RECOVERY FROM PSYCHOSIS IN PRIMARY CARE

A thesis submitted to The University of Manchester for the degree of Doctor of Philosophy (PhD) in the Faculty of Medical and Human Sciences

2011

SEAMUS RYAN

SCHOOL OF MEDICINE
CONTENTS

Figures 6
Abbreviations 7
Abstract 8
Declaration 9
Copyright Statement 10
Acknowledgements 11
The Author 12

Chapter 1 Introduction 13
  1.1 Introduction and Objectives 14
  1.2 Psychosis and its impact 14
  1.3 Psychosis and Recovery in Primary Care: Recent Policy Developments 16
  1.4 Recovery: a contested definition 22
    1.4.1 Biomedical Recovery 23
    1.4.2 Psychosocial Recovery 26
    1.4.3 User led Recovery 27
  1.5 Meanings of recovery for different groups 29
    1.5.1 Lay approaches to recovery 29
    1.5.2 SUs’ and carers’ approaches to recovery 30
    1.5.3 Professionals’ approaches to recovery 31
  1.6 Content of Chapters 32

Chapter 2 Systematic Literature Review & Critical Interpretive Synthesis 34
  2.1 Systematic Literature Review 35
  2.2 Critical Interpretive Synthesis 40
  2.3 Search Strategy 45
  2.4 Examining the constructs used in each of the papers 46
    2.4.1 Recovery as an outcome 48
<table>
<thead>
<tr>
<th>2.4.2</th>
<th>Recovery as a personal process</th>
<th>56</th>
</tr>
</thead>
<tbody>
<tr>
<td>2.4.3</td>
<td>Recovery as a program of care</td>
<td>64</td>
</tr>
<tr>
<td>2.5</td>
<td>Overall Synthesis Output</td>
<td>71</td>
</tr>
<tr>
<td>2.6</td>
<td>Discussion</td>
<td>73</td>
</tr>
<tr>
<td>2.7</td>
<td>Conclusion</td>
<td>81</td>
</tr>
</tbody>
</table>

**Chapter 3**

<table>
<thead>
<tr>
<th>3.1</th>
<th>Social Constructionism</th>
<th>85</th>
</tr>
</thead>
<tbody>
<tr>
<td>3.2</td>
<td>Postpsychiatry</td>
<td>88</td>
</tr>
<tr>
<td>3.3</td>
<td>Positive Clinical Psychology</td>
<td>89</td>
</tr>
<tr>
<td>3.4</td>
<td>Autonomy Enhancement</td>
<td>92</td>
</tr>
</tbody>
</table>

**Chapter 4**

<table>
<thead>
<tr>
<th>4.1</th>
<th>Theoretical background of the methodology</th>
<th>97</th>
</tr>
</thead>
<tbody>
<tr>
<td>4.1.1</td>
<td>Using a qualitative approach</td>
<td>97</td>
</tr>
<tr>
<td>4.1.2</td>
<td>Semi-structured interviews</td>
<td>98</td>
</tr>
<tr>
<td>4.1.3</td>
<td>Focus Groups</td>
<td>101</td>
</tr>
<tr>
<td>4.1.4</td>
<td>Interviewer’s background and training</td>
<td>103</td>
</tr>
<tr>
<td>4.1.5</td>
<td>Reliability</td>
<td>104</td>
</tr>
<tr>
<td>4.1.6</td>
<td>Validity</td>
<td>105</td>
</tr>
<tr>
<td>4.2</td>
<td>Empirical Methodology</td>
<td>107</td>
</tr>
<tr>
<td>4.2.1</td>
<td>Recruitment Strategy</td>
<td>107</td>
</tr>
<tr>
<td>4.2.2</td>
<td>Ethical Issues</td>
<td>111</td>
</tr>
<tr>
<td>4.3</td>
<td>Analysis</td>
<td>111</td>
</tr>
<tr>
<td>4.3.1</td>
<td>Grounded Theory: Its historical background</td>
<td>112</td>
</tr>
<tr>
<td>4.3.2</td>
<td>Modified Grounded Theory</td>
<td>113</td>
</tr>
<tr>
<td>4.3.3</td>
<td>Limitations of Charmaz’s Modified Grounded Theory</td>
<td>114</td>
</tr>
<tr>
<td>4.3.4</td>
<td>Application to the PhD: data analysis</td>
<td>116</td>
</tr>
</tbody>
</table>
Chapter 5 General Practitioners’ views on Recovery in Primary Care

5.1 Importance of continuity of care
5.2 Central role of support networks
5.3 Supporting families
5.4 Informational discontinuity across the interface
5.5 Recovery conceptualised as social functioning or biomedical recovery
5.6 Medication as a recovery tool
5.7 Self-perception of personal expertise
5.8 Perceived importance of comorbid drug misuse

Chapter 6 Service Users’ views on Recovery in Primary Care

6.1 Psychosocial or “whole person” approach to recovery
6.2 Greater autonomy and input for SUs
6.3 Shift responsibility for psychosis from secondary to primary care
6.4 Wider societal context: Stigma & Social Exclusion

Chapter 7 Results of Mixed Focus Groups

7.1 Recovery conceptualisations
7.2 Barriers to promoting recovery in primary care
7.3 Recovery-orientated services at the level of individual GPs
7.4 Recovery-orientated services at the level of the primary care system
7.5 Introducing change to primary care

Chapter 8 Discussion

8.1 Summary of empirical findings
8.2 Theoretical Model: Recovery from Psychosis in Primary Care
8.3 Relevance of Conceptual Framework
8.4 Meeting the research objectives
8.5 Limitations of the PhD
8.6 Implications for Practice 243
8.7 Implications for Future Research 248
8.8 Implications for Policy 250

References 256

Appendices
1  NICE Guidance on Schizophrenia (2009) 280
2  Databases used in Literature Search 282
3  Papers included in the CIS 284
4  CIS Findings: Output Table 289
5  Topic Guide for interviews and focus groups 308
6  Participant Information Sheets & Consent Forms 312
7  Coding of GP interviews 324
8  Coding of SU interviews 329
9  Demographic details of GP participants 339
10 Demographic details of SU participants 340

Word Count: 79,972
FIGURES

1. Theoretical model of recovery from psychosis in primary care 232
<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Full Form</th>
</tr>
</thead>
<tbody>
<tr>
<td>CBT</td>
<td>Cognitive Behavioural Therapy</td>
</tr>
<tr>
<td>CIS</td>
<td>Critical Interpretive Synthesis</td>
</tr>
<tr>
<td>CPN</td>
<td>Community Psychiatric Nurse</td>
</tr>
<tr>
<td>GP</td>
<td>General Practitioner</td>
</tr>
<tr>
<td>GPS</td>
<td>General Practitioner without a special interest</td>
</tr>
<tr>
<td>GPwSI</td>
<td>General Practitioner with a Special Interest in Mental Health</td>
</tr>
<tr>
<td>NHS</td>
<td>National Health Service</td>
</tr>
<tr>
<td>NICE</td>
<td>National Institute for Health and Clinical Excellence</td>
</tr>
<tr>
<td>PCT</td>
<td>Primary Care Trust</td>
</tr>
<tr>
<td>SU</td>
<td>Service User</td>
</tr>
<tr>
<td>UK</td>
<td>United Kingdom</td>
</tr>
<tr>
<td>WOS</td>
<td>Web of Science</td>
</tr>
</tbody>
</table>
This thesis entitled ‘Recovery from psychosis in primary care’ was submitted by Seamus Ryan to The University of Manchester for the degree of Doctor of Philosophy (PhD) in the Faculty of Medical and Human Sciences on June 29th, 2011. It aimed to explore personal definitions and experiences of recovery from psychosis for service users (SUs) and general practitioners (GPs), as well as identify factors which might promote or hinder recovery in a primary care context, and identify interventions which might be required to enhance the promotion of recovery in primary care. A review of existing literature pertaining to the concept of ‘recovery’ was undertaken, and differing conceptualisations of ‘recovery’ were analysed and synthesised through the use of a Critical Interpretive Synthesis. Semi-structured interviews were conducted with 24 GPs and 20 SUs. Two mixed focus groups were also carried out as follow-ups with 5 GPs and 5 SUs. The data was analysed using a modified grounded theory approach. Factors reported to promote recovery in primary care included: autonomy, choice, and empowerment for SUs in treatment decisions; signposting of peer-supported groups and services by GPs; enhancement of SUs’ social support networks by GPs; advocacy and independent analysis provided by GPs; a whole-person approach to recovery (social and biomedical); less stigmatising environment of primary care; and families of SUs and GPs working together in collaboration, often having built up a trusting relationship over time through continuity of care. The following potential interventions for enhancing recovery in primary care were identified: SU-led training for GPs regarding psychosis knowledge and attitudes; raising GPs’ awareness of local services and groups by encouraging service managers and group organisers to visit GP practices; establishing GP peer supervision forums; improving access to GPs with a Special Interest in Mental Health (GPwSIs); shifting a greater degree of responsibility for recovery from psychosis to primary care from secondary care; reinforcing amongst GPs an awareness of the important role which primary care can play in promoting recovery; facilitating continuity of care within large practices where feasible; and encouraging GPs to alert SUs to seriousness of potential side-effects of medication before and during treatment. The implications of the findings for policy, practice, and future research were discussed.
DECLARATION

No part 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.
COPYRIGHT STATEMENT

i. The author of this thesis (including any appendices and/or schedules to this thesis) owns certain copyright or related rights in it (the “Copyright”) and s/he has given The University of Manchester certain rights to use such Copyright, including for administrative purposes.

ii. Copies of this thesis, either in full or in extracts and whether in hard or electronic copy, may be made only in accordance with the Copyright, Designs and Patents Act 1988 (as amended) and regulations issued under it or, where appropriate, in accordance with licensing agreements which the University has from time to time. This page must form part of any such copies made.

iii. The ownership of certain Copyright, patents, designs, trade marks and other intellectual property (the “Intellectual Property”) and any reproductions of copyright works in the thesis, for example graphs and tables (“Reproductions”), which may be described in this thesis, may not be owned by the author and may be owned by third parties. Such Intellectual Property and Reproductions cannot and must not be made available for use without the prior written permission of the owner(s) of the relevant Intellectual Property and/or Reproductions.

iv. Further information on the conditions under which disclosure, publication and commercialisation of this thesis, the Copyright and any Intellectual Property and/or Reproductions described in it may take place is available in the University IP Policy (see http://documents.manchester.ac.uk/DocuInfo.aspx?DocID=487), in any relevant Thesis restriction declarations deposited in the University Library, The University Library’s regulations (see http://www.manchester.ac.uk/library/aboutus/regulations) and in The University’s policy on Presentation of Theses.
ACKNOWLEDGEMENTS

I would like to thank my supervisors - Professor Helen Lester and Professor Anne Rogers - for their invaluable and expert knowledge, direction, and support throughout the course of this PhD.

I would like to thank all those who gave up their time to participate in interviews and focus groups during this research.

I would like to thank the School of Medicine for providing the Strategic Scholarship funding which made this PhD possible.

