was described as a more mechanistic and scripted process.

Chapter 7

Synthesis

7.1 Synthesis Introduction

This chapter synthesises the two qualitative studies (Studies 2 and 3). The rationale for conducting a synthesis of this data was to look collectively at both the IAPT healthcare professionals and patient participant results, hence analysing the data at an advanced level (Atkins et al., 2008). Both were key stakeholders and therefore provided insights of equal importance. It is important to synthesise the data from both studies, as any recommendations made from this research will be strengthened by reporting and articulating what the collective analysed data reveals. Combining both the service user (patient) and service provider perspective (IAPT healthcare professionals) views has the potential to improve the impact and the likelihood of implementation of any recommendations made.

7.2 Synthesis Method and Process

The two sources that have informed this synthesis chapter are from the two primary qualitative studies (See Chapters 5 and 6). A thematic analysis synthesis method was employed to identify the re-occurring themes and areas of similarities and differences. This method allows for the pragmatic and flexible development of procedures utilised. Using thematic analysis synthesis is an effective approach to developing new theories from existing data, however it has been criticised as lacking systematic methods and the ability to account for contradictions in the data (Dixon-Woods et al, 2005). However the pragmatic procedures and process of ongoing reflexivity has allowed for and enabled the identification and reporting of contradictions identified in the data across the two sets of data.

The process of synthesis and procedures employed were achieved by immersing oneself into the results of studies 2 and 3 with equal importance attached to both. The data was examined to explore similarities, conflicts and insights that evolved from the process of viewing the results of this research in their entirety. Two Venn diagrams were initially constructed to identify the similarities across the themes

and shared with the academic supervisory team to develop a consensus ensuring consistency and rigour within the reporting of this chapter. One of the Venn diagrams focused on the identified commonalities across both data sets (Figure 11) and the other outlining the areas of conflicts in opinions that are identified across the data sets (Figure 12). The results and findings from this process were then further synthesised and categorised for reporting and are evidenced in Table 16.

[Intentional Space]

Figure 11 - Commonalities Venn Diagram

IAPT Healthcare Professionals Commonalities Patient Participants

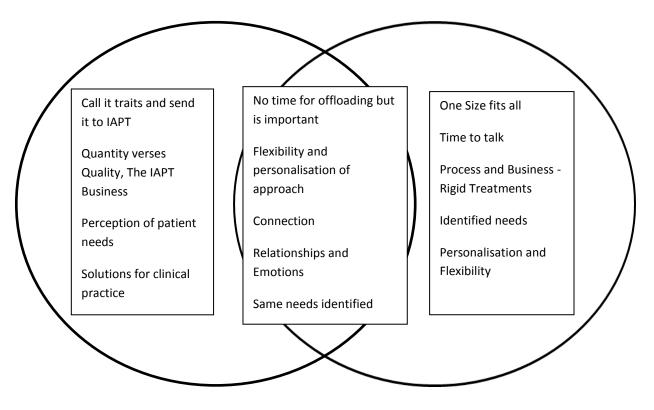


Figure 12 - Conflicts Venn Diagram

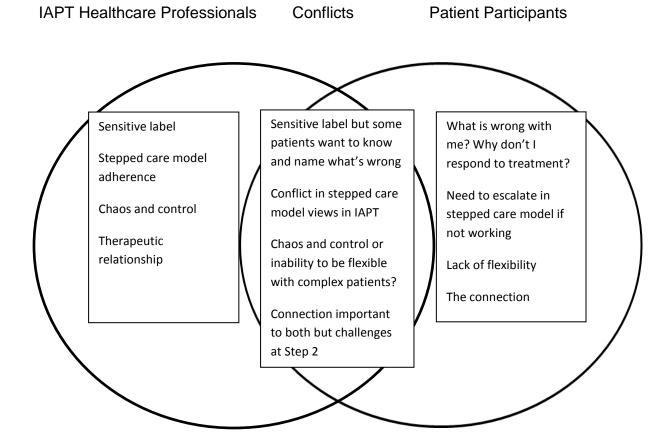


Table 16 – Synthesis Summary

Identified Area	IAPT Healthcare Perceptions	Patient Perceptions	Commonality or Conflict (Similarities across the 2 studies)	Solutions / Considerations
Labelling Personality Disorder	Cautious views about stigmatising and labelling an	Want and need to know what is wrong with them	Conflict	Explore impact of labelling further
	undiagnosed population	Confusion over	IAPT Healthcare professionals were wary of	Unknown reaction of patients to this label
	Based on clinical hunch rather than a dedicated screening	presenting difficulties	using a sensitive diagnostic	Purpose of labelling
	tool		Patients however described	Will labelling open up new opportunities for evidence based treatment
	Pointless to do without being able to offer an evidence		a need to know what is wrong with them	Only open up label once able to offer
	based intervention			something of benefit
IAPT Business	Call it traits send it to IAPT	One size fits all	Commonality	Increased complexity identified in IAPT
	Training skills deficits	Anxiety and depression focus	IAPT Healthcare professionals described	Increased time and flexibility required
	Need for adapted approaches	Quantity over Quality	quantity over quality	Anxiety and depression to remain the main underpinning treatment approach,
	Quantity over Quality	(Mirrored)	Patient Participants described similar concerns	unless it is clear that the patient is unresponsive to this. However adapted
	Demands on Staff	Care dictated by service constraints not patient	using different language instead referring to the	or additional intervention required for this patient group if co-morbid personality
	Conveyer belt	needs	rigidity of treatment and service constraints	disorder is identified
	Changes in service more business focussed increased	Therapist rigidity focussed on anxiety and	Both reported some benefits	Creativity to make adaptions within a constrained service required
	complexity	depression	of the core anxiety and depression interventions	Short sighted demands in conflict with
	Core business Anxiety and depression	Lack of treatment choice / options	Both reported a lack of	longer term solutions
	•	•	treatment options	Increase of treatment options for patients

Patient Needs	CBT here and now focussed	CBT here and now	Commonality	Focus required on interpersonal
	often overlooks past problems	focussed overlooks past		effectiveness
	associated with long standing	difficulties, can feel	High level of consistency	
	difficulties	invalidating	reported amongst both	More flexibility and less rigid treatment for
			groups relating to the needs	this patient group
	Patients needing of time and	Social problems	of the patient group	
	space to access emotions and	overlooked	(emotional regulation and	Space to offload
	offload seen as important		relationship skills important).	
		When flexibility applied		Staff require opportunities to further
	Emotional regulation needs	positive experience	Both recognised a need in	develop understanding and skill for
			the patient group to allow for	working with this patient group
	Interpersonal needs	Interpersonal and	exploration of past problems	
		relationship needs	and early experiences.	More guidance required and treatment
	Experience of chaos and			recommendations for practice to reduce
	control, need to be more	Need space to offload	Both reported a need for	inconsistency of approach
	flexible in approach with this	and be heard	more time, flexibility and	01
	patient group.	No ed for dovelope of of	offloading space for the	Stepped care model should be
	Negative engaginal of every skill	Need for development of	patient group.	considered more flexibly if not meeting
	Negative appraisal of own skill	emotional regulation skills	Conflict	needs, risk of patients dropping out and
	and knowledge	Less time at step 2	Conflict	representing
	Inconsistent use of adaptions	Less time at step 2	Conflict seen in opinions	
	inconsistent use of adaptions	Step 3 more likely to	over the step treatment	
	Stepped care model should	reach core of problem	should be provided at for this	
	be used starting at step 2	and preferred	patient group.	
	bo dood starting at stop 2	and professed	pation group.	
		Escalation to Step 3	Conflicting opinions over	
		should be quicker if Step	chaos and control in the	
		2 not beneficial.	room	
			IAPT healthcare	
			professionals felt they	
			required more advanced	
			skills, patients reported a	
			need for more of the basic	
			interpersonal skill / flexibility	

Therapeutic Connections	Therapeutic relationship important	Therapeutic relationship more difficult to achieve	Commonalities	Staff skills require attention
	Perceptions not helping	at step 2 due to time limitations	The therapist / patient connection is important to both groups	Step 2 for some patients is inadequate especially if relationship and trust issues present.
	Unable to follow treatment	Can be built or broken		
	protocols	quickly	Consensus seen on the need for 'time to talk'	Key factors that aid relationships are very unique to individuals
	Skills and knowledge deficits	Genuine interest		
	Fear and frustration	important Key factors that aid the	Relationships generally harder to achieve in the constraints of Step 2	Some benefit in repairing of therapeutic rifts, openness and honesty important.
		therapeutic relationship shared but inconsistently reported	Conflicts	Relationships unique and may not be afforded the importance.
		Open and honesty and repairs of relationships	Step 2 for some patient inadequate but IAPT healthcare professionals	Staff may require support and guidance to repair relationships
		important	advocate for this being the starting point for IAPT	Early recognition of therapeutic rifts and repairs
		Relationships are unique and connection more complex than being just step specific	treatment	Choice of therapy approaches dependant on therapist knowledge and skill.
		Patients fear reporting a therapeutic relationship that isn't working		
Future Clinical Practice	Anxiety and Depression should remain core business	Patient choice of therapy approaches and inclusion	<u>Commonalities</u>	Evidence based service why change without evidence based alternatives
	Nice guideline evidence	in decisions are important	Both groups support some underpinning use anxiety	Anxiety and depression treatments
	based service	Holistic care not just main diagnosis	and depression interventions	remain the main underpinning treatment approach, unless the patient is
	Adjustments and Adaptions seen as most feasible			unresponsive to this

	Personalisation of	Consensus on the need for	Interim recommendations for practice
Acceptance it is IAPTs	approach important	some additional adaptions to	required
business to work with this		treatment	
patient group	Individualised treatments		Adaptions to treatment preferred
	not blanket prescriptive	Patients and IAPT	
Holistic care and formulation	treatments	healthcare professionals	Need to skill up workforce
driven work supported		reported the need for more	
	Rigid system constraining	holistic care not just	Service to support flexibility in working
Personalised and		diagnosis specific	with patient group
Individualised treatments	Need for offload time		
		Both support need for less	Personalised, individual and flexible
Flexibility and increased time	Step 3 preferred	rigid and more flexible,	treatments recommended
would be beneficial for this		personalised and	
patient group		individualised treatments	Offload time should be factored in
		with this patient group.	
Rigid system and business			Needs most likely to be best met at step
side of IAPT constraining		Offloading space and time	3
		important	
		Conflicts	
		Step 3 preferred by patients	
		for treatment	
		Anxiety and Depression to	
		remain the focus of	
		treatment, patients however	
		describe frustration when	
		other difficulties are	
		overlooked	
		Patients blame rigidity of	
		treatment on therapist -	
		therapists blame it on the	
		system.	
		ayatem.	

7.3 Synthesis outcomes

The synthesis highlighted five areas of similarities from the two qualitative research studies. The five key areas identified included: Labelling Personality Disorder, the IAPT Business, Patient Needs, Therapist Connections and Future Practice (table 14). Each of the 5 areas will be discussed in detail.

7.3.1 Labelling Personality Disorder

Labelling and the identification of personality disorder co-morbidity was directly discussed with IAPT healthcare professionals during interviews. A high level of sensitivity in using this label with an undiagnosed population was encountered. The level of anxiety elicited during interviews around the use of this label with an IAPT patient group was mirrored with the early concerns highlighted in the early developmental phases by the IAPT service leads and research advisory group. The label 'personality disorder traits' was not directly discussed with the patient participants due to ethical sensitivities. However several patients reported frustration in not knowing what was wrong with them and confusion as to why the IAPT treatments were ineffective on them but not others. Several patient participants identified a need to know what was wrong so they could further understand their problems.

Hence when the results were viewed collectively there is an apparent disconnection in the staff reluctance to identify people with this label owing to its associated sensitivities. Conversely, some patient participants reported a need to know what was wrong with them. However we do not know from this research whether the sensitivities attached to the label would have been realised as being counterproductive or offered the patient participants beneficial insight into their difficulties, if this had been shared.

IAPT healthcare professionals felt it was not appropriate to discuss personality disorder with IAPT patients if this had no impact on the treatment pathway that would be offered within the service due to a lack of available evidence based interventions for patients in primary care and the stigma attached to the label. However if in the future evidence based interventions were made available,

identification of this patient group would require further attention to ensure that those effected by the co-morbidity of personality disorder traits are identified and receive the evidence based treatments in a timely manner.

7.3.2 IAPT Business

IAPT is reported to have become increasingly driven by performance related outcomes in recent years. The business nature of IAPT as a service was described by participants in both studies. Patient participants described IAPT as providing a 'one size fits all' treatment. Whilst IAPT healthcare professionals described an evolving service that has become more business-like in recent years due to increased monitoring of outcomes. Specialist secondary mental health services are reported to have become more recovery focussed and less inclusive. IAPT healthcare professionals suggested that this has led to an increase in the complexity of cases presenting to IAPT services in recent years. IAPT healthcare professionals identify themselves as having skills and knowledge deficits for working with this patient group. This is similarly reported in patient views who describe rigid treatments that are not focussed on their presenting or underlying difficulties.

The reported tension between quantity and quality is also shared in patient results. Patient participants commonly described the tension of the service constraints as impacting negatively upon their experiences, particularly at Step 2. IAPT healthcare professionals also reported frustrations, describing changes in their role that do not make best use of their expertise and feelings of being de-skilled by the newer more outcome-focussed and time limited approaches. 'Factory line' type descriptors were used to describe the role of the Step 2 worker. This is mirrored within the patient interviews, where different terms were used to describe the same tensions and rigidity within the treatments they receive.

Whilst it is acknowledged that IAPT is now working with increased complexity, there is an expectation they do so without the additional resources or commitment to develop the staff. Some IAPT healthcare professionals argued they are expected to do more for less.

There was a consensus amongst IAPT healthcare professionals that the service should not become a 'catch all' service that works without defined boundaries of who they can and cannot provide treatment too. Instead it was reported that the focus should remain on anxiety and depression evidence based treatments. Patient participants also acknowledged the benefits of routine cognitive behavioural therapy type interventions that focus on anxiety and depression. It could be argued that this patient group may however benefit from additional strategies. Poorer outcomes are reported in this patient group when routine IAPT treatment are provided (Goddard et al., 2015) therefore identification, additional or adapted approaches require consideration. Patient participants whilst acknowledging some benefits of routine cognitive behavioural treatment also disclosed frustration that often cognitive behavioural therapy treatments were unable to get to the root cause of their difficulties and that interventions were difficult to apply into their everyday lives.

7.3.3 Patient Needs

A high level of consistency in the narrating of the patient group's needs were reported across both studies, with relationships and emotional needs predominately highlighted. Similarly both the IAPT healthcare professionals and patient participants reported how past experiences require recognition when working with this patient group.

IAPT healthcare professionals described an increase of people accessing IAPT services with co-morbid personality disorder traits. A skills deficit was also recognised by the workforce as requiring attention. Whilst the patient participants do not explicitly identify a skills deficit in their therapists, they described with frustration the lack of flexibility of therapists and the therapists need to always return their interventions to focus on anxiety and depression. Social problems that impact on patient's mental health and past significant childhood experiences were also described as often overlooked. Past early experiences were described by both sets of participants as being important to accommodate in therapy. IAPT healthcare professionals recognised that cognitive behavioural therapy is 'here and now' focussed. However, they also recognised that this approach is not always the best fit for people with long standing difficulties.

The lack of flexibility in the therapist and treatment approaches which includes 'out of session work' is described as a negative experience by the patient participants. IAPT healthcare professionals recognise these frustrations also but are often constrained by the demands of the service and its outcomes. More attention to explore emotional regulation and space and time to access emotions in therapy was identified as important by the IAPT healthcare professionals. This was consistent with the messages from the patient participants who highlighted the importance of being allowed time and flexibility within therapy to offload and process worries and concerns.

IAPT healthcare professionals described the chaos and lack of control they have over sessions with this patient group. The chaos and control reported by IAPT healthcare professionals could be represented as occurring due to the inability and lack of flexibility in the IAPT system and therapies that constrained the patient from being able to come away from protocol based treatments to offload and deal with their most distressing or changeable emotive issues as they arise during the course of therapy. IAPT healthcare professionals described this as a challenge, as it is not compliant and deviates away from the IAPT therapy approach which is much more prescriptive. Social and relationship needs were also a topic of contention due to the lack of dedicated interventions or skills, however, the IAPT healthcare professionals recognised the need to be realistic about what needs they could cover in a course of treatment.

Rigid cognitive behavioural therapy driven protocols and the time constraints can create pressures in the IAPT workforce. These pressures could therefore manifest into the reported chaos and control which they attribute to the patient. However it could be argued that this chaos and control occurs as a result of the therapist trying to fit the patient needs into a prescriptive treatment hence creating the tension described.

IAPT healthcare professionals shared a negative appraisal of their own therapeutic skill when working with this patient group. Conversely, patients did not share a need for complex interventions or a highly skilled workforce, instead they highlighted a need for the simple things like: personalised care, time and the flexibility in therapy to offload. This is in conflict with what the IAPT healthcare

professionals believed to be required. It also challenged the IAPT healthcare professionals own self-deprecating view of their skill and ability as they are likely to possess the simple interpersonal skills the patient participants highlight but are somewhat constrained in being able to use these skills within a pressured service.

If IAPT healthcare professionals were supported in the further development of their knowledge of personality disorder, this may allude to guiding them in the importance attached to relationships with this patient group and the basic interpersonal sensitivities that the patient group often present with. The biggest challenge however in meeting the needs of this patient group would appear to be overcoming of the system's rigidity.

The results from both studies indicate that some of the newer approaches can be beneficial. IAPT healthcare professionals have suggested that some adaptions to practice with this patient group are already happening. However the provision of this is inconsistent and cannot be measured for effectiveness as the adaptions appear to be applied in an unstructured way that is guided via suggestion at supervision. Hence identification of adaptions at this stage would prove difficult.

IAPT healthcare professionals felt that this patient group should still go through the stepped care model. Hence all should start at Step 2 and that level of intervention should only be stepped up if it has been ineffective and the patient meets the criteria for an escalation to Step 3. In contrast patient participants disagree with this instead they suggested a need to be escalated to a Step 3 intervention from Step 2 much quicker if the intervention clearly is not meeting their needs. It has been identified from this research, that this patient group require a more flexible, individualised, less prescriptive and less time constrained therapy. Therefore it could be assumed that a Step 3 intervention is more equipped to meet the needs of this patient group. Both patient participants and IAPT healthcare professionals generally share that time to talk and ability to get to root problems is more afforded to Step 3 than Step 2. However this is not clear-cut as a dependency on the therapist and relationship has highlighted some conflicts of opinion which complicate this assumption. The most appropriate step for the provision of treatment for this patient group is not unambiguous, as often the patient group will presents with variable severity, complexity and therapy preferences.

7.3.4 Therapeutic Connections

The relationship or connection is commonly reported as an important component of therapy by both the IAPT healthcare professionals and the patient participants. In IAPT services many challenges were described as impacting upon therapeutic connections. The complexity of the patient group and service constraints are reported by IAPT healthcare professionals as challenging the development of therapeutic connections. Relationships and the importance of repairs when things do not go smoothly were reported as an important relationship experience in both groups. However not all IAPT healthcare professionals were able to relate to the importance of this, therefore a training need and guidance may be of benefit to highlight this. IAPT healthcare professionals described how the service constraints at Step 2 make it harder to develop relationships. Skills and knowledge deficits can lead to fear and frustration in working with this patient group and are reported as impacting negatively on the therapeutic connections.

Patient participants described how very early on in the relationship their opinions are formed. These can be built or broken early on in the therapy. Genuine interest, interpersonal skills of the therapist and the perceived therapist values are highlighted by patients as being important. However, the combinations of the most important therapist characteristics that enable forming an effective relationship is largely dependent on the patient's individual preferences. Patient participants also described a reluctance and fear of raising concerns about a lack of connection with the therapist to the service or requesting a change of worker. It is however not as simple as this being a step specific problem, but is more attuned to the personal and interpersonal connections people make that are complex and unique to therapist and patient individual preferences. The constraints of Step 2 are described by both groups as making the forming of relationships challenging.

Both groups agreed that 'time to talk' is essential for enabling the development of a therapeutic connection with this patient group. The breakdown of therapeutic connections is something identified to be of importance across both studies 2 and 3 results. A process that allows and encourages patients to raise concerns without fear of being judged, early in therapy could be put in place, if the therapeutic connection is not progressing. This could allow for an opportunity for a

skilled therapeutic repair to take place, however this could prove difficult in practice as it appears the therapeutic connection is very unique to the individual's preferences and more complex than just improving the interpersonal processes and the repairing of therapeutic ruptures.