I also wish to thank my family and friends for their constant support over the course of this PhD.
THE AUTHOR

The author holds a first class honours degree in Psychology from Trinity College, University of Dublin (2006), which involved a research project entitled ‘The moderating effect of processing depth on the relationship between counterfactual thoughts and self-efficacy’, supervised by Dr. Kevin Thomas.

The author also holds a master’s degree in Psychology from the University of Manchester (2007), which involved a research project entitled ‘Motivation to confabulate amongst those scoring high on self-discrepancy and/or schizotypy measures’, supervised by Dr. Sara Tai and Professor Richard Bentall.

The author has carried out research in the field of experimental cognitive psychology while working as a Research Assistant at the School of Psychology, Trinity College Dublin in 2006.

The author has conducted service-related research as an Assistant Psychologist for Pennine Care NHS Foundation Trust, evaluating psychological-mindedness training for psychiatric ward staff in 2010/11. As part of this Assistant Psychologist role, the author also provided psychological therapy in both primary and secondary care for service users experiencing anxiety.

The author has volunteered for two Manchester-based mental health charities - as a helpline advisor for Anxiety UK, and as a facilitator of computerised cognitive behavioural therapy for Self-Help Services.

The author will begin training as a Clinical Psychologist (DPsychSc) in September 2011 at the National University of Ireland, Galway, and will be employed by the Health Service Executive, West.
Chapter 1

Introduction
1.1 Introduction & Objectives

The aim of this PhD was to explore what recovery from psychosis means to service users (SUs) and general practitioners (GPs), as well as exploring what factors might promote or hinder recovery in a primary care context, and what interventions might be required to enhance the promotion of recovery in primary care settings. This PhD was undertaken as a response to the perception that there has been limited input from primary care in providing recovery-oriented mental health services for SUs who are experiencing psychosis, or who have experienced psychosis in the past. It was also undertaken due to the lack of research on this topic to-date (see the systematic literature review for further details).

The objectives of the PhD were as follows:

1. Explore meanings and definitions of recovery from psychosis for individual SUs.
2. Explore meanings and definitions of recovery from psychosis for individual GPs.
3. Explore SUs’ personal experiences of recovery in the context of primary care.
4. Explore GPs’ personal experiences of working with psychosis in their own practices.
5. Identify factors which promote recovery in primary care.
6. Identify factors which hinder recovery in primary care.
7. Identify potential interventions which aim to enhance the provision of GP services for SUs who have experienced psychosis.

This chapter introduces the background context to the research area. The concepts of psychosis and recovery are introduced and situated within the context of current United Kingdom (UK) primary care policy. An overview of the content of all the chapters in this PhD is provided in the final section of this introductory chapter.

1.2 Psychosis and its impact

Psychosis is a term used to refer to the most severe psychiatric disorders, in which the individual
to some extent can be said to experience a loss of contact with reality. Psychosis may involve hallucinations, delusional beliefs, or personality changes, and these experiences may be accompanied by unusual behaviour, or difficulty with social interaction and day-to-day functioning. The symptoms of psychosis are most commonly associated with the psychiatric diagnosis of schizophrenia, although people with a wide variety of diagnoses may also experience psychotic symptoms, including bipolar disorder and severe clinical depression such as psychotic depression. Three percent of the population in the UK is affected by schizophrenia, bipolar disorder, and other forms of psychosis (Bird, 1999), with an estimated one in two hundred people having experienced psychosis within the past year (McManus et al., 2009). This PhD used the broad umbrella definition of psychosis, covering a number of experiences associated with the aforementioned psychiatric diagnoses. The SUs invited to participate in this research had experienced psychosis in this broad sense.

One justification for attempting to promote recovery from psychosis in primary care is that the annual economic and social costs of mental illness in England are estimated to be greater than £105 million (Centre for Mental Health, 2010). Roughly half of this figure includes the cost of health and social care and the loss of economic output. The other half of this estimated figure represents the imputed monetary valuation of human costs such as reduced quality of life. A humanitarian justification for attempting to promote recovery is that psychosis can be intensely distressing for the three percent of individuals who experience it, as well as impacting upon their family and friends. The first few years after onset can be particularly upsetting, and chaotic, and there is a higher risk of suicide. Once an acute episode is over, there are often other problems such as discrimination, social exclusion, a reduction in opportunities to get back to work or study, and problems making new relationships (National Institute for Health and Clinical Excellence [NICE], 2009). The employment rate for those with schizophrenia in the UK has been estimated to be only 13% (Marwaha et al., 2007). Also, people with psychosis die an average of 25 years earlier than the general population (Miller, Paschall & Svendsen, 2006). In addition, psychosis is still associated with considerable stigma and limited public understanding (ONS, 2008).
1.3 Psychosis and Recovery in Primary Care: Recent Policy Developments

The important role which primary care can play in the provision of services for people with psychosis is becoming increasingly recognised. Up to an estimated 30% of people with psychosis may be seen solely in primary care in the UK (Kingsland & Williams, 1997; Kendrick et al., 2000). The term “primary care” can represent a range of services provided by a number of different healthcare professionals. These professionals include GPs, practice nurses, and allied healthcare professionals such as psychological therapists. However, for the purposes of this PhD, the usage of the term “primary care” will equate to “general practice”, i.e. the services provided directly by a GP rather than by other primary care health professionals. The decision to focus solely on GPs was taken for a number of reasons. It was felt that a PhD focusing on a number of different primary care professional groups would require resources and time beyond the scope of a PhD. It was also felt that GPs were the professionals within primary care who had most frequent and continuous contact with SUs recovering from psychosis, and their families. Additionally, GPs were identified as the most powerful professional group within primary care, in terms of making decisions regarding mental health care and the provision of psychosis services. Therefore, the exploration of GPs’ views regarding recovery from psychosis in primary care was prioritised for this PhD.

Although, the focus of this PhD is on the role of GPs in providing recovery-oriented services for psychosis in primary care, the important roles of practice nurses and psychological therapists must also be acknowledged. A national survey of practice nurse involvement in mental health interventions found that practice nurses play a significant role in the assessment and treatment of mental health problems (Gray et al., 1999). A majority of practice nurses (61%) in the UK reported administering depot antipsychotics at least once a month. Over half of those who administered depots, also monitored SUs for side-effects. Around 30% of practice nurses also reported being in contact with mental health professionals as part of their work, most frequently with community psychiatric nurses (CPNs) and counsellors.
Psychological therapists have also seen a much expanded role recently regarding the provision of mental health services in primary care settings, with the national roll-out of “Improving Access to Psychological Therapies”. This has enabled a huge increase in the psychological therapist workforce with both high-intensity therapists and psychological wellbeing practitioners providing psychological therapies for those experiencing depression and anxiety in primary care settings (Department of Health, 2008). Cognitive behavioural therapy (CBT) practitioners and clinical psychologists may provide psychological interventions for psychosis, but this is only recommended at a secondary care level (NICE, 2009).

GPs are generalists by definition, and few have undertaken specialist mental health training. GPs’ views on mental health problems such as psychosis are generally closer to those held by the lay person, in contrast to the approach employed by many psychiatrists which is more fundamentally biomedical (Lester, Glasby & Tylee, 2004). The views of practice nurses regarding mental health are generally even closer again to the lay perspective (Crosland & Kai, 1998). Less than 35% of GPs in Britain have had continuing primary care mental health training (Kerwick et al., 1997), while only 2% of practice nurses have had training specifically related to mental health (Crosland & Kai, 1998). GPs have traditionally deemed the treatment of people with psychosis to be beyond their remit (Lester, Tritter & Sorohan, 2005a). As a result, SUs experiencing psychosis tend to be referred to specialist secondary care services for diagnosis, treatment, and follow-up. The less specialised nature of general practice may lead to less awareness of psychosis-related issues, and coherent theoretical approaches to recovery are not always evident amongst GPs. However, even though some GPs may lack specialist knowledge, SUs are more satisfied with GP care than psychiatric care precisely because GPs views on mental health are closer to lay views, and are somewhat distanced from psychiatric views about diagnosis (Pilgrim & Rogers, 1993). SUs also prefer GPs to psychiatrists because of GPs’ greater perceived familiarity with SUs, their problems, their families, and their background; the continuity of care available; and GPs’ listening skills (Lester et al., 2005a). This desire amongst SUs for greater GP involvement in psychosis care was another reason why this PhD was conducted. As an increasing number of SUs are seen in primary care, a viable model of recovery from psychosis in primary care has yet to be
identified. The PhD was envisaged as a way of exploring the possibilities for greater GP involvement in directly providing care for those experiencing psychosis, as well as the challenges which this approach might present.

National Health Service (NHS) policy changes implemented in 2004 as part of the “Quality and Outcomes Framework” have increased the profile of treatment of psychosis in primary care. GPs are now encouraged to develop a register of their SUs who have psychosis, arrange for an annual physical health review with each of these SUs, develop a comprehensive mental health care plan with each SU, and monitor the blood levels of SUs taking Lithium (NHS Employers & General Practitioners Committee of the British Medical Association, 2008).

Recently published guidance by the NICE on the treatment of schizophrenia also specify a role for GPs and other primary healthcare professionals (NICE, 2009). NICE guidance suggests that the physical health of people experiencing psychosis should be monitored at least once a year, with a focus on their increased risk of cardiometabolic disease, i.e. cardiovascular disease and diabetes. According to these current NICE guidelines, GPs are also required to urgently refer all people with a first presentation of psychotic symptoms to a local community-based secondary care mental health service (e.g. early intervention service, community mental health team, crisis resolution and home treatment team). SUs should be referred irrespective of the person’s age or the duration of untreated psychosis, although in some geographical areas SUs are referred to the Child and Adolescent Mental Health Service if they are under 16 years of age. NICE also recommends that SUs should be given the option of returning to primary care for further management once their “symptoms have responded effectively to treatment and remain stable” (NICE, 2009, p.15).

Current NICE clinical guidelines for the treatment and management of schizophrenia emphasise the need for promoting recovery in primary care, and for the first time the guidelines have included an entire set of recommendations on how to promote recovery in primary care (NICE, 2009), see Appendix 1. The exact meaning of “recovery” as used in the NICE guidance is not
clear, although the emphasis of the guidelines on management and treatment of symptoms implies that the meaning may be more biomedical than user-led. However, elsewhere in the current NICE guidance there is evidence that the user-led approach to “recovery” has been taken on-board by current best-practice advisors and policy-makers. For example, more “person-centred care” is explicitly advised in the NICE guidance:

“Treatment and care should take into account service users’ needs and preferences. People with schizophrenia should have the opportunity to make informed decisions, including advance decisions and advance statements, about their care and treatment, in partnership with their healthcare professionals…Good communication between healthcare professionals and service users is essential. It should be supported by evidence-based written information tailored to the service user's needs” (NICE, 2009, p.7).

References to “recovery” in the NICE guidance for the management of bipolar disorder have the sole meaning of remission of psychotic symptoms following an acute episode of psychosis (NICE, 2006). The different approaches to recovery within the NICE guidance demonstrates the lack of clarity regarding how recovery from psychosis is conceptualised. This PhD will aim to clarify conceptualisations of recovery from psychosis, with particular reference to primary care.

In terms of the role of primary care in managing bipolar disorder, NICE recommends that annual physical health reviews be undertaken (NICE, 2006). SUs should be referred to secondary care services if the degree of risk increases, or if there is an acute exacerbation of symptoms. The provision of continuity of care for SUs experiencing bipolar disorder is recommended, either in primary or in secondary care. Integrated care programmes run collaboratively by primary and secondary care organisations are also recommended for SUs experiencing bipolar disorder. It is evident from this guidance, that GPs have an important and recommended role to play in regularly reviewing the mental state and the social functioning of SUs who have experienced psychosis.

The UK Government’s recent draft legislation on changing the structure of the NHS is also an
important development in terms of the provision of care for psychosis in a primary care setting. The Health and Social Care Bill (Department of Health, 2011a) proposes to shift control for the commissioning of secondary care services from Primary Care Trusts (PCTs) and Strategic Health Authorities to GP consortia. Under this new arrangement, GPs would have a much greater role in commissioning mental health services from secondary care providers. This more powerful role for GPs would bring with it additional opportunities for the promotion of recovery-oriented services, as well as potential threats to mental health services in primary and secondary care. There would be an increased responsibility on GPs to be more aware of the needs of SUs experiencing psychosis. Greater knowledge and understanding of psychosis amongst GPs, as well as a greater awareness of the implications of providing recovery-oriented services in primary care, could be particular beneficial for both GPs and SUs in this rapidly-evolving policy context.

The precursor to the Health and Social Care Bill was the Coalition Government’s White Paper called “Liberating the NHS: Equity and Excellence” (Department of Health, 2010). This White Paper introduced policy developments which have also increased the need to develop recovery-oriented services for psychosis in primary care settings. For example, the Government’s new healthcare policy proposals emphasise the need for patient choice and control over the treatment they receive in primary care. The first stated goal of the White Paper was for patients to have “more choice and control, helped by easy access to the information they need about the best GPs and hospitals. Patients will be in charge of making decisions about their care” (p.1).

SU choice and input into treatment decisions is also a key element of recovery-oriented services for psychosis. Thus, the introduction of more recovery-oriented services in primary care could provide a way of facilitating the increased patient choice and control envisaged by “Liberating the NHS” in 2010 and the Health and Social Care Bill in 2011.

The White Paper also suggests that the measurement of clinical outcomes should be more wide-ranging than traditional symptom-based approaches to outcome measures. It makes particular
reference to mental health outcomes in this regard, referring to the need to take account of patient-reported outcomes and the patients’ broader experience of the treatment they receive: “the effectiveness of the treatment and care provided to patients – measured by both clinical outcomes and patient-reported outcomes; the safety of the treatment and care provided to patients; and the broader experience patients have of the treatment and care they receive…The criteria used will ensure that we do not exclude outcomes for key groups and services such as children, older people and mental health” (p.22).

This recent policy emphasis on SU involvement in defining how mental health outcomes are measured, has particular relevance for this PhD. The need to involve SUs in defining what recovery means, has obvious implications for primary care services provided to SUs experiencing psychosis. An exploration of what recovery means in a primary care setting, and how recovery-oriented services might be implemented in primary care, could prove timely in this current policy context.

The enhanced role for GPs in commissioning services is expected to occur alongside a shift in responsibility for mental health services and psychosis care from secondary care to primary care. A shift to primary care, a greater focus on recovery, and the promotion of independence and choice have all been identified recently by the Joint Commissioning Panel for Mental Health (2011) as a likely consequence of GP commissioning. The Joint Commissioning Panel for Mental Health represents the consensus views of the Royal Colleges of General Practitioners and Psychiatrists; SU interest groups such as MIND, the National Involvement Partnership, National Survivor and User Network, and Rethink Mental Illness; and organisations representing other mental health professionals such as psychologists, nurses and social workers.

“The mental health service of tomorrow is likely to be far more focused in primary care and community settings, to work more collaboratively with partner agencies across sectors and professional boundaries, to have a greater emphasis on prevention and promotion of mental wellbeing, to support a recovery focus, to draw much more on the contributions of other sectors towards this end, and to focus far more on enabling self-management and choice. It will be
required to balance personalisation and the promotion of independence and choice with actions to address inequalities in mental health” (p.3-4, Executive Summary).

The Government and the Department of Health published a cross-departmental document in February 2011 outlining their policy proposals in the area of mental health. It was entitled the “Mental Health Strategy” or “No Health Without Mental Health: A Cross-Governmental Mental Health Outcomes Strategy for People of All Ages” (Department of Health, 2011b). This policy document replaced the previous Government’s mental health policy entitled “New Horizons” (Department of Health, 2009). The current “Mental Health Strategy” places a greater emphasis on the role of primary care in mental health outcomes. This enhanced role for primary care and for GPs can be partly attributed to the current Government’s proposals regarding GP commissioning, as well as to the continuing roll-out of services associated with the “Improving Access to Psychological Therapies” program in primary care. However, there remains a scarcity of references in the recent policy document to the potential role of primary care in promoting recovery from psychosis. The only direct reference to the role of primary care in psychosis care is in terms of providing physical health checks for people with severe mental health problems as an indicator for the “Quality and Outcomes Framework”. This absence is an important omission, and suggests that the role of primary care remains somewhat unrecognised at a policy level. However, the policy document does point towards the need for SUs experiencing severe mental health problems to receive care in the least restrictive environment possible, including in their own homes or alternative settings. This policy development may potentially encourage service providers to ensure that SUs receive high quality care and treatment in less stigmatised, less restrictive, and more accessible settings such as GP practices. This PhD will examine the potential for primary care to provide such a setting for SUs to recover within.

1.4 Recovery: a contested definition

The definition of recovery is hotly contested by different social movements, interest-groups, professional bodies, governmental agencies, and individuals in the mental health arena. This has
caused problems for researchers and policy makers who might attempt to define, investigate and implement possible theories and processes regarding recovery from psychosis. It is difficult for researchers to ensure the validity and reliability of their studies in this area, particularly when trying to quantify recovery as an outcome measure. Similarly, policy makers may find it difficult to implement policies which rest on user led recovery-based principles, due to a lack of specificity. Individual SUs, carers, and health professionals develop their own particular definition of what recovery means to them, thus rendering the construction of a singular concept of recovery difficult (Craig, 2008). These aforementioned social groups do not agree on a single coherent account of what recovery from psychosis means. Certain preferences and biases within particular groups may also be observed.

There has been a relative lack of research on the definitions and the processes of recovery from psychosis in primary care specifically. This lack of primary care research may not be surprising given the relatively recent appearance of the recovery-orientated approach, and the tendency to associate psychosis with secondary care services.

Pilgrim (2008) outlined three main competing broad approaches to recovery – the biomedical, the psychosocial, and the user-led approaches. Pilgrim’s examination of recovery as a polyvalent concept was particularly relevant for this PhD, as it examined recovery in a UK context, and in relation to current mental health policy.

1.4.1 Biomedical Recovery

One approach to recovery is represented by biomedicine. This approach to recovery (or to “treatment”) incorporates two views of recovery from psychosis. Recovery may be seen as the intended consequence of a wide range of effective treatments. These medical interventions depend on their skilful application by a practitioner, and psychosis is seen as a biologically determined illness (Pilgrim, 2008). Recovery from psychosis may also develop spontaneously and naturally without the need for treatment. According to one version of the biomedical
approach, the person is conceptualised as a patient recovering from an illness, so that recovery is the outcome of successful treatment.

The position of the biomedical approach in Western psychiatric culture has been strengthened over the past two decades with advances in the fields of genetics and neuro-imaging. An important study linking psychosis with genetics found that an identical twin whose other twin has a diagnosis of schizophrenia stands a 48% risk of also experiencing psychotic symptoms (Gottesman, 1991). What that study clearly illustrated was that psychosis has both a social and a biological causal component. The presence of a gene called catechol-O-methyltransferase on chromosome 22 has been linked to a near-doubled risk of psychosis. This gene depletes the amount of dopamine in the frontal lobe, leading to hallucinations and impairment of reality checking (Weinberger et al., 2001). The search for a neural/biological source of psychosis has been aided by the recent development of scanning technologies, with the first computer assisted tomography study into psychosis being published by Johnstone et al. (1976) and the first magnetic resonance imaging study in the area published by Smith et al. (1984). However, the exact biological component of psychosis remains unknown, although ventricular enlargement has been reported in 80% of psychosis neuro-imaging studies (Shenton et al., 2001).

Since the advent of anti-psychotic drugs in the mid-1950’s, the biomedical approach has been able to use research highlighting the effectiveness of such medication in order to support biological theories for the aetiology of psychosis. However, antipsychotics do not have the desired effect of leading to recovery for all SUs, and the side effects of such treatment regimes can cause added distress for SUs. Possible side-effects of typical antipsychotics such as chlorpromazine and haloperidol include sedation, dry mouth, liver toxicity, constipation, urinary retention, and weight gain (Diaz, 1996). Newer atypical antipsychotics can also lead to side-effects such as weight gain, as well increased risk of diabetes and heart disease (Ucok & Gaebel, 2008). Nevertheless, the use of medication to treat psychosis has allowed psychiatrists to allay the suspicions of many professionals in other medical specialisms that psychiatry is not a “true” medical science. There is an unofficial hierarchy of specialisations within the medical profession,
with neurosurgery often viewed by medical practitioners themselves as being at the summit, while psychiatry and general practice are commonly considered by doctors to be at the bottom of this hierarchy (Llewellyn, 1997). Psychiatrists can defend their desire to be granted parity of esteem with their counterparts in neurosurgery for example, due to their apparent treatment of a biological defect with chemicals. It may be argued that the use of psychiatric medication and the development of the biomedical approach to recovery from psychosis can be partially explained by professional power politics within the medical profession and the health service.

Two important studies have been undertaken in the past 25 years which have examined rates of recovery from psychosis. Both studies defined recovery from psychosis as an outcome measure. Firstly, the *Vermont Longitudinal Study of Persons with Severe Mental Illness* (Harding et al. 1987) found that 68% of 262 long-stay patients improved considerably or recovered 25 years after their first assessment. The successful intervention used was a rehabilitation and community aftercare programme. Recovery was indicated by outcomes such as experiencing slight or no symptoms, not having been in hospital in the past year, having close relationships, living independently, and being employed. This finding challenged the previous consensus of therapeutic pessimism in relation to recovery from psychosis. However, the comparatively very high rates of recovery found in this study have been called into question due to differences in definitions between studies regarding what exactly recovery entails (Harrison & Mason, 1993). A review of 20th century outcome studies on schizophrenia by Warner (1994) concluded that recovery rates did not improve over the course of the century, despite medical and pharmaceutical advances. Eighty-five outcome studies of schizophrenia conducted between 1904 and 1991 indicated that complete recovery rates remained at approximately 20-25 per cent and social recovery rates at approximately 40-45 per cent. Interestingly, the World Health Organisation (WHO) conducted the International Pilot Study of Schizophrenia (WHO, 1973) which found that patients in developing countries had better outcomes at two and five year follow-ups than patients in more economically developed Western countries. Despite a lack of psychiatric services and interventions in developing countries, recovery rates from psychosis are higher than in the developing world. This finding was not congruent with a biomedical approach.
to recovery.