7.3.5 Future Clinical Practice

IAPT healthcare professionals are accepting that co-morbid personality disorder presents within the IAPT population. The IAPT healthcare professionals were willing to work on making adjustments and adaptions to treatment for this patient group and feel that this is required. However, there is also a consensus amongst the IAPT healthcare professionals that the core business of IAPT is to provide evidenced based interventions for anxiety and depression and that this should remain the main underpinning treatment approach, unless it is clear that the patient is unresponsive to this. There was a strong agreement that when personality disorder traits present co-morbidly to common mental health problems, adaptions to treatment that follow the clinical intervention recommendations above should be made. As currently routine and prescriptive IAPT treatment approaches appear to be ineffective for this patient group. The main rationale supporting the idea that anxiety and depression focussed treatments remains a key focus and underpinning treatment approach is an understandable reluctance, to provide nonevidence based treatments for the IAPT patients, however we know from other studies that whilst there is a reluctance from staff to move away from anxiety and depression based treatments we know from others studies that this approach is not having a positive impact on treatment outcomes (Goddard et al., 2015). If a positive evidence base was developed it is likely that new approaches that are not underpinned by anxiety and depression treatments would be embraced on both a practitioner and organisational level.

Solutions when viewed across both studies are not too dissimilar. Choice of different treatments approaches were shared by both groups interviewed. However this is determined by therapist knowledge and skill, therefore approaches available to the patient are by chance and dependant on the therapist they are assigned to. Both groups also mentioned the importance of holistic care and acknowledgment of complexity amongst this patient group. A prescriptive one size

fits all approach is criticised as not addressing the needs of this patient group. Formulation and person centred approaches were described by IAPT healthcare professionals as potential solutions, whilst choice and individualised approaches were more commonly described by the patient population. Many IAPT healthcare professionals however acknowledged a skills deficit amongst their workforce. Furthermore not all of the IAPT healthcare professionals have been able to apply personalised and individualised approaches to meet the needs of this patient group. Instead they described often needing to revert to what they are trained to deliver, hence the provision of the manualised and prescriptive treatment protocols, which are often met with resistance from the patients. A major constraint which is agreed amongst both groups but is a pertinent concern at Step 2 is the lack of time to provide the level of flexibility and personalisation required.

Patient participants reported negative responses to treatment when they felt it is not individualised and blame the rigidity of the therapist. However, the therapists who also acknowledged this constraint and negative impact on patients were more likely to attribute it to the rigidity of the system.

The rigidity of IAPT treatments is a concern and a barrier to any feasible and acceptable recommendations for practice. Whilst Step 2 may be of benefit for some patients and a good place to start, it does not by virtue of its constraints appear best placed to address the needs of this patient group. A preference therefore would be for Step 3 therapy that applies the personalisation, flexibility and embraces adaptions alongside and in addition to the evidence based protocols for common mental health conditions.

Chapter 8

Discussion

This chapter will summarise the main research findings and limitations and strengths will be discussed. The chapter will include an exploration of new emerging literature and research impact. An overview will also be provided outlining the recommendations for practice and future research.

8.1 Brief Methods Overview

This thesis was underpinned by the MRC framework for the development of complex interventions and focused on the 'development phase' of the guidance (Craig et al., 2008a). Hence preparatory research has been carried out by conducting three inter-related studies that have provided increased insight into personality disorder and IAPT services from both IAPT healthcare professional and patient perspectives. This research has enhanced understanding of the experience of people who present to primary care IAPT services with common mental health disorders and co-morbid traits of personality disorder. The data gathered has enabled the development of recommendations for practice that will be used to inform future research.

Study 1 aimed to scope and provide a synthesis of the literature relating to personality disorder policy, treatments, needs and experiences in primary care. This identified a dearth of literature in this field and subsequently informed the development of two qualitative studies. The studies used in-depth qualitative interviews to explore the experiences of the IAPT workforce and patients with traits of personality disorder in receipt of, or who had recently received treatment in IAPT, to address gaps in knowledge, research and understanding. Results of the qualitative studies have been synthesised to provide and inform the recommendations for treatment that will be outlined later in this chapter.

[Intentional Space]

8.2 Summary of Main Findings

8.2.1 Study 1 - Scoping Study Literature Review

The main findings from the policy documents identified a need for a stepped care treatment approach for people with personality disorder. A high prevalence rate for personality disorder in primary care was identified. There appeared to be no UK based studies or evidence based treatments developed specifically for personality disorder in IAPT services. Hence the treatment experiences and needs of this patient group have not previously been explored. The literature review findings provided a rationale for further qualitative investigation to explore the needs and experiences of personality disorder in IAPT services. The gaps in research informed the development of Studies 2 and 3. Both studies were carried out in line with the development of complex interventions guidance outlined by the MRC guidelines (Craig et al., 2008a).

8.2.2 Studies 2 and 3 - Qualitative interviews

The results from the qualitative studies are reported independently in chapters 5 and 6 however they will be briefly summarised followed by the findings of the synthesis of both studies.

8.2.2.1 Study 2

Twenty-eight IAPT healthcare professional were interviewed in Study 2. Four main themes were reported: 1) Recognising Complexity 2) The IAPT system 3) Interaction with Patients and 4) Future Working. Each theme had several subthemes

8.2.2.2 Study 3

Twenty-two patient participants were interviewed in Study 3. Four key themes were reported: 1) Process and Business 2) Needs 3) Treatment Experience 4) What Matters and each theme had several subthemes.

8.3 Synthesis Overview - Key Conclusions

A synthesis of studies 2 and 3 results was conducted in Chapter 7 and this highlighted five areas of similarities including: Labelling Personality disorder, the IAPT Business, Patient Needs, Therapist Connections and Future Clinical Practice. The key conclusions reached from this synthesis are summarised below.

8.3.1 Labelling of Personality Disorder

The label of personality disorder is a sensitive issue in IAPT services. IAPT healthcare professionals preferred to avoid using this label with patients, however some patients described a need to know what was wrong with them. A descriptive approach with patients with co-morbid personality disorder in IAPT was the preferred approach to use in the absence of any evidence-based interventions specific to IAPT treatment of this patient group. Labelling however requires revisiting if evidence based effective interventions are developed so that patients are identified in a timely manner and directed to effective treatments.

8.3.2 The IAPT Business

Both IAPT healthcare professionals and patients reported IAPT as a business like service that was driven by outcomes. Recent changes in specialist secondary mental health services provision have increased the complexity of patients who present to IAPT. IAPT healthcare professionals recognised deficits in their skills and knowledge to work with this added complexity. Tension is reported and described in the context of 'quantity and quality'. Factory line descriptors such as 'conveyor belt' analogies and 'putting cherries on top of cakes in a warehouse' were shared at Step 2. The rigidity of treatment protocols in IAPT were described especially at Step 2 were brief guided self-help is delivered.

IAPT is not and should not become a catch all service, the focus of IAPT should remain on the treatment of anxiety and depression related disorders. Cognitive behavioural therapy alone is described as struggling to get to the root cause of this patient group's difficulties.

8.3.3 Patient Needs

Cognitive behavioural therapy is described as being focused on the 'here and now' patient participants did not like this instead they wanted to make sense of how the past impacts on their present problems and they wanted their stories to be listened to and heard. In light of this past experience should not be overlooked with this patient group. Emotional regulation and the space for patients to access their emotions, process concerns, worries and offload are important. Providing prescriptive models of treatment with this patient group can lead to feelings of chaos and lack of therapist control. Social and relationship needs require increased attention.

IAPT healthcare professionals described deficits in skills and knowledge for working with this patient group, this then impacts on the ability to be more flexible in approach. However patients did not request complex interventions. Instead they identified simple solutions to improve their experiences and treatment such as personalised care, time and flexibility to offload emotions. IAPT healthcare professionals negatively appraised their skills with this patient group however the patient's simple interpersonal solutions noted above are skills IAPT healthcare professionals will already possess. The challenge will be applying them within the rigidity of the IAPT service. Step 3 is identified as the most suitable step to provide treatment to this patient group.

8.3.4 Therapist Connections

Service constraints particularly at Step 2 can make therapeutic connections difficult to achieve. Skills and knowledge deficits of the IAPT healthcare professionals can create fear and frustration when working with this patient group. Early contact experiences are described as important to patients, genuine interest and the interpersonal skill of the IAPT healthcare professional are key areas that enable the development of an effective therapeutic connection, however the characteristics and specific components of interpersonal skill vary between individual patients. Time to talk is an essential component of the therapeutic connection.

8.3.5 Future Clinical Practice

There was an acceptance that personality disorder co-morbidity is present within IAPT caseloads. The IAPT workforce described a willingness and a requirement for them to make adjustments and adaptions to treatment for this patient group. There was a reluctance to move away from anxiety and depression based treatments in IAPT identified, due to the lack of any available evidence based treatments for this patient group in IAPT. Hence IAPT core business should continue to provide evidence based treatment approaches for anxiety and depression as the main underpinning treatment approaches, unless it is clear that the patient is unresponsive to this or they have been identified as having personality disorder co-morbidity. Adaptions to treatment then should be made in line with the recommendations for practice outlined.

The prescriptive 'one size fits all' approach is not sufficiently addressing the needs of this patient group. Holistic care that acknowledges the complexity of the patient group is supported. Formulation and person centred driven approaches are required.

Patients reported therapist rigidity, IAPT healthcare professionals report system rigidity. Step 2 was described as being constrained in its ability to provide flexible and personalised approaches to the treatment outlined. Lower level specialist personality disorder specific therapy may be of benefit to bridge the interface between IAPT and Specialist Secondary Mental Health Services.

8.4 Limitations

8.4.1 Study 1

The scoping study literature reviews whilst appropriate for this research due to the dearth of literature and need to review a variety of literature with differing methodologies, are not without their limitations. The broad scanning methodology used can be prone to missing literature and lacking focus, however in an attempt to methodologically enhance this review, additional procedures were employed including for example the quality assessment of the literature and inclusion of

supervisory team to verify results (Levac et al., 2010). New literature has been published after the review had been conducted that has added to the findings. This new literature will be discussed later in this chapter.

8.4.2 Study 2

A key limitation of this study was that it was conducted in a single NHS trust and therefore the results may not be generalisable to other IAPT sites. In addition the IAPT site that engaged in this research had already been provided with opportunities for the IAPT workforce to receive personality disorder awareness training (Lamph and Hickey, 2012; Lamph et al., 2014). Many participants had received this training however this is not representative of all IAPT services. This may have skewed the baseline knowledge of personality disorder of the included participants. Although this could also be seen as a strength as even in a well-supported and knowledgeable service, deficits in the treatment provision, knowledge and skills of the IAPT workforce continue to be strongly represented and reported as problematic.

A further limitation of this study was that the author is well known within the service from his previous role as an Advanced Practitioner in Personality Disorder. Hence the author was viewed upon as a knowledgeable expert in the field of personality disorder. This may have been a barrier to recruitment for some of the IAPT therapists who are less confident or who held negative views of personality disorder, leading them to refrain from involvement. Conversely previous working relationships with the researcher may have influenced the purposive sample who engaged in the research and it was noted that the first IAPT Healthcare professional participants to express interest in taking part had previously expressed interest in personality disorder to the author in his previous role.

There was a higher proportion of Step 3 participants than Step 2. This was not representative of the service composition that has larger proportion of Step 2 therapists. However, several of the Step 3 participants had also worked as Step 2 practitioners and several continued to work with patients across both steps.

Much is written about the relationship and tension amongst the secondary service and primary care interface (Gask et al., 2009). However, only the perceptions and opinions of the primary care IAPT workforce were represented in this study when discussing the interface.

8.4.3 Study 3

A limitation of this study was in the single site it had been conducted in for the same reasons relating to 'transferability' as Study 2. IAPT healthcare professionals were tasked with supplying the recruitment flyers to those on their current caseloads. This could have resulted in selection bias on who was asked to participate. Despite trying to mitigate this (Chapter 4) it is remains unclear as to whether all potentially eligible participants were invited.

A further limitation of this study is in the lack of ethnic diversity. People of ethnic origin are less likely to use IAPT services (Evans et al., 2014). However, the area in which this research was conducted is one of the least ethnically diverse areas in the North West of England with only 2.7% being from a Black or Minority Ethnic (BME) backgrounds (Public Health England, 2017).

Mixed scores on the SAPAS were identified amongst participants who took part. SAPAS can be over inclusive particularly if implemented on presentation to services (Moran et al., 2003). Those with higher SAPAS scores presented with more complexity generally than those with lower scores, however, we did not differentiate or carry out any additional analysis based on complexity of presentation as determined by higher SAPAS scores.

Nationally available and bespoke models of personality disorder awareness training had been made available in the study site and this may have skewed some of the experiences and reports from participants. Furthermore participant's therapists may have had increased awareness of this research taking place that may have resulted in increased staff awareness of personality disorder. Hence this may have altered how they were working with patients and the patient's subsequent reported treatment experiences, although there was no conclusive evidence that this occurred.

The author's knowledge of personality disorder may have increased bias in some of the questioning approaches and interpretation of patient data. Independent coding may have further improved the rigour of the findings from both studies 2 and 3, however as this was a PhD study this was completed by the author and the coding and processes of analysis was verified by the supervisors.

8.5 Strengths

This research study is original and has generated new knowledge about people with personality disorder traits in IAPT services and new and emerging evidence is supportive of this (Section 8.6). The preparatory work undertaken has provided a strong foundation to guide future research in this area. A robust methodological design was adopted and the research was thorough and rigorous in its design. The inclusion of key stakeholders including the IAPT service and people with lived experience ensured that the inductive and deductive processes have strengthened findings by adopting a bottom and top research approach. This provided a body of evidence that should augment how we enhance clinical work and user experience with this patient group (Ritchie et al., 2014). The challenge now is to explore the efficacy of the suggested changes.

This research provided further evidence in addition Goddard et al (2015) and Hepgul (2016) that this undiagnosed patient group are identifiable and can be differentiated within IAPT. Additionally this research has engaged and directly involved those identified who have displayed a keenness to take part research in the hope it can improve service responses for them and others with similar difficulties. IAPT healthcare professionals and patient participants were representative of the local population in which the research was carried out. Unlike many other personality disorder studies this research did not focus on a specific personality disorder but was all encompassing to capture and understand the main difficulties that are cross cutting across personality disorder types that will be seen in IAPT services. The early developmental work that shaped this research was detailed and methodical and this enhanced the sensitivity of this study by taking a not knowing and descriptive stance with attention to detail.

8.6 New and Emerging Literature

The scoping study literature review was conducted in 2014. However new literature both academic and policy has been published since 2014 and has provided further supportive evidence for this study and also highlights the growing and shared interest in this field of enquiry.

8.6.1 New Academic Literature

Key studies published since the scoping review include a naturalistic observational study (Grant et al., 2014) which was carried out in IAPT services and aimed to explore the impact of co-morbidity of a variety of mental health difficulties on outcomes. This study included the investigation of personality disorder co-morbidity via the use of SAPAS (Moran et al., 2003) which was the chosen tool for screening and initial identification. Results found high levels of co-morbidity of personality disorder amongst IAPT populations with 16% being described as meeting the criteria for BPD and 69% at high risk of personality disorder (Hepgul et al., 2016).

Goddard et al (2015) used a prospective cohort design drawn from a large IAPT service (n=1249) to examine the impact of personality disorder on treatment outcomes and found that poorer treatment outcomes were found with people with a co-morbid personality disorder than those without. Additionally poorer clinical outcomes were reported in those with a higher the SAPAS score. Interestingly a co-morbid personality disorder did not influence treatment dropout rates. Instead higher scores relating to depression were indicative of increased drop out. The key recommendations to come from this study is the need to routinely screen for personality disorder in IAPT to improve identification of those who are unlikely to benefit from routine IAPT treatments and the development of new individualised and effective treatments for IAPT (Goddard et al., 2015). This research provides further supportive evidence of the high prevalence of personality disorder amongst IAPT service users and also provides new evidence that indicates that IAPT treatments currently have a suboptimal effect on this patient group.

8.6.2 New Policy Literature

New guidance emerged that highlighted the progress made in responding more effectively to personality disorder and was entitled 'Meeting the challenge making a difference, working effectively to support people with personality disorder in the community' (Bolton et al., 2014). This publication set out to further raise awareness and support knowledge, challenge stigma and to identify evidence based treatments. Additionally skills were shared for working with people with personality disorder. IAPT services were described in the treatment section of this publication and are recommended for the treatment of anxiety and depression if mild difficulties with personality disorder present. IAPT services are described as being ineffective at treating people with personality disorder, particularly those who present with relationship difficulties. Furthermore it was highlighted that IAPT treatment can have a negative impact on this patient group by bringing problems to the surface that are not sufficiently worked on due to the lack of adequate space or flexibility to process these difficulties. A step up to secondary services was therefore advised (Bolton et al., 2014). It should however be noted that this viewpoint is backed up only by reference to NICE guidelines for BPD (NICE, 2009a) and the recommendation that treatment should not be offered for less than 3 months duration with this patient group. This should therefore be treated with caution as at Step 3 most treatments would be provided in excess of 3 months.

Between, 2012 – 2015, IAPT SMI personality disorder demonstration sites were set up. Three national demonstration sites were identified and were put in place to measure their effectiveness on patient outcomes, staff and the economical impact of the services. Each area was expected to carryout regular and comprehensive assessments of treatment outcomes mirroring that of primary care IAPT services. All selected sites were expected to improve access of personality disorder psychological therapies and were based largely within specialist secondary services. However one of the pilot sites 'Somerset Partnership NHS Trust' complemented their service provision with the development of an additional IAPTplus model. This was set up to provide a bridge between primary care and specialist secondary service, hence providing a whole system response. The IAPTplus model provided specialist interventions for people with significant personality disorder traits in primary care. A mixed method review of the

demonstration sites based on patient experience has been published. Reference is made to the IAPTplus model however the results are shared collectively and therefore primary care participant experiences were not independently reported (Hann et al., 2015). The primary care treatment model provided by the Somerset service included:

- Education of the workforce, via a website, a DVD and four day skills training programme to develop staff knowledge of intervention.
- IAPTplus service included therapists trained relational recovery and guided formulation
- Emotional Skills Group (Dialectic Behavioural Therapy (DBT) informed) 12 sessions
- Cogntive Analytic Therapy (CAT) was additionally offered as a Step 3 therapy

Encouragingly the new academic literature provides further evidence that personality disorder is highly prevalent in IAPT but is also indicative of poorer outcomes. The policy initiatives are however less supportive. Suggestions of IAPT being counterproductive to this patient group are based on current IAPT service provision.

Both IAPT healthcare professionals and patient participants who took part in this research identified similar areas of concern in IAPT namely the overlooking of relationship difficulties. Interestingly this research has pre-empted some of the newer recommendations made and has already started to address some of the concerns such as developing a greater understanding of the patient group in IAPT and need for the development of novel interventions. Furthermore this new literature displays the growing attention to personality disorder in primary care IAPT services and has provided evidence to support the importance of this research project. This research has started to address the deficits in knowledge and the recommendations for practice that have emerged will be outlined in the next section.

8.7 Recommendations for Practice

This novel research project has provided an insight into an area that has previously been unexplored. This has provided a timely and necessary insight into this patient group and those providing their treatments. By collectively drawing on the findings of this research, 4 key recommendations for practice have been developed, which will be described below:

Key Recommendations

- 1. Education of the IAPT workforce.
- 2. Clinical Interventions.
- 3. Provision of Treatment at the Right Level.
- 4. National Recommendations.

1. Education of the IAPT Workforce

A skills deficit in the IAPT workforce has been identified that requires improved procedures to enhance knowledge, skills and awareness. Recommendations have therefore been developed based on the results of this research to address the skills and knowledge deficit amongst IAPT healthcare professionals across the steps. Three phases of training have been identified and include, 'Working with complexity, knowledge and understanding and clinical skills training (Table 17).

<u>Table 17 Recommended Education Matrix</u>

Level of	Working with	Knowledge and Understanding	Clinical Skills
Intervention	Complexity	level education	(Toolbox for Adaptions)
Step 2	YES	YES	Not Required
Step 3	YES	YES	YES

Phase 1 – Working with complexity

The workforce particularly at Step 2 is a transient workforce therefore providing training that enables them to identify and work more effectively with people with

personality co-morbidity is recommended to be incorporated within the IAPT core training curriculum. This would include working with complexity and the interpersonal challenges that can present and the impact of these challenges on the therapeutic relationship. This would provide consistency of knowledge at a basic level that could be implemented nationally in an attempt to reduce fear and improve self-awareness and confidence of the IAPT workforce. Training that focusses on complex cases in IAPT should be provided in both Step's 2 and 3 core curriculums. This will ensure that therapists entering IAPT services do so with a level of knowledge and skill to consistently identify and recognise complexity in IAPT and develop their own self-awareness. Capturing all new healthcare professionals entering IAPT will provide a model of stability and sustainability.

Phase 2 – Knowledge and Awareness

This should then be followed by a step up 'Knowledge and Awareness' training specifically focussed on understanding the development of personality disorder, the different types, prevalence in IAPT, interpersonal interactions, hope, optimism and recovery. This knowledge and awareness training should be made available to all IAPT healthcare professionals at both steps and revisited periodically. This will provide consistency in the identification and understanding of personality disorder traits and will direct treatment approaches towards personality disorder co-morbidity in IAPT. Furthermore it will enable the signposting of patients in an appropriate and timely manner for treatment that incorporates adaptions to meet their needs.