Secondly, a 15 and 25 year follow-up study (Harrison et al., 2001) of three cohorts in 18 countries also found significant cross-cultural variations in recovery, with an average of over 50% improving significantly. The authors of that study believed that the heterogeneity in the course of schizophrenia and in the recovery rates across locations “challenges conventional notions of chronicity and therapeutic pessimism” (p.516).

Possible explanations for superior rates of recovery in developing countries include their stronger familial supportive networks with less emphasis on individual performance (Kua et al., 2003), as well as the fact that developing countries are generally more “medically pluralistic” (Halliburton, 2004). In many of these countries multiple medical systems co-exist and are available, allowing people to try out a variety of therapeutic options and choose one that suits them best.

### 1.4.2 Psychosocial Recovery

Apart from the biomedical approach to recovery, a second view of recovery has become known as the psychosocial approach. This approach emphasises the importance of teaching psychological or social skills to the person recovering. This training is implemented with the intention that the SU can integrate back into society and avoid a return to hospital. Success is contingent on the SU complying with the expectations of health and/or social care professionals (Pilgrim, 2008). Personalised plans are formulated to enhance the skills of SUs, and the SU is helped to rehabilitate and recover in this manner. Diagnosis and drug treatments are given less emphasis in this approach. The person is seen as recovering from impairment, so that recovery is the outcome of successful rehabilitation.

Critics of the psychosocial approach to recovery point out that the approach’s proponents generally do not concede that psychiatry itself contributes to stigmatisation or that it is a tool of social control (Mueser et al., 2002). Professionals following the psychosocial approach still focus
on the inherent defects and pathologies of the SU. This modern psychosocial approach focuses on environmental and social aspects of recovery, yet it retains the view that psychiatrists should hold the right to intervene as professionals, and to treat mental illness. For example, social psychiatrists and clinical psychologists often attempt to encourage “relapse prevention” as part of the recovery process, and promote the use of medication and social skills training to achieve successful “rehabilitation” (Mueser et al., 2002). Lillehet (2002) points out that this puts SUs in a strange position – on the one hand they are trained to be independent, yet at the same time, they must comply with the wishes of the expert psychiatrists in order to be deemed “recovered”. Thus, recovery from psychosis in the psychosocial approach is still defined by successful professional interventions (Pilgrim, 2008).

1.4.3 User led Recovery

The third major approach focuses on SUs’ definitions of recovery and is in opposition to the previous two approaches in its call for greater power-sharing, collaboration, and equality of esteem between SU and practitioner in the recovery process. The user led approach to recovery postulates that the recovery process should be based on the expertise of SUs, and not exclusively on the input of professionals. SUs are seen as “experts by experience”, and mental health professionals are facilitators (Roberts & Wolfson, 2004). According to this approach, some SUs believe they have not always benefited from biomedical psychiatric intervention in the past; instead they have survived the negative aspects of such treatment, e.g. stigma, social rejection, side-effects of medication. Recovery is aided by the validation of the SUs’ experiences and behaviours. Thus, this approach conceptualises recovery as a process involving amelioration of their situation through validation and acceptance. Recovery has been seen by some SUs as the outcome of successful “survival” of health service interventions; interventions which may result in iatrogenesis.

The user led approach to recovery stems from the philosophy of SUs’ movements within the mental health field. These groups represent SUs accessing mental health services, and campaign
for greater rights for SUs and for increased input from SUs into how mental health services are run. This belief-system generally views recovery from psychosis as “a way of growing with or despite continuing disability”, as acknowledged in a joint position paper published by the Care Services Improvement Partnership (CSIP), the Royal College of Psychiatrists, and the Social Care Institute for Excellence in 2007.

Over the past thirty years many British and North American SUs have written about their thoughts on recovery from psychosis based on their own experiences (Chamberlin, 1978; Lovejoy, 1984; Deegan, 1988; Leete, 1989; Unzicker, 1989; Coleman, 1999; Reeves, 1999). Generally for these SUs, recovery meant coping adequately with their symptoms, as well as regaining a personal identity which was not defined by their illness. Although these characteristics of recovery from psychosis are shared by the writers, each individual experience of recovery was unique and had different subjective meanings. User led notions of recovery from psychosis include: personal recovery, regaining meaning in life, getting on with life, as well as regaining dignity and self-respect. Recovery is generally considered to rely on a humanistic, non-professional approach. Outcomes cannot be reflected in psychometric test scores, and treating someone’s symptoms does not guarantee recovery, in the user led definition of the word. This user led approach to recovery has also been applied to other mental health problems such as depression (Ridge & Ziebland, 2006). The spreading of its application suggests that this approach to recovery is becoming a defining feature of an approach to mental health more generally, and is replacing the previously demarcated ideologies represented by biomedicine and clinical psychology. This new language and set of principles seems to be currently guiding key elements of mental health care policy and practice.

There is not always a clear distinction between user led approaches and psychosocial approaches to recovery from psychosis. For example, clinical psychologist Tony Morrison espouses an approach to recovery from psychosis which fuses aspects of both the psychosocial and user led approaches (Byrne & Morrison, 2010). He is an advocate of both CBT and early intervention, which are in line with a psychosocial approach. However, some of his research in recovery from
psychosis is undertaken in collaboration with SUs. Indeed, some studies he has been involved in have been user led, i.e. SUs control all stages of the research process, including design, data collection and analysis, writing-up and dissemination (Pitt et al., 2007). This is congruent with a user led approach to recovery. This combination of the two different approaches highlights the fact that there are not always clear demarcations between such approaches to recovery.

1.5 Meanings of recovery for different groups

Three main recovery approaches as outlined by Pilgrim (2008) have been presented above. Each of the three approaches outlined above may broadly reflect particular disciplinary socialisations and beliefs, i.e. the professional discipline of psychiatry/medicine, the professional discipline of psychology, and SUs’ interest groups. Different social and professional groups have attempted to define recovery, e.g. lay people, SUs and carers, and professionals working in the area of mental health. Each of these groups or disciplines tends to have relatively coherent intra-group approaches to what recovery means, although variations within groups occur in each case. Each of these approaches draw their theoretical foundations from different combinations of the three main approaches (biomedical, psychosocial, user led) outlined above.

1.5.1 Lay approaches to recovery

A lay person coming across the term recovery would often be expected to conceptualise it as something approximating a return to normal everyday living (or normal health/functioning using medical/psychological parlance). Lay conceptions of schizophrenia and psychosis vary greatly. In a study of lay attitudes in the USA, the symptoms most commonly associated with psychosis were nervousness, confusion, irrational fears, persistent intrusive thoughts, and depression (Wahl, 1987). Also, 50% of all lay respondents incorrectly believed that schizophrenia involved exhibiting a split personality or multiple selves. The most commonly endorsed causes of schizophrenia were environmental stress, major unpleasant emotional experience, unsatisfactory social relationships, and biochemical dysfunction, with individual psychotherapy seen as the most
common intervention. Nakane et al. (2005) conducted a cross-cultural survey of lay theories in both Japan and Australia regarding the causes of psychosis. In both cultures, lay people believed that psychosis had primarily social causes and risk factors, with personal vulnerability factors also important. A follow-up study looking at lay understandings of recovery from psychosis (Jorm et al., 2005) found that most Australian and Japanese respondents believed that a person receiving professional help would experience either a full recovery, a full recovery with later relapse, or a partial recovery with relapse. Where professional help was not received, most respondents from both countries believed that the person would get worse. From this evidence, it can be concluded that lay definitions are influenced by both the biomedical and psychosocial approaches to psychosis. The onset of symptoms may be seen as resulting from stresses and distresses in social life, as well as from biological disposition. Thus, for many lay people, recovery from psychosis is to be found through the amelioration of either of these two etiological strands (i.e. social stressors or biological disposition). For many lay observers, professional intervention is seen as a key factor in promoting recovery from psychosis.

1.5.2 SUs’ and carers’ approaches to recovery

Some SUs have accepted the biomedical or psychosocial approaches to recovery from psychosis, and the tenets of those approaches have become internalised (Rogers & Pilgrim, 2005). However, many SUs also contest these approaches to recovery, stating that their own personal understandings of recovery are more valid than the mainstream meanings which have been imposed upon them by professionals. It is worth noting that there are a variety of co-existing approaches and discourses relating to mental health recovery which are circulating amongst SUs.

Similarly, carers have wide-ranging views on what recovery from psychosis means, and what the process of recovery entails. The phrase “users and carers” is frequently used in policy documents and service mission statements. However, SUs and carers are not a single unified entity. The interests and expectations of SUs and their carers are often in conflict with one another. For example, after attending an Early Intervention Service in Surrey, 80% of SUs felt more hopeful
about future recovery, whereas only two-thirds of their carers were optimistic about recovery (Naik & Bowden, 2008).

Some SUs, and the users’ movement in particular, have been critical of medical approaches to recovery, as personified by some GPs and psychiatrists. The over-reliance of the biomedical approach on drugs to the exclusion of other treatments is a problem for many SUs, who feel that counselling and other forms of "talking" therapy are unduly neglected. SUs have also been reported to be dissatisfied with the inadequate provision of information in relation to their mental health problems and the treatment they receive from GPs and psychiatrists (Pilgrim & Rogers, 1993; Kai & Crosland, 2001).

1.5.3 Professionals’ approaches to recovery

Like the other social groups involved in the mental health arena, professionals’ approaches to recovery vary greatly. These variations are generally in line with the secondary socialisation involved in becoming a member of a particular professional discipline – the process of learning what is appropriate behaviour as a member of a smaller professional group within a larger group, i.e. within society as a whole (Parsons, 1965). The socialisation process which takes place during the training of medical doctors has arguably led to negative attitudes amongst medical professionals regarding the treatment of mental health (Sinclair, 1997). Psychiatrists are most likely to adopt a multifaceted theoretical approach to psychosis, containing aspects of both the biomedical and psychosocial approaches. The biomedical approach to medicine views psychotic behaviour and cognition as stemming from biological antecedents, or at the very least that such aberrant behaviours may be controlled or improved through the use of medication (e.g. anti-psychotic drugs) or other physical interventions (e.g. electro-convulsive therapy). Due to their medical training, biological aetiological theories tend to be more deeply inculcated amongst psychiatrists than amongst clinical psychologists (Johnson, 1986). Psychiatrists have the power to prescribe drug treatments for psychiatric problems, as do GPs. This familiarity with medication may contribute to the belief held by many in the medical profession that drugs should be
frequently used as a treatment for psychosis. However, many psychiatrists are now supporting reforms regarding the reduction of social stigma and psychiatric coercion (Rogers & Pilgrim, 2005). Social psychiatrists are prominent as present-day progressive advocates of a psychosocial approach to recovery from psychosis (e.g. Anthony, 1993; Corrigan, 2002).

Both clinical psychologists and social workers frequently encounter SUs who experience psychosis. Psychologists, who are not allowed to prescribe medication, are most likely to offer talking therapies (such as CBT) as a means for achieving a SU’s recovery. CBT may be used to improve a SU’s social skills, thus aiding rehabilitation. The education, training, and professional socialisation which psychologists are exposed to have been postulated as reasons for this less biomedical approach (Knowlton, 1985), with a greater focus on notions such as the ‘self’. Social workers, like psychologists, are also not allowed to prescribe medication. Social workers’ training programmes are focused on improving the functioning of individuals, groups and families in society who find themselves in difficult situations. Social workers have been found to be professionally socialised to focus primarily on social determinants of problems (Weiss et al., 2004).