The provision of an effective educational programme with minimal time away from clinical practice and in a flexible format is recommended for the existing workforce. The author and colleagues have developed a 2 hour e-learning awareness programme that has been evaluated with a multi-disciplinary workforce and has displayed comparable effectiveness to the 3 day national knowledge and understanding framework training for personality disorder (Lamph et al., 2017). Therefore this may prove to be a beneficial tool to support the IAPT workforce knowledge and understanding in a time pressured service due to the flexibility that e-learning provides and the shortened duration of training.

Stage 3 - Clinical Skills Training

At Step 3 IAPT healthcare professionals would benefit from advanced clinical skills training that would equip them to make adaptions and apply flexibility to their practice for this patient group. The clinical skills training would be developed to mirror the clinical interventions outlined in recommendation for practice that follows in the next section.

Collectively this training strategy would provide IAPT healthcare professionals with a focussed training and consistency of knowledge and skill across the workforce in the hope that outcomes and treatment experiences would be improved. Furthermore more timely and appropriate stepping up to more advanced treatments for those do not make progress in IAPT will be achieved.

2. Clinical Interventions

This recommendation provides an overview of the clinical interventions required to best support this patient group in clinical practice. Most IAPT healthcare professionals and some patient participants commented that IAPT services should continue to deliver NICE guideline driven evidence based approaches for anxiety and depression. However it has been recognised that for many people with comorbid personality disorder these approaches are ineffective (Goddard et al., 2015).

A focus should be placed to develop therapist awareness of the importance of therapeutic connection and repairs of therapeutic rifts with this patient group. The benefit of repairing therapeutic rifts through openness and honesty should be considered. Therapists should receive improved insight into the early recognition of therapeutic rifts, so that early and skilled repairs can take place. The importance of the relationship for this patient group requires highlighting. Therapist should be made aware that key factors that aid the relationships and how they are often very unique to the individual patients. Additionally evidence based skills are recommended to complement improved awareness and knowledge. Short term adaptions to treatment taken from evidence based practice in specialist secondary services, such as dialectic behavioural therapy skills could prove beneficial.

In order to provide additional interventions or adaptions to practice, identification of the patient group is therefore required. Whilst IAPT healthcare professionals felt identification should remain an informal process, to gain consistency a routine outcome measure will prove beneficial. The SAPAS has been used in several studies in IAPT services (Grant et al., 2014; Goddard et al., 2015 and Hann et al., 2015) to effectively identify this patient group and is a screening rather than a diagnostic tool, therefore is recommended as the tool of choice.

A formulation driven approach is supported to ensure that treatments for this patient group are unique to the individual and their presenting difficulties not diagnosis led. Therapist flexibility and personalisation of approach to meet the needs of the patient is required and opportunities to link the past to presenting difficulties could be encouraged via a developmental formulation in those who wish to discuss past and present issues.

Relational difficulties and emotional regulation difficulties emerged as unmet needs from the research. In light of this, adaptions to develop staff skills in relationship difficulties via interpersonal skills training and emotional regulation skills development are recommended, alongside problem solving skills. Dialectic behavioural therapy informed skills are largely, psycho-educational in approach so fit well within the cognitive behavioural style of therapy and provide the strongest evidence for effectiveness (Stoffers et al., 2012). Dialectic behavioural therapy skills have key components of: interpersonal skills development, emotional regulation, distress tolerance and mindfulness, all of which were highlighted consistently as the unmet needs of this patient group with the exclusion of mindfulness. Mindfulness could however hold potential utility in developing space and skill with the patient to implement the other skills effectively when in highly emotive states (Linehan, 1993).

Patient participants were not requesting advanced and complex interventions. Their main focus was upon interpersonal effectiveness, the relationship, flexibility in approach, time to offload, consistency and personalisation, which are key components of structured clinical management (Bateman and Krawitz, 2013). Structured clinical management has a growing evidence base and there is an emphasis on 'good customer service' within a well-structured and supportive

service. Any additional skills development will need to be complimented with knowledgeable clinical supervision and consistent and effective identification of the patient group.

3. Provision of Treatment at the Right Level

A clear message emerged from this research regarding the importance of the stepped care model and its cost effective approach to providing the lowest dose of psychological therapy to patients. This model ensures that waiting times are managed more effectively and that access to therapy is improved. All treatment therefore should start at Step 2 unless it is clear from the outset the patient would be better aided at Step 3. If Step 2 has not previously been effective or has led to drop out from the patient then an immediate step up should be considered. However the evidence from this research suggests that there are minimal health benefits in seeing people with the complexity of co-morbid personality disorder at Step 2.

This research has indicated that the treatment of this patient group is likely to be most acceptable and most effective at Step 3. Therefore if co-morbid personality disorder is identified and no health benefit can be determined from a step 2 intervention, it is recommended that Step 2 should be bypassed. As identified the therapeutic connection, personalisation of approach and flexibility are all much more difficult to achieve within Step 2 were a guided self-help model is used and were time is constrained.

At times complexity and co-morbidity may emerge once treatment at Step 2 has commenced. In the event of this occurring IAPT healthcare professionals and patients should be provided with the opportunity for open and honest discussions about the lack of progress which should include exploration of the therapeutic connection. This may guide an earlier step up to Step 3 where more time can be given toward the therapeutic connection and flexibility of approach.

The labelling of personality disorder traits with an undiagnosed population should be refrained, in line with the findings of this study. A descriptive approach should therefore be taken when working with patients who are displaying co-morbid personality disorder traits. However this should be revisited if the availability of evidence based treatments for this patient group are discovered and made available. Within the workforce the use of the term personality disorder comorbidity is acceptable and will provide consistency and clarity amongst the workforce.

The identification of co-morbid personality disorder via the SAPAS should also be routinely used at triage to guide adaptions to treatments in IAPT. A positive identification should then instigate a different approach towards the patient that will follow the recommendations for practice outlined within this thesis.

4. National Recommendations

IAPT Step 2 and 3

This patient group is unlikely to have effective outcomes if routine IAPT approaches continue and do not evolve in line with this and other emerging evidence. This is increasingly likely in those with increased complexity (Goddard et al., 2015). Nationally IAPT services should review systems and enable this patient group to be escalated to the higher steps quicker. If during triage it is suspected that the patient's difficulties have an underlying co-morbid personality disorder that requires attention via adapted interventions a screening should be carried out using SAPAS and those who positively score should bypass Step 2. However this was not discussed with patient participants and there was some reservations about using the term 'personality disorder'. Therefore further exploration regarding the acceptability and feasibility of using such a tool for identification, will require further attention.

The IAPT workforce requires both national and service level support to engage in essential staff training that develops awareness, knowledge and skills for working with people with co-morbid personality disorder. Furthermore there is an identified need for services to support therapist flexibility in approach, hence ensuring that treatments provided to this patient group are; formulation driven, personalised and individual to meet the needs of this patient group. Flexibility in

addressing the added complexity of co-morbid personality disorder traits should also be encouraged to improve treatment experiences and outcomes of this patient group. This should include support for increased duration of therapy with this patient group if required and allowance of time for patients to offload emotional concerns. A reliable, consistent and well communicated system is also required from referral to discharge. This is consistent with the principles of structured clinical management (Bateman and Krawitz, 2013).

In line with the results of this research, the identification of a personality disorder link person with knowledge and interest in this area should be identified and supported as a role within IAPT. This would be helpful in supporting on-going continued professional development and supervisory practices.

The Interface (filling the gap)

The gap between the primary care IAPT services and the specialist secondary mental health care interface requires attention. In the current system patients with co-morbid personality disorder receive a routine IAPT treatment for anxiety or depression. Only those who are deemed to have high risk and complexity are likely in the current system to receive an evidence-based psychological therapy for personality disorder in specialist secondary mental health services. There is therefore a need to consider a level of treatment that can address the gap that occurs at the interface between IAPT and specialist secondary mental health services.

The results of this research highlight the need to address service deficits and enhance treatment within IAPT services due to the high prevalence of personality disorder co-morbidity. People with personality disorder co-morbidity however will by nature of their problems have fluctuating presentations and these needs can be met within IAPT in some cases. Primary care IAPT based therapies and quicker access therefore will prove beneficial and the stepped care model with a clearer pathway to treatment for this patient group are long awaited. However it is also recognised that for some patients the recommended adaptions to treatment in IAPT may not be sufficient to address their needs. Therefore they may require a further step up. A standalone personality disorder specific therapy is therefore

recommended and will require further research to evaluate effectiveness over a shorter duration and lower level than what is currently offered within secondary services. Approaches could include; shortened dialectic behavioural therapy approaches, mentalisation based therapies or structured clinical management. The provision of a specialist treatment could be provided as an IAPTplus model as in the Somerset NHS Trust (Hann et al., 2015). This could be provided as an extension to IAPT services in primary care or as a low intensity treatment provided within specialist secondary services, the latter based on the data received via this research is likely to be more acceptable and feasible. Professor Mike Crawford (Imperial College London) has already started to explore the development of a low intensity intervention for specialist secondary mental health services. The author was recently invited to take part in nominal group meeting to share the results of this PhD research to inform their plans.

Any suggested changes in the treatment pathway for personality disorder will however require further research to measure the effect and impact of these recommendations.

8.8 Future Research

The recommendations for practice that have been formulated as a result of this completed preparatory research now require further work to refine them into a usable clinical manual to guide the treatment of patients with personality disorder in primary care IAPT services and evaluate the feasibility of the interventions proposed. In order to do this identification of a project team is required that will be made up of academic collaborators, clinical service representatives and people with lived experience. This project team would support the development of a bid for further funding. The MRC framework (Craig et al., 2008a) would continue to guide the next stages of this research and particular interest would be placed on the final component of the MRC development phase that focusses on intervention modelling. This would then lead onto to a feasibility study that would test the effectiveness of the proposed changes against IAPT standard treatments. This supportive evidence could lead on to a recommendation for a larger randomised controlled trial. A later full RCT would look at effectiveness, cost effectiveness and

the acceptability of the recommendations for practice from both an IAPT healthcare professionals and the patient viewpoint.

A replication of qualitative studies in other IAPT services would also be beneficial to carry out to confirm the findings of this research. In particular it would be beneficial to replicate this work in a more ethnically diverse IAPT service to further explore the treatment experiences of different ethnic groups.

Further investigation of specialist stand-alone therapies that address the treatment gap at the interface between IAPT and specialist secondary services would also be beneficial to explore, however due to the feasibility issues raised in this study this would need to be accompanied by an economic evaluation.

8.8.1 Intervention Modelling

The completed preparatory research has identified four key recommendations for practice that are outlined earlier in this chapter. The identified recommendations for practice provide a strong foundation for intervention modelling. The next stages would be to share the results of this research and the identified recommendations for practice via focus groups with service providers and IAPT healthcare professionals. Furthermore this patient group and people with lived experience of personality disorder would also be consulted, however a choice of focus groups and individual interviews would be offered to ensure that those who are uncomfortable with groups are still given opportunity to engage and inform this process. During the meetings, feedback on the proposals and barriers and facilitators to implementation would be explored, as would acceptability and feasibility of the proposed recommendations for practice. The process of intervention modelling would provide a refined manual outlining the recommendations for practice.

8.8.2 Feasibility and Piloting

The next phase would be to carry out a feasibility study comparing routine IAPT practice as a control against the refined recommendations for practice. The aim of the feasibility study will be to: explore practitioner adherence and experience,

measurement of clinical outcomes and patient experience using the control group as a comparison, to establish the acceptability of the recommendations for practice, data collection processes and the acceptability of randomisation. This study would provide the necessary evidence required to develop an acceptable and feasible psychological intervention for people with personality disorder traits in primary care IAPT services which could lead to a definitive larger scale funded randomised controlled trial.

8.9 Research Impact

8.9.1 Impact Achieved

During the duration of the fellowship the author has raised the profile of this research and the importance of also exploring personality disorder in primary care via regularly presenting his work at both national and international personality disorder and nurse academic conferences (Appendix 25). The impact of working with a research advisory group with lived experience of personality disorder has also been highlighted via collaboratively developed and delivered presentations at national and international conferences and also via the development of a short video that outlined the experiences of positive patient and public involvement in this research. The patient and public involvement work subsequently led to the author and the research advisory group being nominated for an NIHR North West Coast Clinical Research Network Award in the category of 'outstanding contribution to patient and public involvement'.

Collaborations have emerged as a result of this research with the author being approached by Professor Mike Crawford from the Imperial College, London to take part in a nominal group meeting and share the results of this research (Appendix 28) to inform a research project that aims to provide a low intensity intervention in secondary care, additionally the author has also been invited to assist in the development of an NIHR funded randomised controlled trial research bid as a coapplicant.

The research has led to local IAPT services requesting further training and local commissioners seeking consultation from the author to develop a 'Commissioning'

for Quality and Innovation' (CQUIN) that addressed the complexity of working with personality disorder co-morbidity in local IAPT primary care services.

Finally the author been appointed as the joint secretary of the British and Irish Group for the Study of Personality Disorder (BIGSPD) and this role will continue to enable him to raise his profile and the profile of the research amongst leading national clinicians, commissioners and academics in the field of personality disorder.

8.9.2 Impact Proposed

Post PhD an intervention modelling and feasibility study is proposed. Provisional contact has also been made with the Mental Health Foundation in London to discuss the possible development of a nationally available workbook that describes the recommendations for practice in IAPT for the treatment of personality disorder co-morbidity. The Mental Health Foundation have recently published a similar workbook for making reasonable adjustments in IAPT for people with learning disabilities (Dagnan et al., 2015). Finally the author and his academic supervisory team plan to publish the findings of the research and thesis in high impact journals.

8.10 Conclusion

This research has explored a novel area of interest with a focus on exploration of the available evidence (Study 1) and the identification and theory development (Studies 2 and 3) it achieved using the MRC framework. It has provided for the first time an insight into the needs and treatment experiences of patients with comorbid personality disorder in primary care IAPT services and an exploration of the IAPT workforce perceptions of treating this patient group. This has subsequently led to development of 4 key recommendations for practice.

This thesis provides the foundation and direction for further research to address gaps in the research literature and to develop and test the effectiveness of the proposed recommendations for practice. This research provides the necessary

preparation required to progress onto further intervention modelling and a feasibility study.

Additionally there is likely to be a need to bridge the gap between the primary care and secondary care interface for patients who do not respond to the recommendations for practice outlined. It is hoped this research will have a national impact and that co-morbid personality disorder in primary care will increasingly have a raised profile in its identification and subsequent adaptions to treatment to more effectively meet the needs of this patient group. This research has provided a reliable foundation with which to learn from patients and IAPT staff and provides the necessary preparation for further research.

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Appendix 1 – NIHR CDRF Award Letter



NIHR Trainees Coordinating Centre Leeds Innovation Centre 103 Clarendon Road Leeds LS2 9DF

> Tel: 0113 346 6260 Fax: 0113 346 6272 www.nihrtcc.nhs.uk

Email: cat@nihrtcc.org.uk

Dear Mr Lamph Hollins Park House Hollins Lane Winwick Warrington United Kingdom (England) WA2 8WA

23 December 2013

Dear Mr Lamph,

Letter of Intent to Fund

NIHR/HEE Clinical Doctoral Research Fellowships Our ref: CDRF-2013-04-012

Thank you for accepting your NIHR/HEE Clinical Doctoral Research Fellowships award.

This letter is formal confirmation that the NIHR intends to fund you to undertake a NIHR/HEE Clinical Doctoral Research Fellowships. We are currently preparing a contract between the Department of Health and 5 Boroughs Partnership Foundation NHS Trust. This contract will support you to start your NIHR/HEE Clinical Doctoral Research Fellowships on 01 January 2014 and will run until 31 December 2016.

In the meantime we are looking in detail at the finances of your award. The amount originally requested in your application was £220,950.00. NIHR TCC reserves the right to revise or remove any costs that it considers unreasonable or not fully justified. We will get in touch if we have any queries.

A payment schedule forms part of the contract and will set out the dates when your host institution will receive payment, quarterly in arrears. Once the contracts have been signed, the first payment will be released at the next quarterly payment date.

Individuals can, with the agreement of their employing organisations, establish start dates which fall before the formal contracting process is complete.

NIHR CRN Portfolio Database

- If your study involves the NHS or NHS patients we expect you to apply, where appropriate, for
 consideration for NIHR Clinical Research Network support in England and/or its equivalents in
 the devolved administrations and subsequent inclusion in the NIHR Clinical Research Network
 Portfolio Database. http://www.crncc.nihr.ac.uk/about_us/processes/portfolio/portfolio
- If your study is deemed eligible for consideration for NIHR Clinical Research Network support in England and/or its equivalents in the devolved administrations we expect you to:
 - Keep your study record on the Portfolio Database up to date; and
 - Upload your recruitment data into the Portfolio Database on a monthly basis. Please note that the NIHR Clinical Research Network will share this data with the NIHR TCC through the production of quarterly reports

If I can be of any further assistance, please do not hesitate contact me.

Yours sincerely

Mai Palin Programme Manager

Enc

Annex A: Ensuring publication of NIHR-funded research

Appendix 2 – PhD Offer Letter (Page 1)



The University of Manchester

School of Nursing, Midwifery and Social Work The University of Manchester Jean McFartane Building Oxford Road Manchester M13 SPL +44(0)161 308 0280 www.manchester.ac.uk

16th January 2014

Mr Gary Lamph Holly Lodge 132 Heath Road South Weston Village Runcorn Cheshire WA7 4LZ

Programme of Study: Doctor of Philosophy in Nursing

Mode of Study: Full Time Entry: January 2014 JACS Code: L500

University of Manchester User ID: 9489115

Dear Mr Lamph,

Thank you for your application to study at The University of Manchester. I am delighted to make you an Unconditional Offer of a place on the above research programme.

Your research entitled 'Evaluating the Acceptability, feasibility and Potential Effect Size of a Combined Group Problem Solving / Mentalisation Intervention for People With Personality Disorder Traits in Primary care Mental Health (IAPT) Services; An Exploratory Randomised Controlled Trail' will be supervised Professor Karina Lovell and Dr John Baker. No modification may be made to the approved title without consent from the School.

Please note that we use the research proposal you submitted to assess the originality of your ideas; your ability to think critically; your knowledge of the relevant literature and research methods; and to appoint an appropriate supervisor. On entry to the PhD/MPhil programme students work with their supervisors to develop their original proposal in light of further literature reviewing and consideration of appropriate research methods.

All research students are expected to undertake a skills audit at the beginning of their programme and annually thereafter, to determine their research, transferable and generic skills requirements. Students are also expected to take part in a programme of skills training and development, where applicable, as part of the PhD degree.

Appendix 2 – PhD Offer Letter (Page 2)

Students admitted to the degree of PhD will be required to demonstrate satisfactory progress at the end of each year of registration to be able to progress to the next year. Students who are not able to demonstrate satisfactory progress may, at the discretion of the supervisory team and independent assessor, be offered the opportunity to submit a thesis for the degree of MPhil.

Students are expected to complete all postgraduate research degree work, including research and the writing up of the thesis, within the standard period of the programme (3 years). If the supervisor advises that further attendance is necessary, it must only be for the purpose of completing the writing up of the thesis and is subject to Faculty approval. For this purpose, students would be required to register for a submission pending period, for which a submission pending fee would be charged.

The University charges different tuition fees depending on whether a student is classified as Home/EU or International, using criteria outlined in the Education (Fees and Awards) Regulations 1997. From the information you have provided to us, you have been classified as a Home student for tuition fees purposes. The tuition fee for this course in the academic year 2013/2014 for Home students will be £4390. Tuition fees for future academic years are subject to change. All students are bound by the University's Ordinances and Regulations on the payment of fees and the consequences of non-payment.

Please let me know whether you wish to accept this offer by logging in to www.manchester.ac.uk/track using your University of Manchester User ID shown at the top of this letter. Your password is your date of birth in the format DDMMYYYY.

General terms and conditions relating to this offer can be found on the reverse of this letter/in the attached PDF.

Please note that this is an academic offer of a place on the above programme, and is not an offer of funding. You must make separate arrangements for the payment of fees and living costs.

Further information about fees, funding, living costs and accommodation can be found at www.manchester.ac.uk/postgraduate.

If you have any gueries relating to your offer, please do not hesitate to contact me, and meanwhile we look forward to welcoming you to The University of Manchester.

Yours sincerely.