The views of GPs regarding recovery from psychosis will be collected as part of this PhD. There will be a particular emphasis on recovery in the primary care setting. In addition, SUs’ definitions of recovery in primary care settings will be explored. Both of these groups may express particular ways of defining recovery, possibly as a result of socialisation processes.

1.6 Content of Chapters

Chapter 1 has presented the aims of the PhD, with its focus on exploring what recovery from psychosis means to GPs and SUs. The PhD will focus on the potential for recovery-oriented services in primary care settings, and the factors that might promote or hinder recovery from psychosis in primary care. The justifications for this research topic were presented, with reference to the current policy developments which are likely to see an enhanced role for GPs in psychosis
care provision and commissioning, the potential shift in responsibility for providing psychosis services to primary care, and the lack of research into recovery from psychosis in primary care settings to-date.

Chapter 2 presents the results of a systematic literature review on the topic of recovery from psychosis in primary care. The lack of research in this specific area subsequently leads on to a broadening of the scope of the literature review. This results in the undertaking of a critical interpretive synthesis (CIS) which examines different approaches to “recovery”. The review, critique, and synthesis of existing conceptualisations of recovery are presented.

Chapter 3 presents the conceptual framework employed in this PhD thesis. The conceptual framework is informed by the outcome of the critical interpretive synthesis. The conceptual framework provides the philosophical underpinnings of this PhD. It informs the interpretation of the findings of the PhD in the discussion chapter. The conceptual framework is presented in four sections, with one section dedicated to each of the theories or critiques informing it. These sections are social constructionism, positive psychology, postpsychiatry, and autonomy enhancement.

Chapter 4 outlines the methodology used for the planning, carrying out, and analysis of interviews and focus groups with GPs and SUs. It outlines how modified grounded theory was utilised in this PhD.

There are three results chapters: Chapter 5 presents the results derived from the GPs’ interviews, Chapter 6 presents the results of the SUs’ interviews, and the findings of the mixed focus groups are presented in Chapter 7.

Finally, Chapter 8 will provide the discussion of the findings. The findings will be summarised, and interpreted with reference to the PhD’s conceptual framework. The implications of the PhD’s findings for future research, practice, and policy will also be discussed.
Chapter 2

Systematic Literature Review

&

Critical Interpretive Synthesis
Introduction

Once the aims and the rationale for undertaking the PhD had been clarified, the next step in the research process was a review of the existing literature. This chapter outlines this review process. A systematic literature review was initially chosen as the review method, as this represented the most rigorous form of literature review. The systematic literature review revealed a lack of research specific to recovery from psychosis in primary care settings. A CIS was subsequently undertaken, with a broader remit. Conceptualisations of recovery from psychosis in all healthcare settings (including secondary care) were critically reviewed, compared, and synthesised. The result of the CIS was that a new way of conceptualising recovery from psychosis was established.

2.1 Systematic Literature Review

Methodology

A systematic literature review was undertaken to assess the extent of previous research related to the concept of recovery amongst SUs with psychosis in primary care settings. The first step in the systematic literature review process required the pinpointing of the research question or topic under investigation. Khan et al. (2003) recommended the inclusion of four components when constructing a research review question: populations, exposures, outcomes, and study designs.

It was initially decided to undertake a review with a focus on primary care. The concept of recovery may be viewed both as an outcome and/or as a process (or exposure). The research area specified for review was as follows: recovery (“exposure”, “outcome”) for clients with psychosis in primary care (“population”). All forms of study design were included in the initial search strategy.

The second step of the review process involved the construction of a literature search strategy and the concomitant identification of relevant studies. OVID and ISI Web of Science (WOS) were
employed as a gateway for searching across a variety of databases at once. A list of all the
databases included by in the literature search is provided in Appendix 2.

The following keywords we included in the search, as well as synonyms and other related words:
“psychosis”, recovery, and “primary care”. Searches for each of these three umbrella terms were
conducted separately initially, before the results of each search were subsequently combined.

The following search terms came under the umbrella of “psychosis”:

1 psychosis
2 psychoses
3 psychotic
4 schizo$ (or “schizo*” in Web of Science)
5 bipolar
6 bipolar depression
7 manic
8 manic depression
9 mania
10 serious mental illness
11 SMI

In order to search for studies covering recovery, the search term “recover$”
(or “recover*” in Web of Science) was employed.

The following search terms were employed in the “primary care” search:

1 primary care
2 primary health
3 primary health care
4 primary healthcare
5 community care
6 community health
7 community health care
8 community healthcare
9 primary medical care
10 general practi$ (or “general practi*” in Web of Science)
11 family doctor
12 family medicine
13 physician
14 GP

**Results**

The results of the searches for each of the three individual categories were combined. Only studies common to each of the three search areas (psychosis, recovery, primary care) were retained. The systematic literature search was undertaken on September 12th, 2007. OVID produced 230 individual studies. The breakdown for the number of articles returned from each of the original constituent database sources covered by OVID was as follows:

- Embase – 57
- Medline – 56
- Cochrane – 42
- PsycInfo – 34
- Cinahl – 26
- ACP Journal Club – 5
- Health Management Information Consortium – 4
- British Nursing Index – 3
- International Pharmaceutical Abstracts – 2
- Database of Abstracts of Reviews of Effects – 1
WOS produced 143 such results for the above search strategy. This brought the total number of studies found to 373. The duplicates between the OVID and WOS were then manually removed using Reference Manager. This resulted in a final total of 330 papers which matched the search criteria.

Each of these studies was examined in order to check for their relevance to the subject of interest: recovery from psychosis in primary care. However, none of the studies explored the processes involved in recovery from psychosis in primary care. Likewise, none of the studies measured outcomes related to recovery from psychosis in primary care. Thus, no systematic comparison of quantitative results was possible.

**Updated Search – June 2011**

During the final period of this PhD, the same literature search strategy was repeated in order to ascertain whether any studies had been published in the intervening period which investigated the processes or outcomes involved in recovery from psychosis in primary care. The results of the search on June 8th, 2011 were as follows:

- OVID – 313 papers
- WOS – 768 papers
  (Duplicates removed – 119 papers)
- Final Total – 962 papers

This meant that an additional 632 papers had been published in this area between September 2007 and June 2011. These additional papers were checked for their specific relevance to recovery from psychosis in primary care. However, there were again no studies which investigated recovery outcomes in primary care.

Two papers specifically mentioned a recovery-oriented approach to psychosis in primary care
(Byng, 2008; Griswold et al., 2010). The first of these papers (Byng, 2008) took the form of a literature review/theoretical paper which developed a conceptual model of care for SUs with long-term psychosis in general practice. Byng (2008) pointed out that GPs may be well positioned to be advocates for a recovery-oriented approach to managing psychosis. GPs may be able to get to know a SU, especially if a SU is presenting for a minor physical problem but is otherwise relatively mentally well at the time of the presentation. It was also noted that GPs may be able to signpost SUs with stable psychosis to local mainstream services in the community with the goal of increasing SUs’ social inclusion and leisure activities. However, empirical data was not provided to support these theoretical suggestions, and this element of the paper’s conceptual model may have been based on the author’s experience as a General Practitioner with a special interest in mental health (GPwSI) working within the NHS.

Griswold et al. (2010) investigated access to primary care for SUs following psychiatric emergencies, including episodes of psychosis. It found that SUs who were provided with SU peer support, were statistically more likely to follow through and access primary care following hospital discharge. The provision of SU peer support was seen as being part of the recovery model which promoted self-determination and empowering relationships. It should be noted that this intervention (provision of peer support) was focused on improving access to primary care within the United States health care system, and all SUs recruited to the study did not have a regular primary care provider at the commencement of the study. The study did not investigate what happened within primary care consultations once access had been achieved.

**Conclusion**

Carrying out the systematic literature review proved useful as it highlighted the lack of previous research into recovery from psychosis in primary care. This convinced the author of the need to carry out basic qualitative research in the area as a theory-generating exercise which might then inform future quantitative hypothesis-testing research. The systematic literature review was also useful because during the process of carrying out the literature search the author was exposed to
much relevant literature from different academic disciplines (sociology, psychiatry, psychology, medicine, health service research, genetics, and neuroscience) and theoretical approaches which might not otherwise have been accessed. Thus, the literature search involved in the systematic review acted as an informative scoping exercise and also general introduction and immersion into relevant literature.

### 2.2 Critical Interpretive Synthesis

The systematic literature search revealed a lack of research on recovery from psychosis, in the specific setting of primary care. However, there remained a need to review previous literature relevant to this area. In particular, the author was interested in how recovery had been conceptualised in non-primary care settings, and how these conceptualisations might potentially relate to primary care settings. One way of undertaking a literature review might have been to carry out a traditional narrative review. However, it was felt that a more rigorous approach than a narrative review was needed. It was also felt that a specific focus on recovery conceptualisations would be useful, as this would provide a basis upon which subsequent empirical investigations into recovery could be built. This subsequent empirical research could also focus more particularly on recovery in primary care settings. It was decided to employ a form of literature review and synthesis called a CIS, as it allowed for the comparison and synthesis of recovery conceptualisations gathered from previous quantitative, qualitative, and theoretical research papers.

**Introduction to the Methodology**

The first step involved in this methodology was the identification of literature suitable for inclusion in a CIS of both qualitative and quantitative research on recovery from psychosis in primary care. Based on the results of the literature search for the systematic review, there appeared to be a dearth of research on recovery from psychosis in primary care, but not on recovery from psychosis per se. It was therefore expected that the CIS would also utilise research
on recovery from psychosis in secondary care. Although research on recovery in a primary care setting is largely absent from the literature, it could be, and is, subsumed in the more general context of recovery from psychosis in secondary care and recovery from psychosis in everyday life settings. The quality and relevance of studies from this wide-ranging literature was considered in order to appraise the usefulness of their possible inclusion in the CIS. The main findings were extracted from the selected papers. The aim of the CIS was to develop an overarching conceptual framework which would encompass different definitions of recovery from psychosis, including those competing “refutational” definitions which may stand in opposition to one another. This would entail a mapping of the similarities and differences between definitions. The concepts that underpin the notions of recovery would also be identified. It was envisaged that an original conceptual framework would be produced based on the synthesis of concepts from previous studies and the critique of the existing literature in general.

**What is a Critical Interpretive Synthesis?**

CIS is a recently developed method of reviewing literature (Dixon-Woods et al., 2006a). It borrows heavily from the concepts and processes utilised by the meta-ethnographic approach to reviewing and integrating qualitative research (Noblit & Hare, 1988). Meta-ethnography is a method of reviewing and synthesising qualitative research. Meta-ethnography is similar to traditional narrative literature reviews in the sense that it outlines previous research findings in a particular research area as well as commenting on the methodological and theoretical strengths and weaknesses associated with each individual piece of research. Meta-ethnography differs from traditional narrative literature reviews as it is not only an analysis of previous qualitative literature, but is also a synthesis of concepts used in this literature. The original concepts are borrowed from the reviewed literature in order to compare, contrast, and translate them. A new conceptual framework is then synthesised.

CIS, like meta-ethnography, is a method of analysing and synthesising literature, with an explicit orientation towards theory generation (Annandale et al., 2007). However, CIS also differs from
meta-ethnography. A larger number of papers may be included in a single CIS compared to a meta-ethnography. CIS aims to accommodate a diversity of primary evidence. Qualitative, quantitative and theoretical evidence are all included in CIS, whereas meta-ethnography analyses only qualitative studies. Another difference is that the final output of CIS is a synthesising argument. This synthesising argument consists of a synthesis of both synthetic and “found” constructs, i.e. both new and existing constructs. This allows more flexibility than in a meta-ethnography, where there is a more clearly defined demarcation between so-called “second-order” and “third-order” constructs (Noblit & Hare, 1988).

The processes involved in carrying out a CIS were laid out by Dixon-Woods et al. (2006a), and these processes are presented below with reference to their application to this PhD:

1. A review question was formulated at the outset, but remained open to modification as the review proceeded. In this PhD, the following questions were addressed:
   a) What are the competing notions of recovery from psychosis frequently encountered in primary health care settings, or in broader community-based health settings?
   b) What evidence exists to support/refute each viewpoint.
   c) How are each of the notions conceptually related and differentiated?
   d) What are the conceptual and practical advantages and disadvantages of each notion?

   The search criteria was as broad and inclusive as possible, ensuring all relevant articles were collected. Both quantitative and qualitative papers were included, so long as they were theoretically relevant.

2. Evidence from the included studies was accumulated, critiqued and integrated. The analysis was aimed at producing a synthesising argument (similar to the “line of argument synthesis” in a meta-synthesis). A coherent theoretical framework was developed based on the relationships between existing constructs and synthetic constructs (new concepts generated by the CIS). The synthesis built on explanations and interpretations found in the existing literature, and aimed to provide a method of conceptualising recovery in ways
which were “more insightful, formalised, and generalisable” (p.5). Considering that there were competing notions regarding what “recovery” from psychosis entailed, the synthesis included a refutational argument which considered these competing notions.

3. Formal appraisal of methodological quality and formal data extraction procedures were not essential to the CIS approach. Randomised controlled trials and other empirical studies were given more weight in terms of the evidence they provided. However, methodologically “weaker” studies still provided useful conceptual frameworks and they should not be immediately dismissed. Theoretical and discursive papers were also included as they provided valuable concepts and viewpoints.

4. The limitations of CIS as an approach were explicitly acknowledged. For example, the subjective authorial voice, and the difficulty of reproducing a CIS analysis were noted. The aim of a CIS was to “offer a theoretically sound and useful account that is demonstrably grounded in evidence” (p.10). This evidence consisted of quantitative, qualitative, and theoretical material. Searches were thorough, selections for analysis were fair, and disconfirming evidence was sought in order to challenge the emergent theoretical framework.

5. The critique identified different assumptions, meta-narratives and research traditions that guide and underlie research into “recovery”. The ways in which the literature constructed the problems related to “recovery” were questioned. The influences on how solutions (psychiatric, psychological, medical, social, sociological, cultural, folk, consumer etc.) have been constructed were investigated. The ultimate goal of the CIS was to develop an explanatory framework for the definition(s) of recovery, and the concepts that underpin recovery from psychosis. This overarching framework was not required to be a unifying theory, considering the various competing notions of “recovery” involved in this case. However, the framework enabled a mapping of how differing notions were positioned in relation to each other.

**What is the output created through the use of a Critical Interpretive Synthesis?**
Some similarities exist between CIS as a method, and meta-ethnography (Noblit & Hare, 1988). However, CIS does not adopt the distinct sequential steps of meta-ethnography (i.e. “reciprocal translational analysis” and “refutational synthesis”). Instead, both similarities/translations and contradictions/refutations between concepts used in the analysed papers are included in one all-encompassing step known here as a “translational synthesis”.

The overall output of a CIS is a new conceptual framework or “synthesising argument” (Dixon-Woods et al., 2006a) which incorporates the constructs used in the analysed papers, known as second order constructs. Third order constructs, also known as "synthetic constructs", are the building blocks of the “synthesising argument”. However, the synthesising argument need not consist solely of third order constructs (Dixon-Woods et al., 2006a). Synthesising arguments may also utilise second order constructs already reported in previous literature. Thus, a precise distinction between second and third order constructs does not necessarily exist in a CIS.

**Advantages of CIS**

Systematic reviews are useful for addressing questions of “what works”, and how this can be measured. However not all research questions are straightforward. CIS is more appropriate for use with “messy” questions or “messy” forms of evidence. The iterative approach of CIS means that the research question emerges throughout the process of carrying out the synthesis. A research question is initially formulated, but is open to the possibility of modification and specification throughout. In literature reviews generally, proceduralisation of method confers scientific credibility. However, this is not defensible for all types of research question (Dixon-Woods et al., 2006b).

CIS allows for the combination of different interpretations from different studies. Although, combining interpretations may lead to generalisations and a loss of the uniqueness of individual interpretations, each study has the potential to reveal different aspects of an experience (Jensen & Allen, 1996).
Unlike meta-synthesis which focuses solely on qualitative papers, or meta-analysis which compares and amalgamates quantitative data, CIS allows the researcher to include both qualitative and quantitative papers in its synthesis. This gives the synthesis a greater scope, with the possibility of including papers which exhibit a broad range of methodological approaches, as well as including papers with wide-ranging theoretical differences.

**Disadvantages of CIS**

CIS is subjective and cannot be defended as a reproducible method of review. However, Dixon-Woods et al. (2006b) point out that the CIS should be grounded in the available evidence. In addition, the CIS for this PhD was explicit about its subjectivity and the authorial voice of the work. The CIS was reflexive with regard to these issues.

“*Alternative accounts of the same evidence might be possible using different authorial voices, but…all accounts should be grounded in the evidence, verifiable and plausible, and that reflexivity will be a paramount requirement*” (p.39).

### 2.3 Search Strategy

The process of selecting the papers began by carrying out a literature search. A search for papers covering both “recovery” and “psychosis” was undertaken. This search strategy was broader than the previous literature search strategy outlined earlier in this chapter. The new search strategy for the CIS did not include a narrow focus on primary care, because all conceptualisations of “recovery” from psychosis were to be analysed. This reframing of the question implicitly included papers which examined “recovery” from psychosis in both hospital and community settings.

The search strategy used was as follows:

(psychosis OR psychoses OR psychotic OR schizo* OR bipolar OR manic OR mania OR
"serious mental illness" OR SMI) AND (recover*)

PsychInfo (1806 - present) returned 3262 results.
Medline (1950 – present) returned 2954 results.
EMBASE (1980 – present) returned 2674 results.

Duplicate papers were removed, and the titles of all returned articles were initially scanned for relevance. Through reading these papers, further important papers in the field were encountered through checking references and also citations. Those papers which had titles that were deemed relevant to the overall aims and objectives of the CIS were selected. Relevance was deemed to be achieved if the title indicated that the research was either measuring recovery from psychosis, was exploring definitions of recovery, or represented one of the theoretical frameworks associated with recovery from psychosis. In addition, only papers published since 2000 were included in the synthesis, in order to ensure that they covered topics and concepts which were relevant and up-to-date. 155 papers met these initial criteria.

16 papers were finally chosen for the CIS so as to represent the different theoretical frameworks which exist in the area of “recovery” from psychosis. The papers chosen are outlined in Appendix 3, alongside a brief description of each paper’s content and a justification for their inclusion. They are presented in three groups – firstly the quantitative studies, then the qualitative studies, and finally the theoretical papers. Two quantitative studies, five qualitative studies, and nine theoretical papers were included in the CIS.

2.4 Examining the constructs used in each of the papers

In order to ultimately create a synthesising argument involving the different conceptualisations, each of the conceptualisations of recovery that emerged during the analysis was examined individually. The discourses, the operational criteria used in the conduct of studies (e.g. indicators such as symptoms, social functioning, housing and employment status), and the metaphors (the
way in which “recovery” was talked about or described, as well as definitions of what “recovery” meant to the authors of each paper) were extracted. This was followed by a translational synthesis for each of the conceptualisations. These individual translational syntheses provided an initial critique of the evidence available for the creation of each third order construct. In the final overall “translational synthesis”, the third order constructs were further compared, contrasted, and translated into one other. The outcome of this process was an overall synthesising argument, where all conceptualisations were positioned in relation to each other in an overarching explanatory framework.

It was not necessary to clearly differentiate between “second order” and “third order” constructs in a CIS. This differentiation between “second order” and “third order” constructs is a characteristic of the meta-synthesis approach. Instead, the output from a CIS is known as a synthesising argument. However, identifying constructs which could be termed “second order” constructs was still deemed to be beneficial to the current CIS. A subsequent synthesising argument was more clearly produced, once the basic “second order” constructs had been identified. Input from the literature in general (external to the 16 analysed papers) was employed to aid with the creation of a synthesising argument, with particular emphasis being placed on how conceptualisations of “recovery” were applied to a primary care context.

The individual conceptualisations of “recovery” presented in this section represented the second order constructs of each analysed paper. The term second order constructs was used here to denote both the general approach of each paper to “recovery”, as well as the individual components that constitute that general approach/conceptualisation of “recovery”. It was found that first order constructs were largely unavailable here as the conceptualisations of recovery proposed in the analysed papers were the accounts of either social scientists or medical scientists, whereas first order constructs are provided by lay people. Some papers provided professional or patient narratives regarding “recovery”, but most papers provided “second order” accounts of researchers. It was decided to deal with both of these types of constructs in one section below.
Three conceptualisations of recovery were identified as a result of analysing each of the papers for definitions of recovery, and concepts related to recovery. Three meanings of the term “recovery” were identified which were related specifically to how recovery was conceived of in practice. There was some overlap evident in the definitions proposed by each of these “third-order” conceptualisations.

The three meanings identified were:
- recovery as an outcome
- recovery as a personal process
- recovery as a program of care.

2.4.1 Recovery as an outcome

The individual conceptualisations presented in this section represent the second order constructs of each analysed paper. The third order construct of recovery as an outcome was subsequently identified after having compared, contrasted and amalgamated various proposed “outcome” conceptualisations.

Two papers (Harrow et al., 2005; Harrison et al., 2001) support the view that recovery may be seen as a quantifiable outcome.

Harrow et al.’s (2005) concept of recovery consists of objective outcomes, which are measured using the Levenstein-Klein-Polack scale.

“Recovery was defined by outcome status during the follow-up year. Meeting the operational criteria for recovery requires, first, the absence of major symptoms throughout the follow-up year (absence of psychotic activity and absence of negative symptoms). It also requires, second, adequate psychosocial functioning, including instrumental (or paid) work half-time or more during the follow-up year and the absence of a very poor social activity level; and, third, no psychiatric rehospitalizations during the follow-up year” (Harrow et al., 2005, p.725).
Harrison et al. (2001) also utilise similar outcome measures as a way of defining recovery from psychosis. Their definition of recovery “relied heavily upon absence of symptoms, social disability and resource utilisation” (p.514). In this study, clinicians rated patients on the presence of symptoms and disabilities, using numerical scales similar to Harrow et al. (2005). Although Harrison et al. (2001) view recovery as an outcome, they acknowledge that this definition does not allow them to make a judgement regarding whether a person has recovered a “meaningful and fulfilling life” as the user perspective on recovery from psychosis would do, or as the perspective which views recovery as a process would demand. The perspective espoused by Harrison et al. (2001) conceptualises recovery as an outcome, but also recognises that recovery may be viewed as a process. For Harrison et al. (2001), important aspects of this process can’t be measured, and the outcome definition is more easily applicable to their research question.