Cheryl Johnson

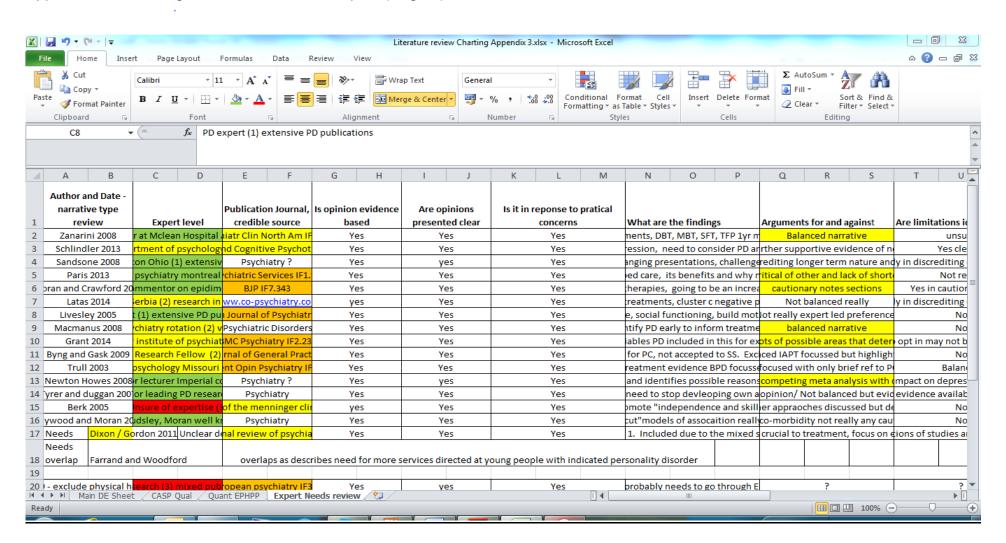
Graduate Admissions Secretary

+44 (0)161 306 0270

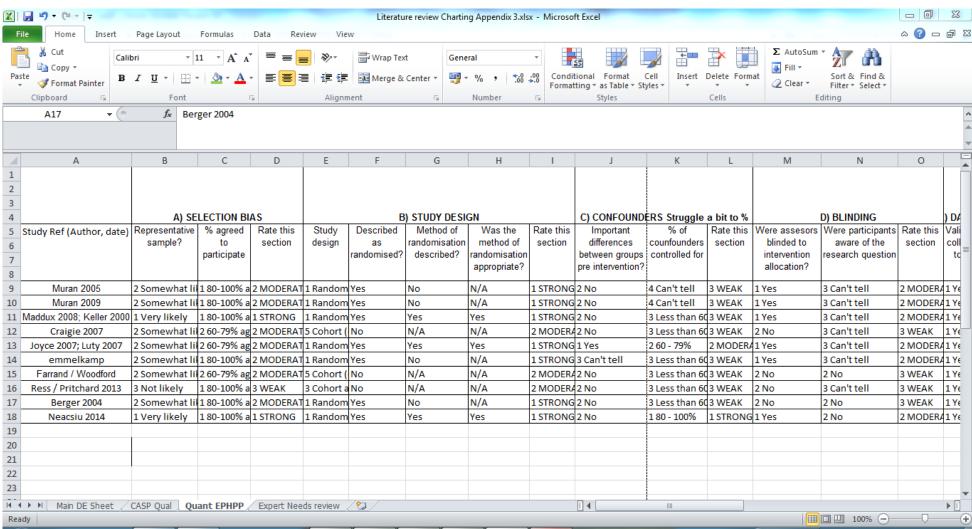
Cheryl.Johnson@manchester.ac.uk

Cc. Dr Sue Kirk Helen Myers

Appendix 3 - Charting Excel Document Examples (Page 1)



Appendix 3 - Charting Excel Document Examples (Page 2)







Research IAPT Health Professional Recruitment Flyer

Title: Understanding Long Standing Emotional Difficulties in Primary Care

We are in the process of recruiting IAPT Healthcare Professional to be involved in an innovative nationally funded research project aimed at improving service responses for those who present with long standing emotional difficulties. Involvement will briefly consist of one face to face interview with a researcher lasting no longer than 90 minutes.

Could you help to make a difference? Have your voice heard?

Help us to understand IAPT staff perspectives of treating people with common mental health problems that are complicated by additional long standing difficulties highlighted below;

"I have long standing difficulties in maintaining positive relationships"

"I have frequent struggles to manage my emotions"

"I cope with my problems in ways others might not understand" "I frequently fear and worry I will get things wrong and make mistakes"

"I find it difficult to fit in"

If you can relate these statements to past and present patients that you have worked with you we would like to hear from you.

Please contact Gary Lamph IAPTEmotionsStudy@manchester.ac.uk or phone 07769673084 to find out more or express your interest to become involved a mutually convenient time to be interviewed will be arranged.

Version 1: 26/03/2015

Appendix 5 – Ethical Approval Letter (Page 1)

NRES Committees - North of Scotland Summerfield House 2 Eday Road Aberdeen AB15 GRE

Telephone: 01224 558458 Facsimile: 01224 558609 Email: nosres@nhs.net



12 May 2015

Mr Gary Lamph
5 Boroughs Partnership NHS Foundation Trust
Hollins Park
Hollins Lane
WARRINGTON
Cheshire
WA2 8WA

Dear Mr Lamph

Study title: The development of a feasible and acceptable psychological

Intervention for people with personality disorder traits in primary

care improving access to psychological therapies (IAPT)

services.

REC reference: 15/NS/0043 IRAS project ID: 173408

The Proportionate Review Sub-Committee of the NRES Committees - North of Scotland (1) reviewed the above application by correspondence.

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 favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager Mrs Carol Irvine, nosres@nhs.net. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Ethical opinion

On behalf of the Committee, the Proportionate Review Sub-Committee gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, 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.

Appendix 5 – Ethical Approval Letter (Page 2)

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.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

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

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

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact https://doi.org/10.1007/jnhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from NRES. Guidance on where to register is provided on the HRA website.

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

Ethical review of research 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").

Summary of discussion at the meeting (if applicable)

Care and protection of research participants; respect for potential and enrolled participants' welfare and dignity

The screening process appeared to be a mini interview and the PR Sub-Committee wondered whether this might worry some patients.

You responded that this was a very brief validated screening tool asking a series of questions to see if the person was eligible for entry into the study and was not a mini interview. As a result, you had amended the telephone screening script to ensure that potential participants being screened were aware that a screening tool asking a series of questions would now be used and ensure they were happy for you to continue and assess their suitability. If they were then worded, this would provide them with the opportunity to seek further clarification or withdraw.

Appendix 5 – Ethical Approval Letter (Page 3)

informed consent process and the adequacy and completeness of participant information

The PR Sub-Committee had concerns about how capacity for consent would be established and how that would be determined.

You responded that capacity should always be assumed when working with people with personality disorders (NICE, 2009) unless anything arose that caused concern to this. However in the case of this research, all those screened into an IAPT psychological therapy by the service would have already had capacity assessed and established.

The complexity of psychological therapy and the two-way process of treatment would mean that capacity was required in order to receive and benefit from treatment in an IAPT service. Anyone lacking capacity would not have been screened in to this service. However if you were to encounter anyone that lacked capacity to consent you would discontinue his involvement and notify the clinical team involved in the individuals care and treatment.

The PR Sub-Committee noted that on p17 – A30-1 stated that patients might decline to sign the Consent Form allowing the interview to be recorded and that in this case, notes would be taken by the interviewer during the interview. This could be distracting for the participant and difficult for the interviewer to do. The PR Sub-Committee would prefer the interview to be recorded.

You replied that this was easily rectified and agreed fully with the points made and therefore would make the necessary changes to the Protocol and Participant Information Sheets by stating all interviews would be recorded. If the potential participant declined to be recorded then they would be unable to take part in the interview. You subsequently made changes to both the PIS forms and Protocol.

Approved documents

The documents reviewed and approved were:

Document	Version	Date
Copies of advertisement materials for research participants: Recruitment Fiyer - Patients	1	23 April 2015
Copies of advertisement materials for research participants: Recruitment Fiyer - IAPT Health Professional	1	26 March 2015
Evidence of Sponsor Insurance or Indemnity (non NHS Sponsors only): Insurance Letter		17 April 2015
Interview schedules or topic guides for participants: Topic Guide - Patients	1	26 March 2015
Interview schedules or topic guides for participants: Topic Guide - IAPT Healthcare Professional	1	26 March 2015
IRAS Checklist XML: Checklist 07052015		7 May 2015
Letter from Sponsor		17 April 2015
Letters of invitation to participant: Cover Letter for Flyer - Patients	1	1 May 2015
Letters of invitation to participant: Cover Letter to accompany PIS - Patients	1	25 April 2015
Basic Demographics Form - Patients	1	23 April 2015

Appendix 5 – Ethical Approval Letter (Page 4)

Document	Version	Date
Basic Demographics - IAPT Healthcare Professionals	1	23 April 2015
Certificate of Employers Liability Insurance - Jun 14 - May 15		7 May 2015"
PI Confirmation 14/15		30 May 2014
Company Public Liability Insurance		30 May 2014
Telephone Screening and SAPAS to accompany Patient Demographics	2	11 May 2015
Participant Consent Form: Patients	1	23 April 2015
Participant Consent Form: IAPT Healthcare Professionals	1	23 April 2015
Participant Information Sheet (PIS): Healthcare Professionals	2	11 May 2015
Participant Information Sheet (PIS): Patients	2	11 May 2015
REC Application Form: REC Form 07052015		7 May 2015
Research protocol or project proposal	2	11 May 2015
Summary CV for Chief Investigator (CI): Gary Lamph		1 May 2015
Summary CV for supervisor (student research): Karina Lovell		April 2014
Validated questionnaire: Telephone screening script and 'Standardised Assessment of Personality - Adjusted Scale (SAPAS) screening tool	1	23 April 2015

[&]quot; date received

Membership of the Proportionate Review Sub-Committee

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

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and compiles 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 quidance 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.

Appendix 5 – Ethical Approval Letter (Page 5)

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/

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

15/NS/0043	Please quote this number on all correspondence	
Yours sincerely	Rectangular Snip	

Professor Helen Galley

Chair

L9(2001

Enclosures: List of names and professions of members who took part in the review

"After ethical review - guidance for researchers" SL-AR2.

Copy to: Ms Lynne MacRae

Dr Anna Pearson, 5 Boroughs Partnership NHS Foundation Trust

NRES Committees - North of Scotland (1)
Attendance at PR Sub-Committee of the REC meeting by correspondence

Committee Members:

Name	Profession	Present	Notes
Ms Sue Harrison	Alternate Vice-Chair /Clinical Property Advisor/ Nurse	Yes	
Ms Kairen Griffiths	Adult Cystic Fibrosis Clinical Nurse Specialist	Yes	
Mrs Sylvia Stephen	Lay Member - Human Nutrition Manager	Yes	

Also in attendance:

Name	Position (or reason for attending)
Mrs Carol Irvine	Senior Ethics Co-ordinator

Appendix 6 – IAPT Health Care Professional Participant Information Sheet





Participant Information Sheet (Version 2: 11/05/2015)

IAPT Healthcare Professionals Participants

Study Title: Understanding Long Standing Emotional Difficulties in Primary Care

You are being invited to take part in a study that aims to explore the needs and treatment experiences of Improving Access to Psychological Therapies (IAPT) healthcare professionals who are delivering treatments or managing services. Please take time to read the following information and discuss it with your friends, colleagues and managers if you wish. Please contact us if there is anything that it is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

This study aims to gain an in **depth** understanding of the needs and treatment experiences of patients who are in receipt of a psychological intervention in primary care IAPT services. The study is particularly interested in the investigation of the experiences IAPT Healthcare Professionals that are responsible for providing and delivering psychological therapies to people who experience common mental health difficulties (anxiety and depression) but who additionally may have any of the following long standing and re-occurring difficulties with managing emotions, impulsivity, relationships, coping responses and problem solving. Sometimes these difficulties are referred to as personality disorder traits but this doesn't mean that the patient reaches full diagnosis. These difficulties often go unrecognised and can mean that patients with these difficulties may benefit less from routine therapy. Up to 13% of the general population will endure these difficulties but will often go unrecognised.

This is a very under researched area and the intention is not to label anyone or judge current service provision but instead gain a better understanding of the experiences of healthcare professionals perspectives on providing treatment to those with personality disorder traits in IAPT. Furthermore the interviews will enable a deeper understanding of the needs of this client group and the needs of the workforce responsible for providing the treatments. It is hoped that your contribution will inform the development of future treatments to better support the recovery of people with the difficulties outlined with consideration of the constraints that may present in an IAPT compliant service.

Why have I been chosen?

You have been selected because you expressed interest in taking part in this research either in response to the staff recruitment flyer or recruitment presentations. Your experiences of personality disorder in primary care IAPT services and sharing what you feel the needs are of this client group will provide valuable insights into the primary care treatment of people who present with these traits. This study is the first of its kind and therefore has potential to provide new information to improve future treatments for people with personality disorder traits in IAPT services. Taking part will provide you with a valuable opportunity to share your views and opinions and potentially improve the efficacy of future interventions.

Do I have to take part?

It is up to you to decide whether or not to take part. Even if you consent to take part, you are still free to withdraw at any time, without giving a reason.

What will happen to me if I take part?

If you agree to get involved you will be invited to take part in an interview lasting up to but no longer than 90 minutes. During the interview you will discuss with a researcher your experiences of personality disorder in primary care, difficulties you may encounter with this client group and discuss their needs. You will also be asked to reflect on things that you feel work for this client group well within IAPT and areas you feel could be improved.

What do I have to do?

If you are still interested in this research you should contact Gary Lamph via his NHS Work Mobile 07769673084, in person or via email on IAPTEmotionsStudy@manchester.ac.uk. You will then be contacted by Gary Lamph via phone to arrange an interview slot at a time convenient for you. This can be arranged in normal office hours or evenings if you work unsocial hours. It is planned to carry out between 15-30 interviews. We will discontinue our recruitment once we feel we have enough participants to reach clear conclusions on our findings.

What are the possible disadvantages and risks of taking part?

No risk or disadvantages have been identified in taking part in this study. Your managerial team has agreed to you taking part in this study, in addition to director level managers at the Trust. This research is National Institute of Health Research (NIHR) funded and is being conducted with the academic support of the University of Manchester. The interview may involve discussing some emotive issues or areas of frustration you may have. If you do chose to take part and become uncomfortable with any questions asked you do not have to answer them, nor do you need to complete the full interview. You can stop and leave the interview at any point. The researcher will not be upset by you declining to answer questions or leaving the interview early.

What are the possible benefits of taking part?

At the end of the study, we will have a better idea about the experiences of the IAPT Staff perspectives and experiences of treating people who present with traits of personality disorder in IAPT. The study will provide us with a unique insight that could inform the development of future psychological treatments for people with personality disorder traits in IAPT. It is important that the staff experiences are considered.

What will happen to the data?

All interviews will be audio recorded if you decline to be audio recorded you wont be able to be interviewed as part of this study. Recording interviews ensure the researcher can pay full attention to you and is less distracting than taking notes. Interviews that are recorded will be transcribed. Only the researcher, transcribers and his supervisory team will have access to these recordings. The recordings will be stored on a password protected digital audio device, written transcriptions will be anonymised and stored securely. Audio recordings will be destroyed once the study is complete. All other research data will be stored in locked cabinets within the chief investigators office at the university and on a password protected university computer. This information will only be accessed by members of the research team. On completion of the study, data will be transferred to the university's authorised and secure archive storage facility. All Transcriptions as per University Policy will be destroyed after 5 years.

How long will the study last?

This study is likely to last a further 18 months however your involvement will only be for the one off 90 minute long interview.

What if something goes wrong?

If you are unhappy with any aspect of the way that you are treated, you should inform Gary Lamph in the first instance and then his supervisors.

Complaints

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. If they are unable to resolve your concern or you wish to make a complaint regarding the study, please contact a University Research Practice and Governance Co-ordinator on 0161 275 7583 or 0161 275 8093 or by email to research.complaints@manchester.ac.uk. Or to the Trusts research office on 01925 664000. Any concerns you raise will be taken very seriously. The project will be covered by the University of Manchester's and 5 Boroughs Partnership NHS Foundation Trust indemnity insurance for research studies.

Harm

In the event that something does go wrong and you are harmed during the research you may have grounds for a legal action for compensation against the University of Manchester or 5 Boroughs Partnership NHS Foundation Trust but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you.

What will happen if I get upset during the study?

It is possible that the questions asked may raise issues or concerns for you. If this happens, you can ask the researcher to move on to the next question. The researcher will not inform your colleagues or leadership team about anything you have said in the interview unless you ask them to do so. However, if you disclose any issues that indicate a serious risk to yourself and/or others the interviewer will have a duty of care to disclose this to your line manager.

Will my taking part in this study be kept confidential?

All information collected about you during the research will be kept strictly confidential. Any information about you will be stored in a locked cabinet at the University of Manchester or on an encrypted computer. All interviews will be recorded on an encrypted audio device. No participants will be named in the reports we write as part of the study. Instead participants will be given part false names and any identifiable information will be removed. Your occupational positions may be described in reports if you wish for this not to be used in the reporting of data collected you must state must make this clear during the written consent prior to your interview. You will be invited to be interviewed in the therapy department unless you request an alternative venue. Individuals from the University of Manchester, regulatory authorities and NHS Trust may need to look at the data collected during the study to make sure that the research is being carried out appropriately. With your permission, this will include your identifiable data. All individuals that may access the data will have a duty of confidentiality to you as a research participant. A third party transcription service will be used however only University approved transcription suppliers will be used to ensure terms and conditions in related to data protection and confidentiality are adhered to.

Individuals from the University of Manchester, regulatory authorities or NHS Trust may need to look at the data collected during the study to make sure that the research is being carried out appropriately. With your permission, this will include your identifiable data. All individuals that may access the data will have a duty of confidentiality to you as a research participant.

What will happen to the results of the research study?

In the interest of further learning and dissemination of the research findings it is planned to publish articles relating to this research in Nursing, Psychological and Medical Journals. It is also planned to share our findings at national / international health related conferences. Please however be reassured that we will ensure that it is not possible to identify you individually in any reports, papers or presentations. If you take part in this study a summary of our results will be available to you on completion of the research. If any direct quotes are used and you could be identified by your role we will cluster roles by grouping into leadership and clinician groups (for example if only one service manager to state this would mean identifying that participant especially if area of research is also identifiable).

Is this study being undertaken as part of an educational qualification?

This study has received funding from the National Institute of Health Research in England. As part of this study the lead researcher and interviewer is completing a PhD at the University of Manchester but is also an employee of the 5 Boroughs Partnership NHS Trust with a clinical nursing and psychological therapies background. The author is supervised at the University of Manchester by Professor Karina Lovell, Dr Tommy Dickinson and Professor John Baker from the University of Leeds.

Who is organising and funding the research?

The study is funded by the National Institute of Health Research (NIHR). The lead researcher is Mr Gary Lamph who is responsible for the day to day conduct of the study. Gary can be contacted at the address below, by email IAPTEmotionsStudy@manchester.ac.uk or by his NHS telephone on 07769673084. Other researchers involved in the study can be contacted via email karina.lovell@manchester.ac.uk j.baker@leeds.ac.uk or tommy.dickinson@manchester.ac.uk

Who has reviewed the study?

This study has been reviewed by the North of Scotland Research Ethics Committee.

Please feel free to discuss this information with others (e.g. your family, leadership team or colleagues) before deciding whether or not to take part. You can also contact the research team directly (details above), if something is unclear. If you would like to take part, please contact Gary Lamph via email IAPTEmotionsStudy@manchester.ac.uk or 07769673084.

Thank you for taking the time to read this information.

Who do I need to contact for further information

The lead researcher, Gary Lamph is responsible for the day-to-day conduct of the study (contact details above). Other researchers included in the project are Professor Karina Lovell, Professor John Baker, Dr Tommy Dickinson.

Mr Gary Lamph
University of Manchester
Jean McFarlane Building
Oxford Road
Manchester
M13 9PL

IAPTEmotionsStudy@manchester.ac.uk NHS Works Mobile: 07769673084

<u>Appendix 7 – Consent Form IAPT Healthcare Professional Participants</u>





Centre Number:

Study Number:

Name of Person taking consent

Participant Identification Number for this trial:

	IAPT HEALTHCARE PROFESSIONAL - CONSENT FOR	RM	
Na	me of Researcher: Gary Lamph	Please initia	al all
box	kes		
1.	I confirm that I have read and understand the information sheet dated 11/05 (version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	/2015	
2.	I understand that my participation is voluntary and that I am free to withdraw time without giving any reason, without my medical care or legal rights being		
3.	I agree that the interview can be audio recorded and the recording written or (transcribed).	ut in full	
4.	I give permission to use my direct quotes in any reports or publications, if the used in a way that I am not identifiable.	ey are	
5.	I agree to take part in the above study.		
6.	I understand that my contributions will be kept confidentual unless I share at that highlights danger or risk to myself or others.	ny thing	
7.	I understand that data collected during the study, may be looked at by indivi- from the University of Manchester, approved third party transcription service regulatory authorities or from the NHS Trust, where it is relevant to my takin- this research. I give permission for these individuals to have access to my contractions.	or from g part in	
8.	I give permission to use my occupational role in any reports or publications, are used in a way that I am not identifiable.	if they	
Nar	me of Participant Date Signature	,	

Signature

Date

Appendix 8 – IAPT Healthcare Professional Information Gathering Form



What Site: (Wigan / Leigh etc)

The University of Manchester





Basic Demographics - IAPT Healthcare Professional Participants

Centre Number:		
Study Number:		
Participant Identification Number Y/N	er:	Verbal Consent
Signed:		Dated:
Gender		
Ethnicity (circle participant choice)	White White - British White - European Mixed / Multiple ethnic group White and Black Caribbean White and Asian White and Black African Other Mixed Asian/ Asian British Indian Pakistani Bangladeshi Other Asian Black / African / Caribbean / Black British African Caribbean Other Black Other ethnic group Arab Other Ethnic Group	White - other Chinese
Age	7 Hub Street Earline Group	
Professional Background	Clinical Psychologist, Nurse, etc.	
Clinical Experience		
Occupational Role in IAPT		
Time working in IAPT Services		

Appendix 9 – Research Protocol



The University



Study protocol

Qualitative Study title: Understanding Long Standing Emotional Difficulties in Primary Care

Title of PhD fellowship: The development of a feasible and acceptable psychological intervention for people with personality disorder traits in primary care IAPT services

Chief Investigator: Gary Lamph

Supervisory team: Professor Karina Lovell, Professor John Baker and Dr Tommy Dickinson

BACKGROUND

Personality disorder (PD) affects up to 13% of the general population. It is a psychological developmental disorder that affects people's ability to function in their everyday lives. It is often attributed to significant childhood experiences and trauma (National Institute for Mental Health in England, NIMHE, 2003). The complex aetiology of PD is described by Sampson et al (2006) who explains how a variety of factors can be attributable to the development of PD including, biological, social, psychological and environmental factors however determining vulnerability of one person against another is complex.

PD has been defined as;

"an enduring pattern of inner experience and behaviour that deviates markedly from the expectations of the individual's culture, is pervasive and inflexible, has an onset in adolescence or early adulthood, is stable over time, and leads to distress or impairment" (American Psychiatric Association (APA) 2000 page 710).

Key patterns of behaviour or traits often associated with PD include long standing difficulties in maintaining stable relationships, negative self-image, an inability to manage emotions effectively and reduced problem solving abilities which results in impulsivity, careless coping styles, interpersonal difficulties, self-injurious behaviour and anger outbursts (Lamph, 2011; McMurran et al, 2008).

PD has been until very recently one of the most excluded and stigmatised of all mental health problems with the lack of knowledge and recognition of the condition (DOH, 2009; NIMHE, 2003; NICE, 2009; HM Government, 2011). The provision of evidence based psychological treatments have increasingly become available for people with complex / severe PD and high levels of risk to self or others in secondary care mental health services (NIMHE, 2003; NICE, 2009).

However currently there are no evidence based treatments developed for people with mild-moderate PD or emerging PD in the UK (Paris, 2013) that specifically focus upon personality disorder difficulties in primary care populations. It is well documented that there is a high prevalence of PD reported in these settings (Moran et al, 2000). Those who present in primary care are less likely to benefit from the routine treatment that is offered within primary care Improving Access to Psychological Therapies (IAPT) services. However understanding of why this may be and what could improve treatment responses, has yet to be explored.

This research is a qualitative study that will focus on two inter-related populations. The first population focus aims to provide an in depth exploration of the needs and treatment experiences of people with traits of personality disorder who are in or have recently undergone psychological treatment in IAPT services. The second will focus upon the IAPT healthcare professionals to provide an in depth understanding of the experiences of front line workers in delivery of IAPT treatments to this client group.

AIMS OF THE RESEARCH PROJECT

Primary aim

• To explore via patient and IAPT health professional interviews, the needs and treatment experiences of people with long standing emotional difficulties consistent with personality disorder traits in primary care.

Study Questions Patients Interviews

"What are the treatment experiences of people who are in IAPT treatment with PD traits?" "What are the needs of people who are in IAPT treatment with PD traits?"

Secondary aims

Patient interviews

- To explore the treatment experiences of people who present to IAPT services with traits of PD.
- To identify and understand the needs of patients with PD traits in primary care IAPT services.

Study Question IAPT Healthcare Professional Interviews

"Are current treatment approaches in IAPT effective for people with traits of PD?"

IAPT healthcare professionals interviews

- Map and understand current practice and treatment provision of IAPT services.
- Identify and understand the needs of the IAPT workforce in relation to the treatment of patients who present with comorbid personality disorder traits in primary care.
- Explore service responses in IAPT to this client group.
- Explore the viewpoints of IAPT healthcare professionals relating to the treatment efficacy when working with people with PD traits and identify areas for improvement that could be achieved within the constraints of an IAPT compliant service.

DESIGN

Individual semi structured in depth interviews will be conducted with 2 interlinked populations groups including both, a patient focussed qualitative interviews and an IAPT healthcare professional interviews.

- 1) Patients (n=15-30)
- 2) IAPT Healthcare Professionals (n=15-30)

Each consenting participant will be interviewed on one single occasion. The interview will last up to but no longer than 90 minutes.

PARTICIPANTS

It is anticipated that a maximum of 60 interviews will take place. (N=30 Patients, N=30 IAPT healthcare professionals), however recruitment will continue until saturation is achieved. The study will take place in 5 Boroughs Partnership NHS Foundation Trust, initially focussed on the Wigan and Leigh IAPT services but in contingency will also recruit from neighbouring boroughs if recruitment is slow or saturation has not been reached.

SELECTION CRITERIA

Inclusion criteria

Patients Interviews

- Screened as requiring an intervention in IAPT
- Scored 3 or more on the SAPAS Screening tool.
- Received a minimum of one treatment session
- Have received last treatment session within the last 12 months
- be able to provide informed consent
- English speaking (due to a lack of resources to fund interpreters)
- Aged 18 and over

Exclusion criteria

Participants will be excluded if they have problems that would;

- Have any significant language barriers that would require a translater
- Any significant literature problems
- Are actively suicidal
- A diagnosed learning disability that could impact on the interview process and consent
- Florid psychosis
- Substance misuse dependence
- Organic impairment

However it should be noted that in order to qualify for an IAPT treatment the following exclusion criteria is likely to have been already screened out at the IAPT screening assessments as not being suitable for treatment within an IAPT service.

IAPT Health Professionals Interviews

Inclusion criteria

 Frontline clinical staff and/or involved in the clinical leadership or direct line management of IAPT services (Psychological wellbeing practitioners (PWP's) high intensity cognitive behavioural therapist, clinical psychologists and clinical leaders and IAPT clinical service managers).

Exclusion criteria

 There are no reasons to exclude IAPT healthcare professionals that hold an occupational position within the services of the 5 Boroughs Partnership NHS Foundation Trust.

PROCEDURE

Materials

Recruitment flyers, consent forms and participant information sheets have all been developed in collaboration with the research advisory group which is made up of people with lived experience of PD to ensure that the information is provided in a clear and unambiguous language.

A short questionnaire has been developed to outline the basic demographics of participants and to ensure they meet criteria for involvement. The information collected via the questionnaire will include gender, ethnicity, and age for both sets of participants. Additionally it will ask for information regarding any previous/current psychological or pharmaceutical in patients and diagnosis and for IAPT healthcare professionals, clinical experience, occupational role and time working in IAPT services. This will be employed during the screening stage for patients via phone or informal meeting and prior to interview for IAPT healthcare professionals. Verbal consent to be screened will be sought at this stage and documented.

Recruitment

Recruitment will commence at the same time for both of the inter-related study populations. Contact points have been made available via a works NHS Mobile number 07769673084 and a study specific email account based at the university IAPTEmotionsStudy@manchester.ac.uk

Patients Interviews (see Appendix 1 flow diagram)

Patient participants will be recruited from within the 5 Boroughs Partnership NHS Foundation Trusts, IAPT services.

Sampling

Potential participants will be recruited from all new IAPT referrals, treatment completers in past 12 months and those currently in treatment. This recruitment strategy is anticipated to

commence in May 2015 until saturation is reached. The identified IAPT service in which this trial is to be conducted receives an average of 350 referrals each month over its two sites.

- A flyer and cover letter will be sent out to all new IAPT referrals and those currently in treatment.
- The flyer will can also be shared and displayed in patient waiting rooms as a reminder.
- As a contingency plan patients who have received an IAPT treatment in the past 12 months will also receive the flyer and share retrospective experiences via interview. A minimum of 1 completed session is required for involvement as it is as important to interview those who have prematurely dropped out of treatment, as it is those who are treatment completers.
- Other Trust IAPT sites will be approached if recruitment is proving difficult.

Strategy to recruitment

The recruitment interest flyer and accompanying cover letter will be sent out to all patients in Wigan and Leigh IAPT service in the first instance. This flyer (see appendix 1) has been developed with the SAPAS screening tool in mind hence will ensure those expressing interest in being involved are likely to be screened into the trial using the Standardised Assessment of Personality – Abbreviated Scale (SAPAS) screening tool (Moran et al, 2003). The SAPAS (Moran et al, 2003) is a brief 8 point screening assessment and will be conducted via telephone screenings in order to identifying participants who meet the threshold score of 3 or above for involvement into the study.

All new referrals awaiting treatment will have a flyer and cover letter attached to their notes to be shared at first treatment session. This recruitment drive is anticipated to commence in May 2015.

In contingency if recruitment is slow and saturation not being reached all those who have been discharged from the service in the past 12 months will be sent the flyer and cover letter. In order to ensure this is manageable rather than send flyers to all discharged patients from the past 12 months, it is planned instead to send flyers to all those who were discharged in a staggered approach targeting those discharged in May 2015 first, then April 2015 and so on. This process will be complete every couple of weeks until saturation is reached. If recruitment remains low, this process will then be expanded to the trusts other local IAPT services, mirroring that of the IAPT healthcare professional recruitment strategy.

Potential participants can express interest in being involved in the research by following instructions on the flyer.

Screening process

At the point of telephone screening a brief script will be read out to gain explicit verbal consent, if the participant is in agreement the SAPAS (Moran et al, 2003) will be the screening tool used alongside a demographic questionnaire will be complete. During a preliminary validation the SAPAS tool has been tested in its accuracy to identify PD with a score of 3 being indicative of a DSM IV (APA, 2000) diagnosable PD in 90% of cases and has been deemed

feasible for usage in routine clinical practice for the identification of people with PD (Moran et al, 2003). Furthermore the SAPAS has been used in other current studies as a reliable predictor of PD and is being most recently selected as the screening tool for use in the identification of PD in a naturalistic research protocol that aims to explore the prediction of outcomes in IAPT service in the UK (Grant et al, 2014).

The SAPAS will be conducted by the chief investigator when interest in the study has been generated from the flyer in order to establish the patient participant appropriateness for involvement. If they meet the SAPAS criteria with a score of 3 or more they will be informed of this during the call and offered the choice of an informal meeting with the chief investigator to discuss further involvement in the study or offered to be sent out more details of the study via a cover letter, the participant information sheet and consent form (Consent form is sent out to provide information to potential participants to ensure they are aware of what it is they are agreeing to but they will be asked to provide written consent on the day of interview). If criteria for involvement is not met or at any point before the interview takes place the participant withdraws, the information provided will be immediately destroyed.

This cover letter will advise and provide a phone number and email address that the potential participant can contact if they wish to withdraw but will also advise that the chief investigator will make contact one week after they are sent the research information to establish if they still wish to take part. Potential participants who don't wish to take part do not need to explain why they wish to withdraw. Those who remain happy to be involved will be given a date and venue and the interview will be scheduled. If an informal meeting has taken place the chief investigator will offer the participant a 24 hour cool off period in order to reach their decision for involvement a number and email will again be provided for them to withdraw. If no contact is made the chief investigator will again contact to establish if they still wish to take part.

Recruiting to interview and out of pocket expenses

Interviews for the patient participants will take place only once 6 weeks post initial treatment session has been attended but no later than 12 months since final session to ensure that perspectives shared are in line with the current service provision and that treatment experiences are fresh in the mind of the participants. The process of recruitment will take place until saturation is reached. Participants who drop out of treatment once recruited will not be excluded as long as they attended a minimum of 1 session.

Consent forms will be sent out for information purposes at the same stage point as the participant information sheets. Written consent will be completed in person on the day of interview.

If, during the intervening period between the first contact and the interview, the patient decides to withdraw from the research they can contact the chief investigator directly or advise the therapist they are working with, of their decision, who will let the lead researcher know.

Out of pocket expenses will be paid to those who participate to cover travel, time and loss of earnings. This will be provided in the form of an 'One4all' Post Office Voucher at the value of £40 once the interview has been brought to a close.

IAPT healthcare professionals Interviews (See Appendix 2 flow diagram)

Research generated data will be gathered following IAPT healthcare professional interviews. Therefore a purposive sample will be identified that will focus on those working in IAPT and may include interviews with management, clinical leads and a mixture of front line staff to ensure a breadth of information is gathered across the workforce in IAPT in the 5 Boroughs Partnership NHS Trust.

Consent will be given prior to interview, those expressing interest in taking part can contact the lead researcher via email or phone to express interest and a date for interview will be arranged. A brief demographic form will be complete prior to the interview and only once written consent is provided.

Target population for sampling

Several meetings have taken place with leading trainers of IAPT workers at all steps to discuss the research and gain insight into where the research should focus its attention. From these meetings it has been agreed that people will present with co-morbid personality disorder traits across the whole IAPT service regardless of treatment level and therefore interviews should represent this diversity. Hence interviews with patients and IAPT healthcare professionals from both low intensity and higher intensity will provide important insights. Furthermore those who don't complete treatment may also provide important insights to this research particularly if they drop out.

The composition of IAPT services can greatly differ from one service to the next however the main service that the author will recruit from is strictly developed and implemented in line with IAPT compliance standards and is the highest performing IAPT service in the North West for recovery covering two sites (Wigan and Leigh).

Recruitment to the study will be open to a mixture of front line psychological therapists from both low and high intensity steps will be interviewed as will the clinical leadership team and managerial team with direct line management for the IAPT service.

Strategy for recruitment

A strategy will be put in place to generate the interest and raise the profile of the study to staff members and request for consenting participants. Those who express interest will be provided with a participant information leaflet and offered the opportunity to ask any questions prior to the interview via email.

The chief investigator will near the time of staff recruitment attend a series of IAPT staff meetings to provide an overview of the research and begin the recruitment process by generating interest from potential IAPT healthcare professional participants. Flyers will promote recruitment and will also be made available to all potential participants electronically via the staff email list.

A contingency and follow up plan will also be put in place to remind busy clinicians of this opportunity for involvement during the recruitment phase of the research. Further to this contingency plan if recruitment is low and saturation isn't reached, then this opportunity for

participation will also be opened up to other IAPT healthcare professionals who work for the Trust in neighboring boroughs, such as Halton, Warrington, Knowsley and St Helens will be approached.

Interview process

All interviews will be digitally audio recorded. Interviews with patients will take place within the therapy unit in a private room or in an alternative venue including other Trust buildings, the University of Manchester or their own home if they request this. Interviews with IAPT healthcare professionals will take place in the therapy unit in a private room or the University of Manchester inpatients will take place in a side room on the ward. The option of carrying out interviews via phone will be offered to people who wish to be involved but do not wish to meet in person.

Audio recordings of all interviews will take place using an encrypted device. A method of transcribed verbatim will be used. A participant coding system of any data stored will be employed to identify and protect the data of those involved.

Consent

Consent will be revisited at each stage of interaction between the researcher and the participants in order to ensure they are aware of this being a voluntary involvement and one in which they can disengage at any point. They can also request for data already gathered to be destroyed.

Prior to any interviews commencing, the chief investigator will explain the process of the interview and research, check participant understanding and also complete written consent with the participant, explaining their rights to withdraw at any point The consent form will highlight areas of consent including;

- 1) Understand the research proposed
- 2) Agreement to participate in the study and right to withdraw
- 3) Agreement to be digitally audio recorded and the interview transcribed
- 4) Agreement to have direct quotes used in the final report and any subsequent publications
- 5) Agreement to take part in the study
- 6) Understand confidentiality and duty of care of researcher in the event of risk to self or others being shared.
- 7) Permission for regulatory authorities, the Trust and the University of Manchester to access data.
- 8) Agreement to use their occupational role in any reports or publications, so long as they are used in a way that they are not identifiable (IAPT Healthcare Professionals only)

Patient participants must agree to all items with the exception of point 4. If a participant declines to consent for the use of direct quotes in the final report or other forms of distribution of data and findings then a note will be placed upon their records to ensure these quotes are not used.

IAPT healthcare professionals must agree to all sections with the exception of point 4 and point 8 that presents only on the staff consents form relating to occupational role. It must

however be noted that due to limited numbers of clinical leads and managers in the service they may be more at risk of assumed identification.

ANALYSIS

The in depth interviews will be transcribed verbatim and data will be analysed using a framework analysis approach (Ritchie et al, 2014) and NVivo software.

An initial coding framework will be developed and transcripts checked against the framework to ensure that there are no significant omissions. Codes in each interview will be examined across individual transcripts as well as across the entire data set and allocated to the framework. Written notes will be used for non-verbal responses or to clarify points of interests.

Within qualitative research the reliability of the analysed data can be criticised if just a lone researcher has picked out the themes. Therefore the research team will meet to gain a consensus on agreed themes this being an approach the chief investigator will utilise via the academic supervision process (Richie et al, 2014).

On completion of this study and its analysis the academic team will seek to publish the findings.

LONE WORKING

For interviews that take place within a non-university or non-NHS meeting venue (i.e. home of participant), the School of Nursing, Midwifery and Social work's lone working policy will be in place. This will mean that the chief investigator will take responsibility to contact one of the academic supervisors before and after interviews to ensure his where about and safety are assured. If the lead researcher fails to contact the supervisor at the agreed time, the supervisor will take action according to an agreed protocol. A 'PeopleSafe' badge will be used by the lead researcher during any interviews outside of NHS or University premises as stated in the lone working policy. Peoplesafe badges are an electronic device through which researchers can request assistance in an emergency.

MANAGING RISK OF PARTICPANT DISTRESS

It is possible that participants particularly the patient participants may become distressed during interviews as they may be discussing very emotive difficulties, needs and experience (although it should be noted that the researcher is very experienced in interviewing patients with these difficulties and is used to listening to difficult and emotive experiences). Participants will be advised that they are not required to answer any questions that they are uncomfortable with or to complete the full interview but instead are free as volunteers to withdraw at any time. This will not affect their reimbursement of costs.

The chief investigator will not tell the GP or therapist or managers about anything participants share unless the participants request that he does so. However if the participants disclose any issues that indicate a serious risk to themselves and/or others the interviewer will have a duty of care to disclose this to the relevant people involved in their care.

We do not anticipate that taking part in the study will cause participants any problems. If, however, they are unhappy with any aspect of the way that they are treated, contact detail will

be made clearly available to them to raise these concerns. Any complaint they make will be taken very seriously, the project will be covered by the University of Manchester's and 5 Boroughs Partnership NHS Foundation Trust indemnity insurance for research studies. The participant information sheets make reference to managing situations of distress and will be adhered too.

CONFIDENTIALITY

All participant information collected during the research will be kept strictly confidential. Any information about participants will be stored in a locked cabinet at the University of Manchester or on an encrypted computer. All interviews will be recorded on an encrypted audio device. No participant's names or identifiable data will appear in any outputs of the research. Although staff roles may due to limited managers or clinical leaders mean there is an increased risk of those members being identified. False names and removal any information that could identify participants will be carefully adhered to. Health professionals or line managers will not need to be aware of participant involvement in the study unless it is felt there is a serious risk of harm to self or others from the information divulged during contact with the researcher. Only then would confidentiality need to be breached in line with the author's duty of care and code of professional conduct. Attending the interview at the base of the IAPT services may identify participants if they were to be seen by workers or colleagues therefore the choice of alternative venue is offered to both groups.

DISSEMINATION

It is intended to publish and write articles relating to this research in Nursing, Psychological and Medical Journals. It is also planned that the study findings will be shared at national / international health related conferences. The results will also be shared with the involved services and Trusts and participants. All participants in this study will be provided with a summary of the research once completed.