Most of the other papers which outline “outcome” definitions of recovery do so in order to contrast “outcome” definitions with the preferred definitions of recovery used in each of the papers, many of which are either “process” or “program/model of care” definitions of recovery, or a mixture of the two.

Davidson et al. (2008) writes about “recovery from” schizophrenia - this form of recovery relies on outcome measures. Andreasen et al.’s (2005) definition of reaching a state of “recovery” is cited by Davidson et al. (2008). The individual “becomes relatively free of disease-related psychopathology and is able to function in the community over a prolonged period of time” (p.442).

Bellack (2006) also presents a definition of recovery based on Andreasen et al. (2005): “Ability to function in the community, socially and vocationally, as well as being relatively free of psychopathology” (p.433). This is an outcome-based conceptualisation of recovery, which contains both psychosocial (ability to function in the community) and biomedical (free of psychopathology) elements. The related “scientific” definition is also outlined: “Elimination or reduction of symptoms and return to premorbid functioning” (p.433).
Roberts and Wolfson (2004) outline two definitions of recovery that may be categorised as being outcome-based. Recovery may entail a complete “cure” or “getting back to normal” (p.38). Recovery may also refer to an approximation to cure on clinical and social dimensions used in outcome studies.

Resnick et al. (2005) describe recovery as an outcome in the following manner: “Traditionally, recovery has been narrowly defined as a discrete point in time after an illness when one’s health is entirely regained” (p.119).

Ramon et al. (2007) cite the following definition of recovery as an outcome from Warner (2004): “Loss of psychotic symptoms and return to pre-illness level of functioning” (p.109). Even though Ramon et al. (2007) and the cited paper from where the definition originated (Warner, 2004) both display a preference for users’ definitions of recovery, both papers also present alternative definitions of recovery from a biomedical perspective. This approach to presenting more than one definition of recovery is evident in most of the papers analysed here.

Corrigan (2006) notes that recovery may be conceptualised as either an outcome or a process. Again, recovery as an outcome may be seen as more aligned to the biomedical perspective. The four benchmarks of recovery as an outcome are relief from psychotic symptoms, independence in matters related to housing, at least part-time work or school, and regular social and recreational activities.

Farkas et al. (2005) write that evidence-based practice has produced “specific outcomes such as reduced symptomatology, decreased hospitalisation, fewer relapses or improved employment” (p.155). Farkas et al. (2005) also point out that this evidence-based perspective may “vary on its compatibility with recovery values and ingredients” (p.155). “Recovery values” here means user-led recovery.
Deegan (2005) supports the argument that recovery should be considered to be a process, but also outlines what a definition of recovery based on outcomes consists of:

“In seven worldwide longitudinal studies on recovery from major mental disorders including schizophrenia, recovery has been found to include living and working in the community in a fashion similar to that of other community members, being free of psychiatric symptoms, using or not using psychiatric services (including psychiatric medications), having a network of friends and/or family, and living in fully integrated housing” (p.29).

Ng et al. (2008) cite an outcome-based definition of recovery produced by Liberman et al. (2002):

“To be considered as recovered, individuals have to meet all the criteria which include two consecutive years of:

1. Absence of clinically significant positive and negative symptoms.
2. Adaptive work and social functioning
3. Cordial familial and peer relationships (a social gathering or joint interaction) at least once a week.
4. Independent living.
5. Subjective satisfaction with life.
7. Participation as a citizen in voting, self-advocacy and other civic areas” (p.119).

Hopper (2007) mentions how outcomes such as independent living and gainful employment have been used to measure social recovery:

“Social recovery proved common enough outside the hospital, when measured by independent living and gainful employment” (p.869).

McCabe, Saidi and Priebe (2007) write about outcomes in relation to schizophrenia. However, these outcomes are patient-reported, which contrasts with the traditional clinical outcomes outlined in other papers.
“A patient-reported outcome is any outcome based on a patient’s perception of a disease and its treatment(s) scored by the patient, without any interpretation by a clinician or researcher...capturing psychopathological symptoms only is not sufficient to reflect relevant outcomes” (p.21).

The remaining two papers - Ridgway (2001) and Lester et al. (2005a) - do not refer to the concept of recovery from psychosis as an outcome.

**Translational synthesis**

The individual conceptualisations presented above represent the second order constructs of each analysed paper. The final third order construct of recovery as an outcome was subsequently identified after having compared, contrasted and amalgamated various proposed “outcome” conceptualisations.

The majority of papers analysed here specify an absence of major psychotic symptoms as a prerequisite outcome for complete recovery. Definitions of recovery as an outcome tend to utilise biomedical linguistic terms such as disease, cure, symptoms, and psychopathology.

However, not all papers state that recovery as an outcome consists of complete absence of symptoms. Indeed, examples are available amongst the papers which refute the idea that conceptualising recovery as an outcome requires recovery to consist a complete absence of symptoms. Corrigan (2006) views recovery as an outcome as “relief from psychotic symptoms”, while Farkas et al. (2005) refers to “reduced symptomatology”. Similarly, Davidson et al. (2008) defines someone as being recovered if they are “relatively free of disease-related psychopathology”. Unlike other definitions of a recovery as an outcome, neither of these definitions of recovery as an outcome specifies total elimination of symptoms, being disease-free, being cured, entirely regaining health, or returning to pre-illness/pre-morbidity states. Definitions of recovery as an outcome analysed here also include “no psychiatric hospitalisations
in the follow-up year” (Harrow et al., 2005) or “decreased hospitalisation” (Farkas et al., 2005), as well as “fewer relapses” (Farkas et al., 2005). These indicators of recovery are similar to the concept of “absence of symptoms”. The former indicator (no psychiatric hospitalisations) is a consequence of such an absence of symptoms. The latter indicator (fewer relapses) is synonymous with a reduction in the frequency with which the elimination of symptoms is temporarily or permanently reversed.

In addition to the papers included in this CIS, Beresford et al. (2010) point out that recovery is often conceptualised according to a medical model of mental illness which focuses on the individual rather than society as a whole. This research indicates that SUs find a social approach to understanding mental illness to be more useful than a medical approach. Beresford et al. (2010) further argue that the social model of disability has provided disabled people with a framework for understanding the oppression and barriers they face, and the social model of disability could also provide a potentially relevant framework for mental health SUs to understand such barriers in the future.

There is a consensus found within the analysed papers which views “adequate psychosocial functioning” or “functioning in the community” as a measure by which recovery as an outcome may be assessed. Depending on which paper is in question, the definition of functioning in the community consists of slightly different components. However, none of the variations are refutations of each other, and all can be included under one umbrella term. Thus, functioning in the community can be said to consist of functioning vocationally (engaging in work or attending school on a part-time or full-time basis), functioning socially (regular social and recreational activities), living independently in terms of housing arrangements, and having a network of friends and/or family.

Civic engagement is a concept mentioned as a measure of recovery by Ng et al. (2008) who cite its use by Liberman et al. (2002). Civic engagement refers to participation as a citizen in voting, self-advocacy and other civic areas. This concept may also come under the umbrella outcome
measure of “functioning in the community”.

Recovery as an outcome involves “living and working in the community in a fashion similar to that of other community members” (Deegan, 2005). This quotation from Deegan (2005) points to a problem present in definitions of recovery as an outcome. These definitions require people to live in “a fashion similar to other community members”. This is a prescriptive definition which demands that service-users should conform to societal norms. Not only that, but it also expects people from different cultures to behave in accordance with Western ideals of what constitutes a “normal” life. These ideals are often culturally-specific and have been socially constructed. Not all people would agree that they are necessary requirements for “recovery”. For example, Ng et al. (2008) highlight the differences that exist between service-users’ in Chinese and English-speaking countries regarding expectations of what constitutes normality, and thus recovery. It is reported that in Hong Kong “most young people live with family members until they marry, and some even after they have married” (p.128). Thus, “independent living” is not as important in Hong Kong as it is in Western societies, and is not necessary for achieving an outcome of “recovery”. However, as illustrated by this example, the influence of Western culture and science on the rest of the world may lead to the application of inappropriate outcome measures to the definition of “recovery” in non-Western contexts.

Another contentious issue is the use of an absence of “social disability” as a measure for assessing recovery. This measure is used in the study carried out by Harrison et al. (2001). Social disability was assessed using two measures:

(a) Modified form of the WHO Disability Assessment Scale.

(b) Adapted form of the Global Assessment of Functioning - Disability Scale.

Harrison et al. (2001) note that “the Disability Assessment Scale requires knowledge of local norms and conventions in order to rate dimensions of social disability, which may have reduced intercentre reliability for this instrument” (p.514). This study assessed longitudinal rates of recovery in a number of different countries throughout the world, but different cultures have different norms regarding what constitutes social disability.
There is a further problem with using absence of “social disability” to assess recovery. The discussion of social disability theory presented by Hopper (2007) is of relevance here. According to this theory, a person may have an “impairment”, but this is not considered to be a “disability” until the impairment is “converted into social markers of esteem or disrepute” (Hopper, 2007, p.875). “This undeclared social conversion process…transforms injuries of body and mind into locally salient distinctions” (Hopper, 2007, p.875). Hopper (2007) argues that the application of the socially constructed concept of “social disability” may cause stigma, which in turn would reduce the likelihood of recovery.

Deegan (2005) points out that recovery from psychosis has traditionally been measured by the individual’s continued use of psychiatric services (e.g. adherence to a prescribed program) and also by the individual’s non-use of such services or resources (e.g. no longer needs anti-psychotic medication). The corollary of this is that the use of psychiatric services is not necessarily an indicator of recovery, just as non-use of services is also not necessarily an indicator. Recovery depends on the type of service in question. However, the approach to defining recovery in terms of service use is grounded in directly measuring what people do rather than measuring abstracted symptoms.

Ng et al. (2008) cite Liberman et al.’s (2002) definition of recovery which includes two outcome measures. These two outcome measures could be interpreted as being incongruent with a biomedical view of recovery. These two measures are also unique because they are not mentioned in any of the other 16 papers analysed. The first of these measures is “two consecutive years of subjective satisfaction with life”, while the second is “two consecutive years of stable identity and self-esteem” (p.119). Both measures combine biomedical and user-led approaches to defining recovery. The use of these concepts is based on a biomedical assumption that they are measurable like the other outcomes discussed in this section. The use of these two measures is also based on a user-led assumption that recovery is a subjective experience. Liberman et al. (2002) combine these two approaches to defining recovery by assuming that a person’s subjective
experience of life satisfaction and self-esteem can be measured. However, many service-users would disagree with the need to measure subjective life satisfaction and with its use as an “objective” assessment of a person’s recovery status. Indeed, a user-led perspective would argue that the concept of “recovery” itself is not measurable.