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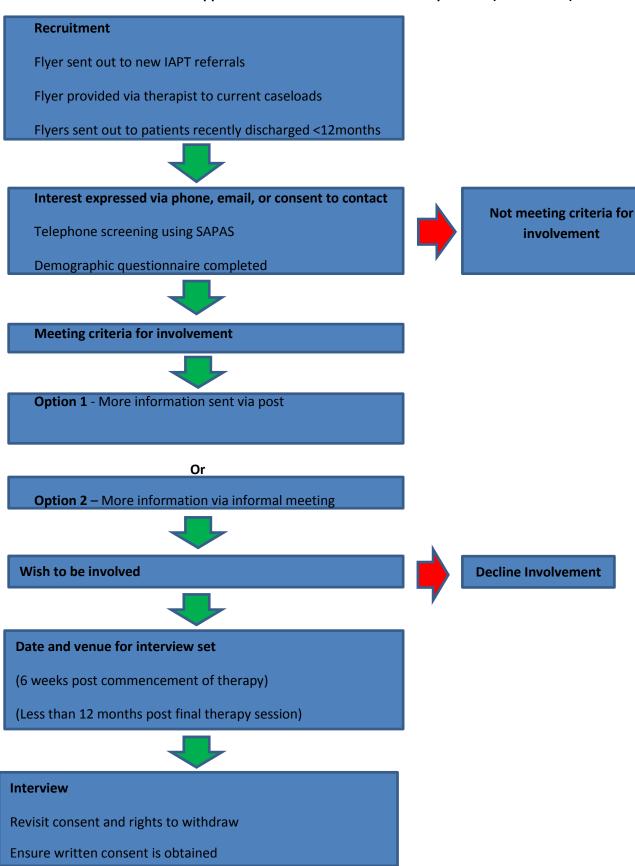
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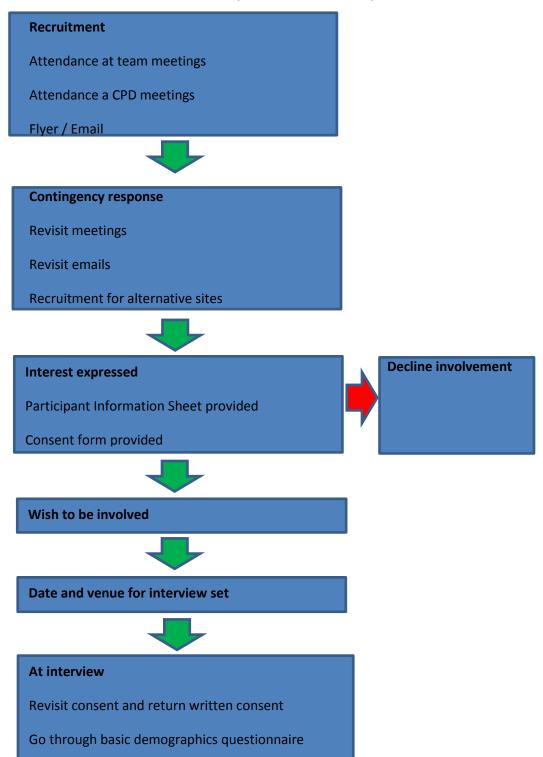
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Research Protocol Appendix 1 Patient Interviews research protocol (recruitment)



Research Protocol Appendix 2 - Research Protocol Flow Chart

IAPT healthcare professional research protocol (recruitment)



Appendix 10 – Patient Participant Recruitment Flyer





Research Patient Recruitment Flyer

<u>Title: Understanding Long Standing Emotional Difficulties in Primary</u> Care

We are in the process of recruiting patients to be involved in an innovative nationally funded research project aimed at improving services for those who present with long standing emotional difficulties. Involvement will briefly consist of one face to face interview with a researcher.

Could you help to make a difference? Have your voice heard? Help shape the future of services for people to ensure their needs are met?

If you can relate your own difficulties to the statements below we would like to hear from you;

"I have long standing difficulties in maintaining positive relationships"

"I have frequent struggles to manage my emotions"

"I cope with my problems in ways others might not understand" "I frequently fear and worry I will get things wrong and make mistakes"

"I find it difficult to fit in"

Those interviewed as part of this study will get travel reimbursed and also out of pocket expenses for any time they put into taking part in this research.

Please contact Gary Lamph IAPTEmotionsStudy@manchester.ac.uk or phone 07769673084 to find out more. Alternatively you can consent to be contacted by informing your therapist that you would like to become involved in this research, who.uk will make contact with Gary to inform him of your interest

Appendix 11 – Patient Recruitment Cover Letter



Research Patient Recruitment Flyer

Dear Sir / Madame,

The 5 Boroughs Partnership NHS Foundation Trust have been asked to send out the attached flyer and research information on the behalf of the University of Manchester. Your information and details have not been shared with the University instead you have been sent this information due to your involvement with our services as you may be able to become involved in this research. Everyone who is currently undergoing treatment within the IAPT service has been sent this as will new referrals and those recently discharged.

The research looks to recruit 30 participants. Once this number is reached, recruitment will discontinue.

Please see flyer for more information and contact details of the researcher (Gary Lamph) should you wish to find out more.

Many thanks

5 Boroughs Partnership NHS Foundation Trust - IAPT Services.

Appendix 12 - Patient Telephone Screening Script





The University of Manchester

5 Boroughs Partnership NHS Foundation Trust

Telephone Screening

Explicit Consent Script; Read out prior to carrying out screening and basic demographics

Thank you for expressing you interest in taking part in this study. Before I go on to gather any further information from you, I will first need to go through this brief script to ensure you are happy to progress. Are you happy for me to go through this with you?

- 1. All data you are about to provide will only be used if you meet the eligibility criteria for the study.
- 2. This data we will gather today is to inform us if you meet the eligibility criteria.
- 3. If you don't meet the criteria for involvement in the study any information you provide me with today will be immediately destroyed.
- 4. If you do meet the criteria today any information you provide will be securely stored at the University of Manchester and will be stored and used as part of the research and held for up to 5 years.
- 5. If at any point you decide you no longer wish to be involved you can without explanation withdraw and request all your information is destroyed by contacting me directly.
- 6. Any data you do provide will only be accessed by myself and my academic supervisors.
- 7. Are you still happy to progress with this telephone screening. (if yes progress and sign off verbal consent on the Demographics form).

I will now go onto ask you ask you 8 brief screening questions and then some demographic questions that will determine your eligibility for involvement. Are you still happy to progress? Do you have any questions at this point?

Standardised Assessment of Personality - Abbreviated Scale

Only circle Y (yes) (or N (no) in the case of question 3) if the patient thinks that the description applies most of the time and in most situations.

- 6. Are you normally a worrier?..... Y/N. (yes=1, no=0)
- 7. In general, do you depend on others a lot?.. Y/N. (yes=1, no=0)
- 8. In general, are you a perfectionist?...... Y/N. (yes=1, no=0)

<u>Appendix 13 – Patient Participant Information Gathering Form</u>







5 Boroughs Partnership NHS Foundation Trust

Basic Demographics - Patient Participants

Centre Number:	Study Number:
Participant Identification Number:	Verbal Consent: Y / N
Signed:	Dated:

Gender			
Ethnicity (circle participant choice)	White White – British White - European White - other		
		nite and Asian her Mixed	
	Asian/ Asian British Indian Pakistani Other Asian	Bangladeshi Chinese	
	Black / African / Caribbean / Black British African Caribbean Other Black		
	Other ethnic group Arab Other Ethnic Group		
Age			
Previous Treatment	<u>Psychological</u>	<u>Pharmaceutical</u>	
Current Treatment How many sessions in? What treatment? What Site: (Wigan /Leigh etc)	<u>Psychological</u>	<u>Pharmaceutical</u>	
Diagnosis	<u>Past</u>	Present	
Therapist:	GP:	GP Practice:	

Appendix 14 - Cover letter to accompany Patient Participant Information Sheet





5 Boroughs Partnership

NHS Foundation Trust

[26/06/2015]

Dear Sir/Madam,

Study Title: Understanding Long Standing Emotional Difficulties in Primary Care

We would like invite you to take part in our research study. The study invites participants to take part in a one off interview that will enable us to explore the needs and treatment experiences of patients who have received primary care psychological therapy treatments. To be included we are looking to recruit people with common mental health disorders such as anxiety and depression but also long standing emotional difficulties, relationships difficulties, difficulties coping with stress and problem solving. You have been invited to take part following your recent screening phone call.

Please note that you are free to refuse to take part in this study without explaination.

The enclosed information sheet describes the study in more detail, a consent form is also provided so that you know what it is you will be agreeing to if you decide to take part. Please take time to read it carefully and discuss it with others if you wish. The North of Scotland Research Ethics Committee has approved this study.

Please use the below contact details to book in a date for your interview if you still wish to take part. If you don't wish to be involved at any point or wish to withdraw your interest please also contact myself, Gary Lamph, using the following details:

Email: IAPTEmotionsStudy@manchester.ac.uk

NHS Works Phone: 07769673084

If we don't receive any contact one week after sending out this information we will make contact to determine if you are still interested.

Those who meet criteria for involvement and go on to be interviewed will receive out of pocket expenses to the value of £40 in the form of a 'One4All' post office voucher.

Yours sincerely,

Gary Lamph

National Institute for Health Research Clinical Doctoral Research Fellow, The School of Nursing, Midwifery and Social Work
The University of Manchester
Jean McFarlane Building
Oxford Road
Manchester
M13 9PL

Appendix 15 – Patient Participant Information Sheet



The University of Manchester



Participant Information Sheet (Version 2: 11/05/2015)

Patient Participants

Title: Understanding Long Term Emotional Difficulties in Primary Care

This is an invitation to take part in a research study. Please take time to read the following information carefully. Discuss it with your friends, relatives and your GP/ therapist if you wish. Please contact Gary Lamph (Lead Researcher, using the contact details below) if there is anything that it is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

This study is interested in exploring the needs and experiences of people with common mental health difficulties (anxiety and depression). We are interested in talking to people who also have long standing difficulties managing emotions, emotional control, relationships difficulties, coping with stress and problem solving. These difficulties can sometimes be traced back to your teenage years and early adulthood. These difficulties often go unrecognised and can in some circumstances mean that people with these problems may benefit less from routine psychological therapy. We therefore aim to explore the difficulties and the impact of them on you, your life and your treatment experience.

This aim of the research is not to label or diagnose participants but instead to gain a better understanding of people's experiences and needs. It is hoped that this will help us in the development of future treatments to better support the recovery of people with the difficulties outlined. By interviewing patients with long standing emotional difficulties we hope to better understand their needs and experiences of treatment.

Why have I been chosen?

You have been chosen because you have replied to the recruitment poster that has been sent to all patients referred to the IAPT service for treatment. Sharing your experiences and needs will provide a valuable understanding into the services and treatments you are currently receiving. Interviewing you will enable us to identify what areas of treatment are good and where improvements can be made. This study is the first of its kind. Taking part gives you a valuable opportunity to share your views and opinions and potentially influence future treatments for the better.

Do I have to take part?

It is up to you to decide if you do or don't wish to take part. Even if you agree to take part, you are still free to change your mind at any time, without giving a reason. If you decide you don't want to take part this will not affect the standard of care you receive now or in the future. If you chose to take part in the study but subsequently drop out of treatment, provided you have attended one session of treatment you will still be able to take part in this study as it is recognised that you will still have important contributions to make.

What will happen during my involvement in this research?

If you agree to become involved you will be invited to take part in an interview lasting up to but no more than 90 minutes, during which time you will discuss with a researcher (Gary) your experience of treatment, any difficulties you have experienced and how well your treatment needs are being met.

What do I have to do?

If you are still interested in this research after reading this you can call Gary (07769673084) or email him on IAPTEmotionsStudy@manchester.ac.uk to ask him to contact you. During your phone call with Gary you will be asked 8 short questions about your difficulties. However you should note that not everyone will meet the criteria to take part and you will be advised of this during the call. Between 15-30 patients will be interviewed. If you meet the criteria a date will be arranged for the interview to take place. You will never be offered an interview without giving you at least 24 hours to consider your involvement but a date can be arranged at a time convenient for you even if that is in several week's time. We will stop our recruitment once we feel we have enough participants to reach clear conclusions on our findings. Gary will make contact a week after this information sheet has been provided to you if you haven't already contacted him with your decision.

What are the possible disadvantages and risks of taking part?

This study *does not* involve you taking any new medications or changes to your care and therefore there is minimal clinical risk to you taking part. It does however involve talking about your treatment experiences, any difficulties and unmet needs. The interview may therefore involve discussing some emotive issues for you (although it should be noted that the researcher is very experienced in interviewing patients with these difficulties and is used to listening to difficult and emotive experiences). If you do choose to take part or you are uncomfortable with any questions asked you do not have to answer them. You also don't need to complete the full interview. You can stop the interview at any point. The researcher will not be upset by you declining to answer questions or leaving the interview early.

What are the possible benefits of taking part?

At the end of the study, we aim to have a better idea about the experiences of people who have long standing, recurrent and persistent difficulties with emotions, relationships and coping responses. We hope that the study will provide us with sufficient information to inform the development of future psychological treatments for people with similar difficulties to you. It is important that patient experiences are considered. It is recognised that patients are uniquely placed to guide any future development of psychological treatments.

What will happen to the data?

All interviews will be audio recorded if you decline to be audio recorded you wont be able to be interviewed as part of this study. Recording interviews ensure the researcher can pay full attention to you and is less distracting than taking notes. Interviews that are recorded will be transcribed. Only the researcher, transcribers and his supervisory team will have access to these recordings. The recordings will be stored on a password protected digital audio device, written transcriptions will be anonymised and stored securely. Audio recordings will be destroyed once the study is complete. All other research data will be stored in locked cabinets within the chief investigators office at the university and on a password protected university computer. This information will only be accessed by members of the research team. On completion of the study, data will be transferred to the university's authorised and secure archive storage facility. All Transcriptions as per University Policy will be destroyed after 5 years.

Will I be reimbursed for time and travel?

All participants who are involved and meeting eligibility will be reimbursed with a £40 'oneforall' post office voucher to cover time and travel out of pocket expenses. This will be given to you immediately after you interview has been complete.

How long will the study last?

This study is likely to last up to 18 months however your involvement will only be for the one off interview.

What if something goes wrong?

We do not anticipate that taking part in the study will cause you problems. If, however, you are unhappy with any aspect of the way that you are treated, you should contact Gary Lamph in the first instance and then his supervisors (See Below).

Complaints

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. If they are unable to resolve your concern or you wish to make a complaint regarding the study, please contact a University Research Practice and Governance Co-ordinator on 0161 275 7583 or 0161 275 8093 or by email to research.complaints@manchester.ac.uk or the 5 Boroughs Partnership NHS Foundation Trusts Research Office (01925 664000). Any complaint you make will be taken very seriously. In order to protect you further, the project will be covered by the University of Manchester's and 5 Boroughs Partnership NHS Foundation Trust indemnity insurance for research studies.

Harm

In the event that something does go wrong and you are harmed during the research you may have grounds for a legal action for compensation against the University of Manchester or 5 Boroughs Partnership NHS Foundation Trust but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you.

What will happen if I get upset during the study?

If this happens, you could ask the researcher to move on to the next question or the researcher can pass on any concerns to the most relevant person with your permission. The researcher will not tell your GP or therapist about anything you have said in the interview unless you ask them to do so. However if you disclose any issues that indicate a serious risk to yourself and/or others the interviewer will have a duty of care to disclose this to your GP or therapist or other relevant people. As an alternative you could discuss the issues or concerns with a friend or relative. If you suddenly left the interview in a distressed state and the researcher has concerns regarding risk for yourself or others, the researcher would by his own professional accountability responsibilities have to liaise with necessary people to ensure your welfare and safety.

Will my taking part in this study be kept confidential?

All information collected about you during the research will be kept strictly confidential. Any information about you will be stored in a locked cabinet at the University of Manchester or on a password protected computer. All interviews will be recorded on a password protected audio device. We will not name anyone in the reports we write as part of the study. We will give people taking part false names and remove any information that could identify them. We will not tell any health professionals involved in your care of your involvement in the study unless it is felt that there is a serious risk of harm to self or others. You will however be invited to be interviewed in the therapy department or other NHS buildings unless you request an alternative venue. A third party transcription service will be used however only University approved transcription suppliers will be used to ensure terms and conditions in related to data protection and confidentiality are adhered to.

Individuals from the University of Manchester, regulatory authorities or NHS Trust may need to look at the data collected during the study to make sure that the research is being carried out appropriately. With your permission, this will include your identifiable data. All individuals that may access the data will have a duty of confidentiality to you as a research participant.

What will happen to the results of the research study?

So that others can learn from this study, it is intended to publish and write articles relating to this research in Nursing, Psychological and Medical Journals. It is also planned that the study

findings will be shared at national / international health related conferences. Please however be reassured that it will not be possible at any time to identify any participant individually in any reports, papers or presentations. All participants in this study will be provided with a summary of the research once completed.

Is this study being undertaken as part of an educational qualification?

Yes this study has received funding from the National Institute of Health Research in England. As part of this study the lead researcher and interviewer is completing a PhD at the University of Manchester but is also an employee of the 5 Boroughs Partnership NHS Trust with a clinical nursing and psychological therapies background. The author is supervised at the University of Manchester by Professor Karina Lovell, Professor John Baker and Dr Tommy Dickinson.

Who is organising and funding the research?

The study is funded by the National Institute of Health Research (NIHR). The lead researcher is Mr Gary Lamph who is responsible for the day to day conduct of the study. Gary can be contacted at the address below, by email lAPTEmotionsStudy@manchester.ac.uk or by NHS works telephone on 07769673084. Other researchers involved in the study can be contacted via email karina.lovell@manchester.ac.uk j.baker@leeds.ac.uk or tommv.dickinson@manchester.ac.uk

Who has reviewed the study?

This study has been reviewed by the North of Scotland Research Ethics Committee.

Please feel free to discuss this information with others (e.g. your family, therapist, GP) before deciding whether or not to take part. You can also contact the research team directly (details above), if something is unclear. If you would like to take part in the study and be interviewed please contact Gary via email IAPTEmotionsStudy@manchester.ac.uk or 07769673084 to arrange a date for interview at a time, venue and date that is best for you. Out of pocket expenses via the 'One4All' voucher will be provided on completion of your interview to cover your travel expenses and time.

Thank you for taking the time to read this information.

Who do I need to contact for further information - The lead researcher, Gary Lamph is responsible for the day-to-day conduct of the study. Gary can be contacted at the address below, or by email IAPTEmotionsStudy@manchester.ac.uk or by telephone on 07769673084. Other researchers included in the project are Professor Karina Lovell, Professor John Baker, Dr Tommy Dickinson.

Mr Gary Lamph
University of Manchester
Jean McFarlane Building
Oxford Road
Manchester

M13 9PL IAPTEmotionsStudy@manchester.ac.uk NHS Works Mobile: 07769673084

Appendix 16 - Consent Form Patient Participants









Study Number:

Centre Number:

Patient Identification Number for this trial:

Study Title: Understanding Long Standing Emotional Difficulties in Primary Care

	PATIENT PARTICIPANT - CONSENT F	ORM
	ame of Researcher: Gary Lamph	Please initial all
9.	I confirm that I have read and understand the information sheet d (version 2) for the above study. I have had the opportunity to cor information, ask questions and have had these answered satisfactors.	nsider the
10.	 I understand that my participation is entirely voluntary and that I a at any time without giving any reason, without my medical care or affected. 	
11.	 I agree that the interview can be audio recorded and the recordin (transcribed). 	g written out in full
12.	 I give permission to use my direct quotes in any reports or publications used in a way that I am not identifiable. 	ations, if they are
13.	3. I agree to take part in the above study.	
14.	4. I understand that my contributions will be kept confidential unless that highlights danger or risk to myself or others. If this was to on may need to discuss this further with members of the my care tea include GP and/or Therapist.	cur the researcher
15.	5. I understand that data collected during the study, may be looked from the University of Manchester, from regulatory authorities, from party transcription service or from the NHS Trust, where it is releved part in this research. I give permission for these individuals to had data.	om approved third vant to my taking
Nan	ame of Participant Date Sign	ature
	ame of Person Date Sign.	ature

Appendix 17 – Indexing Flow Chart

<u>Process of Indexing / Developing the Framework (Study 2)</u>

Initial Index (Informed by known literature, policy and evidence)

Scoping Study 1 (deductive themes emerged)

Topic Guide developed

Inductive themes emerged

Revised topic guide during data collection

Areas of Topic guide inform the 1st Initial Index

(N=2 cases coded into the framework developed via the initial index)

Lots of cross over and terms too broad / not qualitative enough / largely deductive themes

Back to Indexing Design

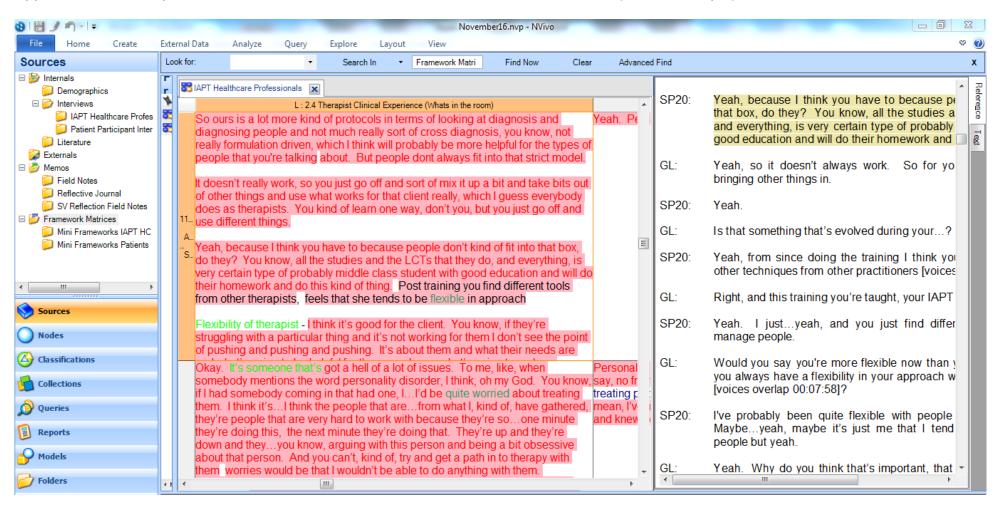
- Immersed self into Transcripts and Audios
- Listen & read a selection of interviews, to develop a clearer index using original framework as a foundation (Post it note exercise)
 - Allowed for the emergence and inclusion of inductive themes
- This provided me with a more flexible approach to re-organisation of the indexing
- Listing key information/ feedback areas down checked to see how they fit with themes emerging (colour coded for each participant)
- Participants selected from (n=5 x step 2 n=5 x step 3 n=1 x leadership) Included those who are noted as bringing in new ideas and opinions to capture a range of potential inductive themes

Refined Index by merging similar repetitive themes / re-organising

Listen to N=3 (step 2 x 1, step 3 x 1, management x 1) new interviews to test Index list before setting up the framework in NVivo

Begin Coding (continue to revise for inclusion of new inductive themes)

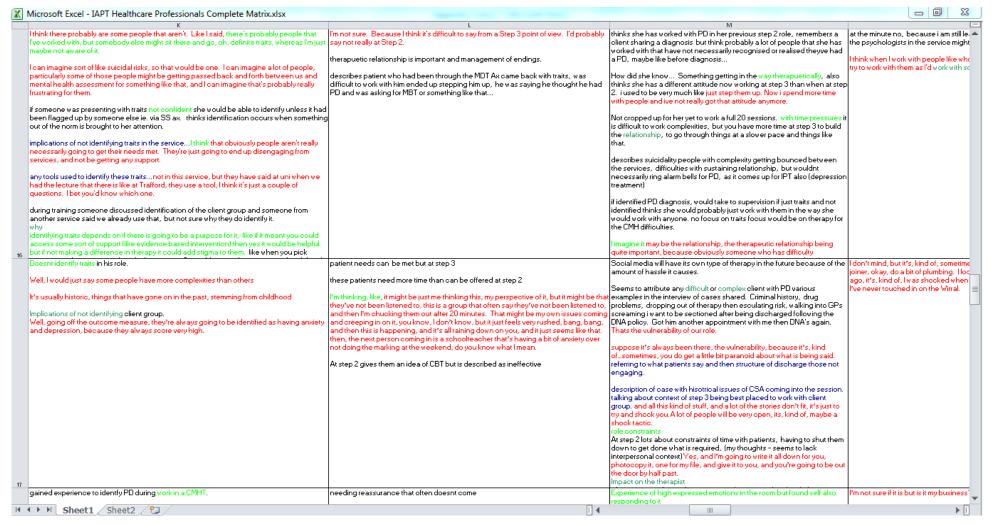
<u>Appendix 18 – Example of NVivo/Excel Framework Matrix – Healthcare Professional (NVivo Example)</u>



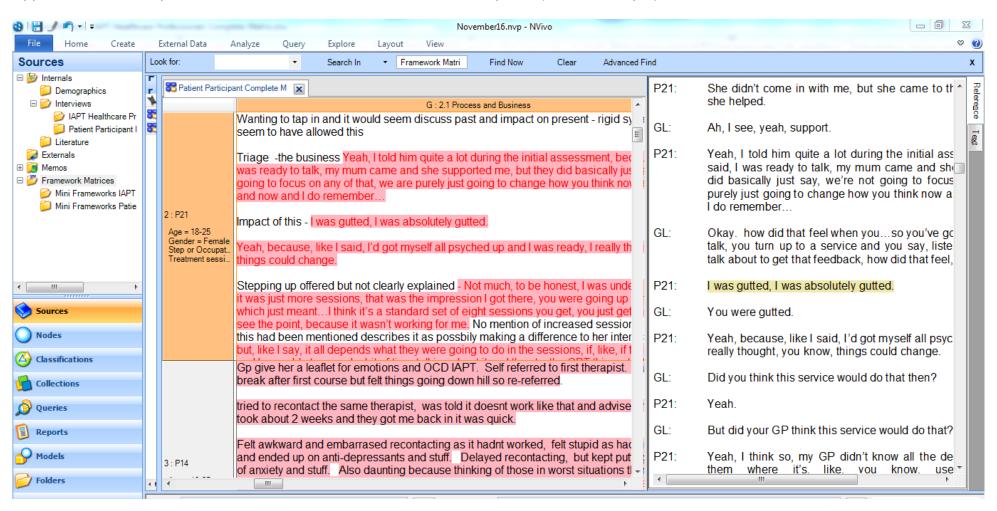
<u>Appendix 18 – Example of NVivo/Excel Framework Matrix – Healthcare Professional (Excel Examples)</u>

Υ	Z	AA	AB	
X : 4.2 At What Step	Y : 4.3 The Service as a Business	Z : 4.4 Key Themes	AA: 4.5 Other	AB : 5. Next Steps (Se
robably seen at step 2 to work with anxiety and depression but have train referral form if bounced back from step 3.label of traits not even onsidered We're told to stick to the anxiety and depression. In this is most definately a gap in the service Then stepped up never really fed back on what actually happens to them	s So some people think actually you're paid to do a certain job, just do that job, don't do anything extra around that. Other people are quite encouraging. From a service point of view. It's tough isn't it, because we've got so many contacts to be made, but I think, like we said before, there's not that time		Misconception that primary care just see people with phobias etc. I think there is no such thing as mild to moderate really. Critique of telephone therapy we had a lecturer coming in and she was really saying the telephone is really good and moving away from that, but actually I think there's something lost in that, and I think you're missing out a whole lot of people in that. So if you're not offering one to one what happens to the old lady who can't hear anything in the session?can see benefit in fleixiblity, says telephone based services are no where near them in terms of recovery rates, so something must be getting lost.	think in terms of unique, but I stil way to go.
oth, looking at it from the IAPT perspective, you know, it doesn't matter hat someone comes in with. If they come in with anxiety or common lental health problems that's what we're treating. So we can always tempt to treat that at Step 2 in the step care model and if they need mo me, more sessions, then go on to Step 3. So that'll be like having colorbid traits would impact the therapy if we knew how to interact better a uild a therapeutic relationship with them. I feel like once that's been chieved we're just going as normal, like we normally would essentially. I would imagine across the board because in general it feels like everybod ones to Step 2, then they're stepped up following I think they're trying the get back to the model that weeven if you, you know, do a triage and ou really are more suitable for Step 3 you come through step care and yestthere's an attempt at Step 2 then stepped up. So I feel like they	business idea, like we seewe have everybody, just anybody from anywhere doing anything, employed, unemployed. Changes in IAPT I think so. I think it's come to realise that you can't just target specific groups, we all experience this and it affects us in different ways, so. Need for legislations in order to meet requirements, without them it doesnt			

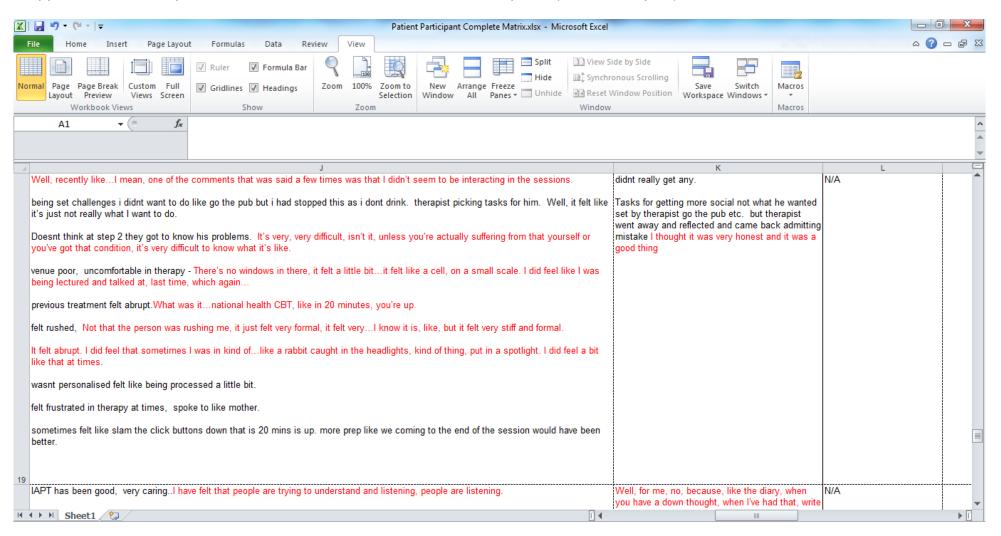
AS:5.5 rearwise. AS:5.5 rearwise. AS:5.5 rearwise. Constraints of learning more solds as a PMPPFrom the unhersity side of things, definitely. From a service point of view it's mixed. More understanding of PD in core university training also suggest PPN conference to share recommendations from this research Skills and resources. If had more skills and resources to hand wouldn't feel like you was incompetent as you are going down a treatment order that isn't ree's a big gap, and it think in IAPT, some services, like I talked at lelephone one, we're taught to be person centred, but they send out and right, this week a useful and more competent with this group. Training should apply to all steps and management not service level but above that, for example You've got the commissioners who don't quite know what's coming through our service. They see it as a midl to moderate service, overyone fits that same bill, and it doesn't quite fit that does it's Sol think education on their part really needs doing. Understanding from a practitioner point of view New trainees should be the target for training Talks about PWP training and patient involvment in it, someone telling us what they need, what would work better for them, what they would dislike about the service and what would make them drop out think having a patient perspective would be useful and help others as well than the service and what would make them drop out think having a patient perspective would be useful and help others as well than the service and what would make them drop out think having a patient perspective would be useful and help others as well than the service and what would make them drop out think having a patient perspective would be useful and help others as well than the service and what would make them drop out the think perspective would be useful and help others as well than the service and what would make them drop out the perspective would be useful and help others as well than the service and what would make them drop out the	
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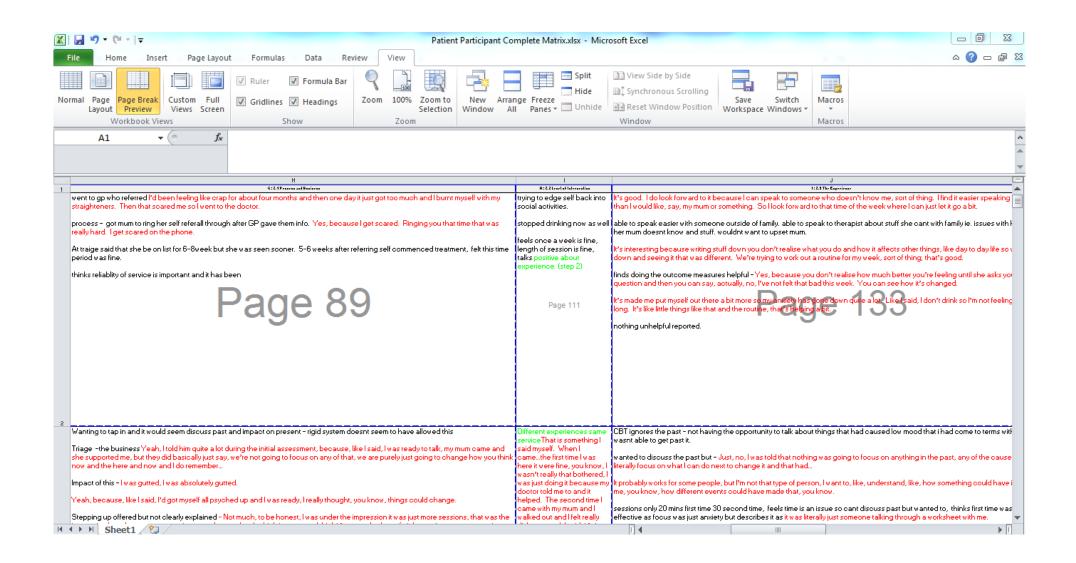


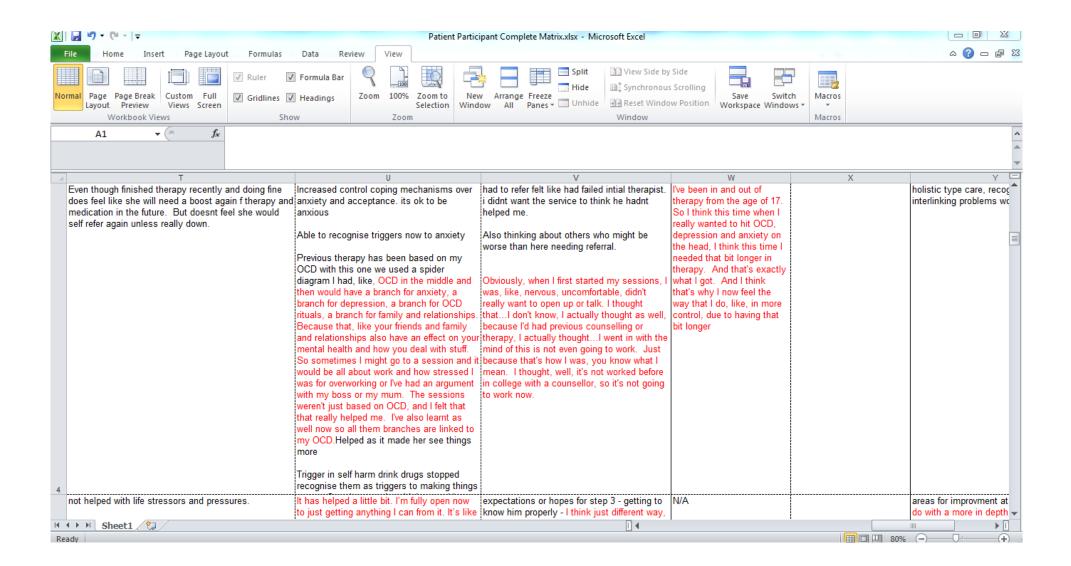
<u>Appendix 19 – Example of NVivo Framework Matrix – Patient Participants (NVivo Example)</u>



Appendix 19 - Example of NVivo Framework Matrix - Patient Participants (Excel Examples)











Topic Guide

Title: Understanding Long Standing Emotional Difficulties in Primary Care

IAPT Healthcare Professional Interviews

"Are current treatment approaches in IAPT effective for people with traits of PD?"

IAPT healthcare professionals interviews

- Map and understand current practice and treatment provision of IAPT services.
- Identify and understand the needs of the IAPT workforce in relation to the treatment of patients who present with comorbid personality disorder traits in primary care.
- Explore service responses in IAPT to this client group.
- Explore the viewpoints of IAPT healthcare professionals relating to the treatment efficacy when working with people with PD traits and identify areas for improvement that could be achieved within the constraints of an IAPT compliant service.

Introduction

Aim: To introduce the research and set the context for the proceeding discussion.

- Introduce self
- Introduce the study: What is it about (see aims and objectives above) in connection with NIHR
- Recap on how participant has been selected
- Consent START RECORDING
- Confirm you have gone through information above and that the participant is happy to proceed.

1. Background

Area of enquiry: to introduce the participant to interview process, highlight any background particulars that may inform the interview.

Prompts

- Occupational Position, length of service
- Understanding of PD
 - Training
 - Experience of working with people with personality disorder

2. Understanding IAPT

Area of enquiry: Map and understand current practice and treatment provision of IAPT services.

Prompts

- Identify those who they struggle to progress with
- Why do people drop out
- Explore where do people with PD present in IAPT service
- SV for complex cases, long standing emotions or pd traits. Pathway to treatment barriers,
- Service constraints
- Treatment of PD traits, how differs if identified?

3. IAPT Healthcare Professional Needs

Area of enquiry: Identify and understand the needs of the IAPT workforce in relation to the treatment of patients who present with comorbid personality disorder traits in primary care.

Prompts

- Training
- Interventions /Evidence based approaches
- Recognition and screening of client group (benefits of not recognising or recognising PD)
- Supervision

4. <u>IAPT responses to PD</u>

Area of enquiry: Explore current service responses in IAPT to this client group.

- Constraints and Barriers of working with this client group
- Needs met / unmet
- Mode of treatment group / individual
- Length of treatment
- Constraints of service
- Supportive factors for working with PD

5. Next Steps

Area of enquiry: Explore the viewpoints of IAPT healthcare professionals relating to the treatment efficacy when working with people with PD traits and identify areas for improvement that could be achieved within the constraints of an IAPT compliant service.

- Expectations is this your business
- Needs of workforce
- What if anything needs to change
- Willingness to work with and identify PD in primary care
- What would be acceptable / feasible way forward (new interventions, add ons to current treatment, group, individual)
- Discharge process



Topic Guide

<u>Title: Understanding Long Standing Emotional Difficulties in Primary Care</u>

Patient interviews

Aims and Objectives

Primary aim

MANCHESTER

 To explore via patient and IAPT health professional interviews, the needs and treatment experiences of people with 'long standing emotional difficulties' in primary care.

Study Questions Patients Interview

"What are the treatment experiences of people who are in IAPT treatment with long standing emotional difficulties?"

"What are the needs of people who are in IAPT treatment with long standing emotional difficulties?"

Secondary aims

Patient interviews

- To identify and understand the needs of patients with long standing emotional difficulties in primary care IAPT services.
- To explore the treatment experiences of people who present to IAPT services with long standing emotional difficulties.

Introduction

Aim: To introduce the research and set the context for the proceeding discussion.

- Introduce self
- Introduce the study: What is it about (see aims and objectives above) in connection with NIHR
- Recap on how participant has been selected
- Consent START RECORDING
- Confirm you have gone through information above and that the participant is happy to proceed.

1. Background

Area of enquiry: to introduce the participant to interview process, highlight any background particulars that may inform the interview.

Prompts

Previous Treatments

- Diagnosis
- IAPT treatment
 - where are they up to in treatment
 - -Referral experience (barriers, constraints)

2. Needs

Area of enquiry: To identify and understand the needs of patients with long standing emotional difficulties in primary care IAPT services.

Prompts

- Needs met
- Needs not met
- Expectations
 - Explore Changes Required
 - Explore what changes the patient feels treatment should bring

3. Treatment Experiences

Area of enquiry: To explore the treatment experiences of people who present to IAPT services with long standing emotional difficulties.

Prompts

- Past treatment
 - -Medication
 - -Psychological
- Current treatment experience
 - Frequency of Treatment
 - Sessions offered and session received
 - Group / Individual
 - Reliability of Services
 - Most useful elements, least useful
 - Treatment impact
 - Therapist Relationship

4. <u>Discharge processes</u>

Area of enquiry: To understand needs and patient perspectives on discharge

Prompts

- Expectations
- Discharge needs
- Needs post discharge

- Handover process
- Concerns re: discharge

5. For only those who drop out - Additional Treatment Drop Out Section

Area of enquiry: To understand reasons for treatment drop out

Prompts

- Reasons for drop out
- Therapy Relationship
- Recovery
- Current view on decision to drop out
- Future Plans for Coping / Treatment

Appendix 22 – RAG Developed Conference Poster



NHS National Institute for Health Research



The University of Manchester Identification and research recruitment of an unidentified population of patients with traits of personality disorder in primary care psychological

therapy services (A UK based study)
Ethical Sensitivities Explored and Overcome



ABSTRACT-

The identification of a previously undiagnosed population of people who present with common mental health difficulties (Anxiety and Depression) but also present with the added complexity of personality disorder traits is discussed. The ethical sensitivities of their recruitment to a research study is described. Engagement of key stakeholders and a patient led Research Advisory Group (RAG) guided the solutions to overcome the ethical concerns raised. A sample of narratives from qualitative research data provides further complimentary insight into the highlighted concerns. Solutions for overcoming recruitment barriers for an undiagnosed population are presented. Patient and public involvement was at the heart of overcoming these dilemmas.

METHODS

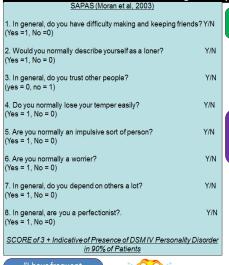
A pragmatic health research approach has been taken. Within this study engagement of patient and public involvement (PPI) has been central in the design, implementation and reporting of the research project. Exploration of the sensitivities and ethical concerns raised were addressed via a series of meetings with service leaders and the RAG, who informed the development of the research protocol and recruitment research materials ensuring they were sensitively written and patient friendly. Qualitative interviews with the primary care psychological therapists (N=28) also further explored the use of diagnostic language and the labelling of personality disorder traits with this largely unrecognised patient group.

RESULTS

A focus on the techniques employed and key principles that took place to overcome the ethical dilemmas and also aid recruitment are described including a sample of the primary care psychological therapist narratives. Despite progress sensitivity and stigma appears to still surround the use of the term 'personality disorder'. Refraining from using the term 'personality disorder traits' by taking a more descriptive approach of traits has ensured recruitment has been achieved sensitively

CONCLUSION

Recruiting patients with traits of personality disorder sub-threshold diagnosis or pre-diagnosis is achievable if careful planning and inclusion of people with lived experience of personality disorder work in collaboration with service raised concerns. PPI at the heart of sensitive recruitment using descriptive non-stigmatising methods (Adapting SAPAS to inform patient recruitment materials for an undiagnosed patient population)





"I find it difficult to fit in" (Q.1,2,3,8)



"I have long standing difficulties in maintaining positive relationships Q 1, 2, 3)



or cope with my problems in ways others might not understand"





Qualitative Data

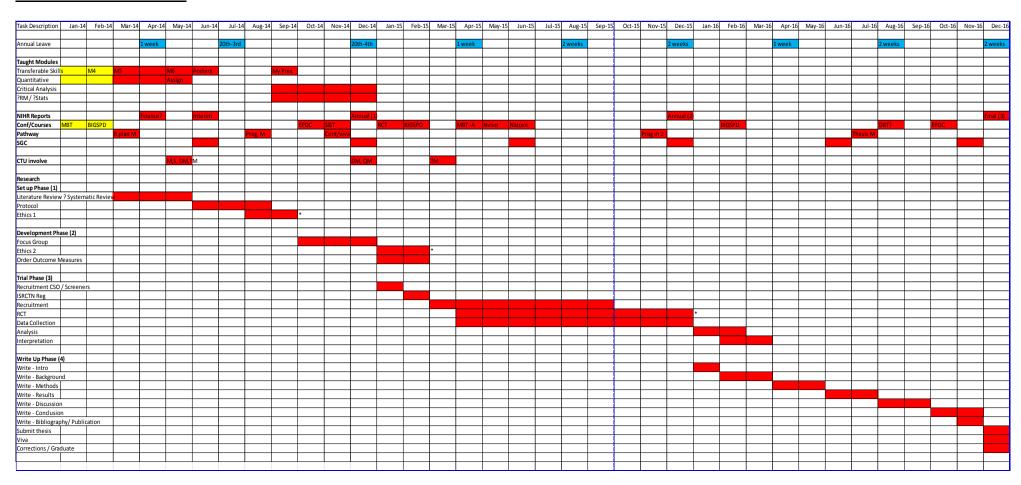
The Label - Personality disorder traits "It brings up images of difficult people "(SP5) "To say there is something wrong with your personality comes a little extreme to some people" (SP30) "It freaks people out" (SP21)

The Descriptive Approach – "I don't think I'd label it as such, I'd say I notice that this is a particular problem, maybe lets try this technique and see if that helps with the issue" (SP10)

References: 1. Craig et al (2006) Developing and Evaluating Complex Interventions: New Guidance. London: MRC. 2. Department of Health (2009) Recognising Complexity: Commissioning guidance for personality disorder services. London: Crown Copyright. 3. Department of Health (2011) Talking Therapies: A four year plan of action. London: Crown Copyright. 4. Moran et al (2000) The prevalence of Personality Disorder among UK primary care attenders. Acta Psychiatr Scand. 102, 52-7. 5. Moran et al (2003) Standardised Assessment of Personality – Abbreviated Scale (SAPAS). British Journal of Psychiatry. 203, 163-64. 6. Paris (2013) Stepped Care: An alternative to routine extended treatment for patients with Borderline Personality Disorder. Psychiatric Services. 64, 1035-1037. Acknowledgements; Academic Supervisory Team – Prof Karina Lovell, Prof John Baker, Dr Tommy Dickinson, Dr Mark Sampson, NIHR Funders. 5 Boroughs NHS FT Involvement Scheme

Appendix 23 - GANTT Project Management Charts

Commencement of PhD



Start of Year 2

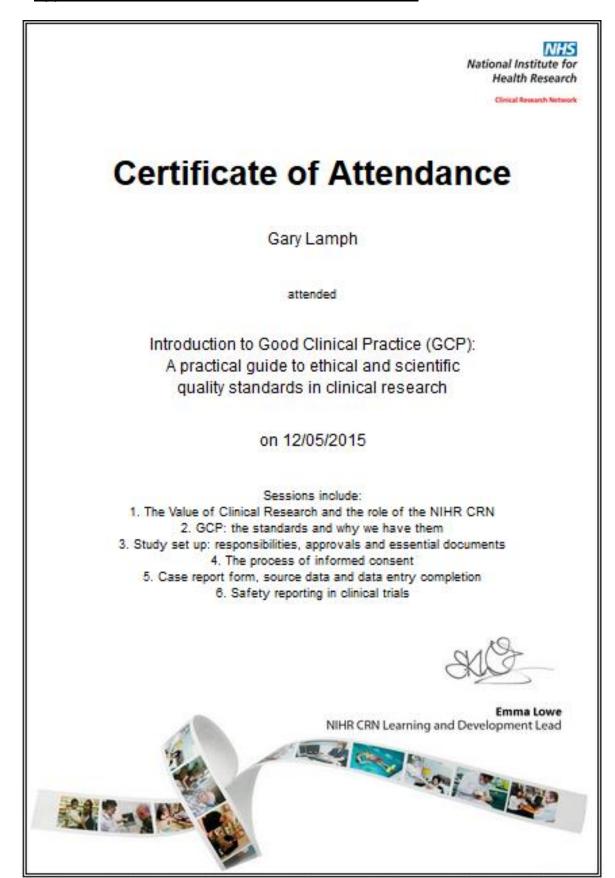
Task Description	Jan-15	Feb-15	Mar-15	Apr-15	May-15	Jun-15	Jul-15	Aug-15	Sep-15	Oct-15	Nov-15	Dec-15
Annual Leave				1 week				2 weeks		1 week		1 week
Taught Modules												
Qualitative Methods												
Oral Presentation												
Critical Analysis												
Other Courses		NatcenQA	Nvivo	GCP								
Conferences (Poster)			BIGSPD									
Clinical Training?												
NIHR Reports				Finance								Annual
Phd Pathway											Yr2 report	
RAG meetings Pr	otocol5	Tguide6										
RSGC meetings												
Research												
Refine Protocol												
Ethics Application												
Lit review Publication												
Study 2 - IAPT Healthcai	re Profes	ssionals										
Recruitment Drive												
Interviews												
Transription and Analys	sis											
Study 3 - Patient Interviews												
Recruitment Drive / Screening												
Interviews												
Transcription and Analysis												
Synthesis, Initial Treatn	nent Ma	nual Deve	opment									

Start of Year 3

Task Description	Jan-16	Feb-16	Mar-16	Apr-16	May-16	Jun-16	Jul-16	Aug-16	Sep-16	Oct-16	Nov-16	Dec-16	
Annual Leave				1 Week			1 Week	1 Week		1 week		1 week	
Courses													
Conferences (Oral)			BIGSPD			BABCP			European				
Clinical Training?													
NIHR Reports				Finance								Annual	
Phd Pathway						Thesis Me	eting				Submit Th	?Viva	
RAG meetings													
Research													
Study 2 - Patient Par	ticipant (Re	cruitment	Anticipate	d to Close	January 20	16)							
Final Interviews					,	-,							
Analysis													
Publication													
Study 3 IAPT Staff Pa	rticipant (R	ecruitmen	t Anticipat	ed to Close	Decembe	er 2015)							
Analysis			•			_							
Publication													
Write up Phase													
Methods													
Intro Background													
Results													
Discussion													
Conclusion													
Bibliography													
Submit Thesis								Ì					
Viva													
Corrections / Gradua	te												
Synthesis, Initial Tre		nual Devel	opment										

Final Write Up Period

Task Description:												
Final Write Up Period	Jan-17	Feb-17	Mar-17	Apr-17	May-17	Jun-17	Jul-17	Aug-17	Sep-17	Oct-17	Nov-17	Dec-17
Abstract												
Chapter 1												
Chapter 2 Methodology												
Chapter 3 Study 1 Scoping												
Review												
Chapter 4 Working Methods												
Chapter 5 IAPT HCP results												
Chapter 6 Patient Result												
Chapter 7 Synthesis												
Chapter 8												
Merge Reference List				·								•
Format												
Print and Bind												



Appendix 25 – List of Conference Presentations and Publications

Conference Presentations

2016

Lamph, G (2016) The development of a feasible and acceptable psychological intervention for people with personality disorder traits in IAPT primary care services (**Oral Presentation**) The British and Irish Group for the Study of Personality Disorder Conference (BIGSPD) Isle of Man.

Lamph G., Lovell, K., Baker, J., Dickinson, T and Sampson, M (2016).

Understanding the Treatment Experience of Patients with Personality Disorder

Traits in Primary Care (**Poster Presentation** *1st Prize Awarded) NIHR

Celebrating Clinical Research Nurses Conference,12th May 2016 (Birmingham).

Lamph, G (2016) Nurses in Research (Symposia Chair and Oral Presentation)

'Mental Health Nurses in Research' (University of Manchester Annual Mental
Health Student Conference) (June 2016)

Lamph G., Lovell, K., Baker, J., Dickinson, T and Sampson, M (2016). The development of a feasible and acceptable psychological intervention for people with personality disorder traits in primary care psychological therapy services. 4th Int. Congress on Borderline Personality Disorder & Allied Disorder, 8 - 10 September 2016 **Poster Presentation** (Vienna, Austria).

Lamph, Gary (NIHR Clinical Doctoral Research Fellow) University of Manchester / 5 Boroughs Partnership NHS Foundation Trust. 2. Ian Cooke 3. Kim Ratcliffe 4. Heather Shepherd 5. Mie Wall 6. Cameron Latham 7. Tina Simon (Research Advisory Group Members, Experts by Experience 5 Boroughs Partnership NHS Foundation Trust) Identification and research recruitment of an unidentified population of patients with traits of personality disorder in primary care psychological therapy services (A UK based study) Ethical Sensitivities Explored and Overcome. 4th Int. Congress on Borderline Personality Disorder & Allied Disorder, 8 - 10 September 2016 Poster Presentation (Vienna, Austria).

Lamph G (2016) The development of a feasible and acceptable psychological intervention for people with personality disorder traits in primary care IAPT psychological therapy services (**Oral Presentation**) (Results) 22nd International Network for Psychiatric Nursing Research Conference (NPNR) RCN, (Nottingham) (September 2016)

Lamph, Gary (NIHR Clinical Doctoral Research Fellow) University of Manchester / 5 Boroughs Partnership NHS Foundation Trust. 2. Ian Cooke 3. Kim Ratcliffe 4. Heather Shepherd 5. Mie Wall 6. Cameron Latham 7. TinaSimon (Research Advisory Group Members, Experts by Experience 5 Boroughs Partnership NHS Foundation Trust) Identification and research recruitment of an unidentified population of patients with traits of personality disorder in primary care psychological therapy services (A UK based study) Ethical Sensitivities Explored and Overcome. 22nd International Network for Psychiatric Nursing Research Conference (NPNR) RCN (Nottingham) Poster Presentation (September 2016).

2015

Lamph, G (2015) Keynote Lecture 'Delivering the 6C's in Mental Health Nursing' (Oral Presentation and Conference Organising Committee Member)

(University of Manchester Annual Mental Health Student Conference)

Lamph G (2015) The development of a psychological intervention for people with personality disorder traits in IAPT services (**Oral Presentation**) 21st International Network for Psychiatric Nursing Research Conference (Manchester)

Lamph G., Lovell, K., Baker, J., Dickinson, T and Sampson, M (2015) The development of an acceptable and feasible for people with personality disorder traits in primary care IAPT services. (**Poster Presentation**) Annual British and Irish Group for the Study of Personality Disorder Conference (Leeds)

Lamph G (2014) E-Learning and Personality Disorder Awareness Training: Does using service user developed video's make e-learning more effective? (**Oral Presentation**) Annual British and Irish Group for the Study of Personality Disorder Conference (Lincoln)

2013

Lamph G (2013) A strategy for Inclusion – Wigan Multi-Agency Personality Disorder Strategy (**Oral Presentation**) Annual British and Irish Group for the Study of Personality Disorder Conference (Belfast)

2012

Lamph, G., Latham, C., Smith, D., Brown, A. and Sampson, M. (2012) Evaluating the impact of a nationally recognised training programme that aims to raise the awareness and challenge attitudes of personality disorder in multi-agency partners (Initial Outcome Data Reported). (**Poster presentation**) Annual British and Irish Group for the Study of Personality Disorder Conference (Manchester)

Lamph G (2012) Nursing Times Award Winner 2011. A Strategy for Inclusion. (Oral presentation Invited as a keynote speaker) St Andrews Health Care Nurse Leadership Conference

2011

Lamph, G., Latham, C., Smith, D., Brown, A and Sampson, M. (2011) Evaluating the impact of a nationally recognised training programme that aims to raise the awareness and challenge attitudes of personality disorder in multi-agency partners. (Study design outlined). **Poster presentation** provided as part of trust wide Research and Audit Conference 2011.

Publications

Lamph G., Sampson, M., Smith, D., Williamson, G., and Guyers, M (2017) Can an interactive e-learning training package improve the understanding of Personality Disorder within mental health professionals? *The Journal of Mental Health Training, Education and Practice*. Submitted for publication

Lamph, G., Latham, C., Smith, D., Brown, A, Doyle, J. and Sampson, M. (2014) Evaluating the impact of a nationally recognised training programme that aims to raise the awareness and challenge attitudes of personality disorder in multiagency partners. *The Journal of Mental Health Training, Education and Practice, 9* (2), 89-100. Paper awarded the Highly Commended Paper Award in the Emerald Literati Network Awards for Excellence in 2015

Lamph, G and Hickey, E (2012) An Inclusive Approach to Personality Disorders. *Nursing Times.* 108, 39, 18-20.

Lamph, G (2011) Raising Awareness of Borderline Personality Disorder and Self-Injury. *Nursing Standard.* 26, 5, 35-40.

Lamph, G (2010) Early Psychosis: Raising Awareness among non-mental health nurses. *Nursing Standard.* 24, 47, 35-40.

Appendix 26 - Research Advisory Group Social Media Work

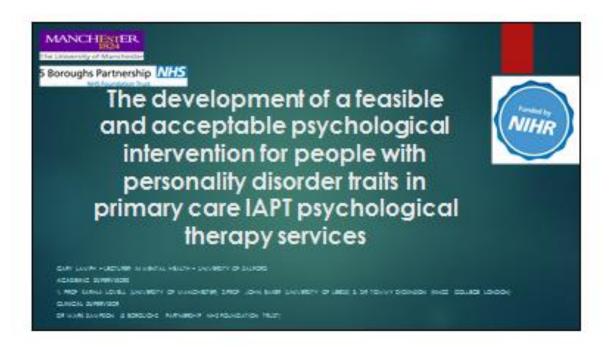
A short video short that highlighted the positive experiences of research involvement in this project and things that are important to them was developed into a video short. The project was entitled 'Positive Patient and Public involvement (PPI) in Research'. This project provided an insight into the values that the research advisory group members felt should be embraced within patient and public involvement. The video has been shared on twitter and received lots of interaction from both health professionals and researchers, including shares from the high profile 'the mental elf @mental_elf' who has 43k followers and NIHR-Involve twitter feed. Recently contact has also been made from the Coordinator of Patient & Public Involvement, Nuffield Department of Primary Care Health Sciences /NIHR CLAHRC Oxford (Collaboration for Leadership in Applied Health Research and Care) who wishes to embed this video into one of her training programmes. It can be viewed following this link;

https://spark.adobe.com/video/kc0sinIHCsp9h

Appendix 27 – Research Governance Overview

In the UK, a research governance framework was developed by the Department of Health (DOH, 2005). This framework inforce's the principle of good research practice in health care and provides health researchers with clear expected standards and responsibilities to follow. This has been put in place to ensure that the institutions supporting the research, the researcher and the sponsors adhere to the necessary safety procedures, responsibilities and standards (DOH, 2005). Research governance is focussed on ensuring that studies are ethical, of a high scientific standard and have procedures in place to ensure the safety and avoidance of harm for all those involved in the research including both research staff and participants (Walsh et al., 2005). Support processes are required if any risks are identified but each unique study will require their own procedures to offer reasonable protection to anyone involved. Plans are required to offer adequate support should any problems arise (Shaw and Barrett, 2006).

Appendix 28 – PhD Results Power Point Presentation





Background

Personality Disorder:

- Stigmatised / Excluded
- Lack of timely/appropriate treatment options
- Escalation in risk / complexity before treatment
- Lack of research for undiagnosed / less complex presentations / shorter term treatments
- Those who present to primary care with co-morbid traits of personality disorder less responsive to treatment.

Why this research is important!

- Addresses a high profile service deficit, gaps in the research and patient need
- Evolved from patient, public and occupational insight
- 1 in 4 GP consultations
- Impact on wider system resources
- Early Intervention (stepped care approach)
- Shapes the way for future research
- Personality disorder in IAPT indicative of poorer outcomes

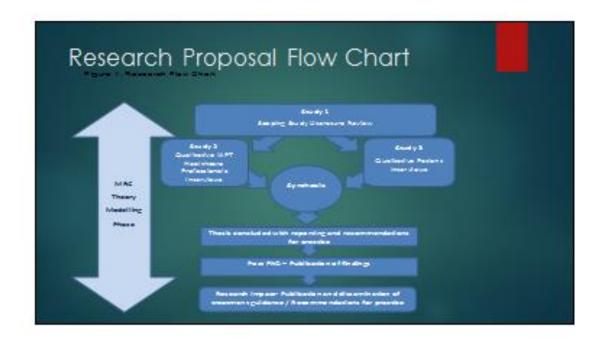
Supportive Emerging Literature Goddard et al (2015)

- "The presence of co-morbid personality difficulties adversely affects treatment outcome among individuals attending for treatment in an IAPT service"
- Routine PD screening encouraged in IAPT to support "More provision of effective, personalised treatment in IAPT"

Research Proposal

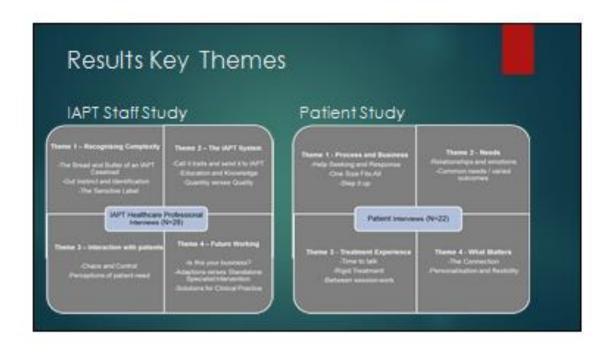
- Preparatory study to develop a treatment manual / recommendations for practice
- ▶ Inter-related series of studies

Overall Aim To improve service provision for people who present to primary care IAPT services with common mental health disorders and co-morbid traits of personality disorder.



Literature Review Results

- Literature review told us very little other than there is a lack of evidence based treatments in primary care IAPT services for this patient group
- Policy indicates there is a need to work more effectively with personality disorder within primary care
- There in no literature relating to the current treatment experiences of this patient group in IAPT services or of their needs



Results - Synthesis Studies 2/3

- Labelling Sensifive label with undiagnosed population and no clear treatment pathway. Professionals Avoid / Patient need to know
- The Business IAPT business like driven by outcomes. Increased complexity in IAPT. Quantity vs Quality. Factory line descriptors (step 2). IAPT cant catch all. CBT often struggles to get to root cause of problems.
- Patient Needs Past experiences important to make sense of. Lock of flexibility in approach. Need to access emotions / offload. Prescriptive models lead to feeling of choos and control. Social and relationships needs to be addressed. Patients not requesting complex interventions, instead interpersonal basics, personalised care, time, flexibility to offload emotions. IAPT staff negatively appraise their skills with patient group. Not about skill is about rigidity of the system. Step 3 more suitable for treatment delivery.

Synthesis Studies 2/3

- Therapist Connection Step 2 challenges in building therapeutic connections. Sals
 and knowledge deficits add to fear and frustration in the workforce. Early contacts
 are when judgements formed. Time to talk is essential.
- Recommendations for practice
- Acceptance personality disorder co-morbidity presents within IAPT populations.
- IAPT workforce willing and feel it is a requirement to make adjustments / adaptions to treatment for this patient group.
- The 'one size fits all' approach is not meeting the needs of this patient group.
- Holistic care is required that is formulation driven and person centred. Reluctance to move away from NICE Anxiety / Depression Treatments.
- Patients report therapist rigidity / Therapists report system rigidity.

Recommendations for Practice

- 1. Education of the IAFT workforce
- Core Curiculum
- Working with Complexity
- Knowledge and Understanding
- Clinical Skills (Tool Box of Adapters)
- 2. Clinical Interventions
- Nice Guidelines Focussed
- Relationships and Repairs
- Identification via SAFAS
- Formulation driven (Individualised treatment glans)
- Adaptions DBT Skills, Problem Solving, Revibility (Official, Consistency, Personalisation)

Recommendations for Practice (2)

- ▶ 3. Provision of treatment at the right level
- Step 2 as start off
- Those not engaging or dropped out should be stepped up earlier
- Needs most likely to be met at Step 3
- If co-morbidity identified bypass Step 2
- Labelling should be avoided (Descriptive Approach)
- ▶ 4. National Recommendations
- Service to support stepping patient group up earlier
- Service level support required to implement education strategy
- Services should support therapist flexibility with patient group
- Increased treatment duration if required should be supported
- A reliable, well communicated service should be provided.