Definitions which conceive of recovery as an outcome often rely on the assumption of professional authority. This is particularly the case with those conceptualisations of recovery which emphasise outcomes such as absence of psychopathology or psychiatric rehospitalisation. Professionals are seen as having expert knowledge and have the ability to diagnose pathology, observe symptoms, and measure improvement or recovery. The assumption that clinicians have the ability or the right to measure recovery is disputed by user-led approaches to recovery from psychosis. Other outcomes which may be used as a measure of recovery include how a person functions in their community in terms of employment, education, social activities, and independent living arrangements.

2.4.2 Recovery as a personal process

The individual conceptualisations presented in this section represent the second order constructs of each analysed paper. The third order construct of recovery as a personal process was subsequently identified after having compared, contrasted and amalgamated various proposed “personal process” conceptualisations.

Recovery is generally viewed as an outcome by those adhering to a biomedical perspective. By contrast, those who espouse SUs’ conceptualisations of recovery tend towards a view of recovery as either a personal process, or alternatively as a way of structuring a program of care. Conceptualisations of recovery which identify recovery as a process will now be examined.

According to Davidson et al. (2008) recovery “refers to a unique and personal process rather than to a uniform end state or outcome and that it involves a person’s self-determined pursuit of
“a dignified and meaningful life in the communities of his or her choice” (p.7).

The American Psychiatric Association’s (2005) position statement on recovery is also cited by Davidson et al. (2008): Recovery “emphasizes a person’s capacity to have hope and lead a meaningful life...[and includes] maximization of 1) each patient’s autonomy based on that patient’s desires and capabilities, 2) patient’s dignity and self-respect, 3) patient’s acceptance and integration into full community life, and 4) resumption of normal development. The concept of recovery focuses on increasing the patient’s ability to successfully cope with life’s challenges, and to successfully manage their symptoms” (p.7).

Spaniol et al. (2006) see recovery as a developmental process of healing physically and emotionally, of adjusting one’s attitudes, feelings, perceptions, roles and goals in life. Recovery, derived from first person narratives, is defined as the development of new meaning and purpose in one’s life. This represents a holistic approach to recovery. During the recovery process, growth is experienced, although this growth also brings periods of instability and increased vulnerability. Four phases of the recovery process are outlined: overwhelmed by, struggling with, living with, and living beyond the disability. These phases are not necessarily experienced in a linear, unidirectional manner. Three tasks commonly associated with the recovery process are:
1) Developing an explanatory framework for understanding the psychosis experience.
2) Getting some control over the illness itself.
3) Moving into roles that are meaningful, productive and valued by society.

Bellack (2006) cites the definition of recovery originally presented by the Substance Abuse and Mental Health Services Administration (2005):
“A journey of healing and transformation for a person with a mental health disability to be able to live a meaningful life in communities of his or her choice while striving to achieve full human potential or ‘personhood’ ” (p.436). Bellack (2006) points to four limitations associated with this definition of recovery as a process or journey. It is limited in its specificity, in its criteria for research, in its usefulness for evaluating the effectiveness of clinical programs, and in its scope for developing public policy.
Roberts and Wolfson (2004) speak of a radical redefinition of recovery as “a process of personal discovery, of how to live (and to live well) with enduring symptoms and vulnerabilities opens the possibility of recovery to all. The ‘recovery’ movement argues that this reconceptualisation is empowering, raising realistic hope for a better life alongside whatever remains of illness and vulnerability” (p.37). According to this subjective and humanistic approach, service-users want to “make the important measurable, not the measurable important”. This contrasts with scientific and biomedical conceptualisations of recovery, where the emphasis is on measuring outcomes in order to ascertain recovery status.

Resnick et al. (2005) describe recovery as follows: “Recovery is a process representing the belief that all individuals, even those with severe psychiatric disabilities, can develop hope for the future, participate in meaningful activities, exercise self-determination, and live in a society without stigma and discrimination” (p.121). Recovery is seen as a fluid process and an orientation or attitude in the consumer definition. This process is multi-faceted and can include any of the following: “the development of spirituality, a sense of identity, hope, choice, social relationships, availability of peer support, feelings of independence and autonomy, and involvement in meaningful activity” (p.120). However, according to Resnick et al. (2005), user-led conceptualisations of recovery as a process are not empirically derived, and lack precision.

Ramon et al. (2007) cite the definition of recovery given by Anthony (1993): “Recovery is a way of living a satisfying, hopeful, and contributing life even with the limitations caused by illness. Recovery involves the development of new meaning and purpose in one’s life as one grows beyond the catastrophic effects of mental illness” (p.111). Ramon et al. (2007) also cite Deegan (1988) who suggested that recovery is a process, with the focus on the journey there, rather than on reaching its end. There is an emphasis on hope, which is a component of successful recovery for SUs, but does not feature in biomedical or outcome-based conceptualisations of recovery. Ramon et al. (2007) detail the ten central innovative elements of the new meaning given to recovery (recovery as a journey):
1. “It is not about going back to a previous pre-illness state.
2. Instead it is about forging a new way of living controlled by the newly found self-agency of users.
3. Recovery is from the trauma of psychosis, treatment, stigma, lack of skills and opportunities for valued activities (Wallcraft, 2005).
4. Inter-dependency and self-help are encouraged; other people can be a source of support and confirmation of self-worth.
5. Hope is a core component (Repper & Perkins, 2003).
6. Developing one’s own coping strategies sits side by side with strategies for giving to others.
7. It requires a systematic effort, which entails risk taking, as well as risk avoidance.
8. The right to fail is an integral part of the new meaning (Deegan, 1996).
9. Unlike the original meaning of the term recovery, the new meaning is partly created by users and adopted by them, and has transformative implications (Wallcraft, 2005).
10. It entails a move from a deficit model of living with mental illness to a strengths perspective (Saleeby, 1992; Rapp, 1998) which Davidson (2003) aptly called living outside of illness. The deficit model is based on an assumed overall, often permanent, vulnerability of the person expressed in both difficulties to function in life, and in symptoms which contribute to malfunctioning. On the other hand, the strengths approach assumes that people with mental illness also have abilities and ambitions which motivate them to put these abilities to use” (p.111).

Corrigan (2006) defines recovery as follows: “Recovery is a process; it reintroduces such important values as hope, empowerment and goal orientation” (p.993). This form of recovery is described as having four important benchmark processes: hope about the future, psychological well-being, personal empowerment, and goal orientation. It is “more concerned with a sense of meaning in life and personal comfort rather than being symptom free and without disabilities”, as well as “validation of personhood, recognition of common humanity and tolerance for individual differences” (p.995). Corrigan (2006) puts forward an argument in defence of using
consumer definitions of recovery in research arenas. Bellack (2006) believes that this form of recovery is limited for research purposes due to the underspecified nature of its criteria. However, Corrigan (2006) writes: “Although recovery as a process deals with relatively more nebulous issues of purpose and vision...we do not believe that the presence of barriers in using more traditional research methods highlights a failure of the theory as much as a challenge for researchers to develop strategies for testing the models” (p.995).

Deegan (2005) outlines her definition of recovery as a process as follows: “Qualitative studies and contemporary first-person accounts suggest that although recovery is a unique process for each person, there are common themes, challenges, and strategies used by most people” (p.29). In Deegan’s experience as a SU, recovery was found to be promoted by “personal medicine” which included “those activities that gave life meaning and purpose, and that served to raise self-esteem, decrease symptoms, and avoid unwanted outcomes such as hospitalization” (p.29).

Hopper (2007) refers to the recovery “movement” (i.e. user-led recovery) and its watchwords, of which process is one: “The movement’s watchwords - voice, authenticity, process, settling old scores and filing fresh grievances” (p.873). Hopper (2007) criticises the concept of recovery as a process due to its lack of “operational specificity”. Recovery as a process includes the “delicate, sometimes achingly slow work of rebuilding a functional self - a person apart from the reality of illness—to determined action to deny stigma a destructive power in one’s own life. For some, a persisting sense of casualty does daily battle with a struggling one of agency. For others, the transformation is spiritual” (p.871).

Ridgway (2001) refers to narratives that many SUs construct for themselves once the process of recovery is set in motion. This narrative changes from “I have a mental illness and will never get better” to “I am a unique individual, struggling with a psychiatric disorder, and through my attitudes and daily actions, with the help of caring others, I can and have reclaimed a meaningful life. I tell the story of my ongoing journey of recovery so that others may recover as well” (p.337). Ridgway (2001) points out that an exact formulation of this recovery process is not
possible: “Each person’s journey of recovery is individual and unique. Recovery processes cannot be forced into a preset mould or formulated as a cookbook full of recipes for everyone to follow. In fact, recovery holds a quality of chance, a measure of mystery, and often involves transpersonal events and spiritual passages” (p.339).

In addition, Ridgway (2001) analysed first person narrative accounts of the recovery process. Eight themes were found to be common amongst each of these narrative accounts:

1. Reawakening of hope after despair.
2. Breaking through denial and achieving understanding and acceptance.
3. Moving from withdrawal to engagement and active participation in life.
4. Active coping rather than passive adjustment.
5. No longer viewing oneself primarily as a person with a psychiatric disorder and reclaiming a positive sense of self.
6. Moving from alienation to a sense of meaning and purpose.
7. A complex and nonlinear journey.
8. Not accomplished alone – the journey involves support and partnership.

McCabe et al. (2007) presents two ways of measuring the phases or stages of the recovery process: Firstly, the “Mental Health Recovery Measure” (Young & Ensing, 1999) assesses three phases of recovery: overcoming sickness; discovering and fostering self-empowerment; and striving to attain overall well-being and reach new potentials.

Secondly, the “Stages of Recovery Instrument” (Andresen et al., 2006) measure which covers five stages: moratorium, awareness, preparation, rebuilding, and growth.

Farkas et al. (2005) do not refer directly to recovery as a process. However, related ideas of growth and meaning are mentioned as central to the idea of recovery: “based on the notion that a majority of people can grow beyond the catastrophe of a severe mental illness and lead a meaningful life in their own community” (p.141).
Ng et al. (2008), Harrison et al. (2001), Harrow et al. (2005) and Lester et al. (2005a) do not refer to recovery as a process.

**Translational synthesis**

The individual conceptualisations presented above represent second order constructs provided by each analysed paper. The final third order construct of recovery as a personal process was subsequently identified after having compared, contrasted and amalgamated various proposed “personal process” conceptualisations.

Overall, a majority of papers state that service-users’ conceptualisations of recovery consist of viewing recovery as a personal process, not as an outcome. This personal process is described in a variety of ways but with essentially the same meaning: recovery is a unique, personal, non-linear developmental process/journey of healing and spiritual transformation. Davidson et al. (2008) refer to this form of recovery as being “in” recovery, as opposed to the biomedical concept of recovering “from” an illness. Being “in” the process of recovery consists of a wide-range of different concepts, varying between papers. These include: a self-determined pursuit of a dignified, meaningful, satisfying life; developing a purpose and new goals; a capacity for hope about the future; psychological well-being and personal comfort; self-empowerment; coping with and managing symptoms and life’s challenges; living well, even with enduring vulnerabilities; attempting to achieve full human potential; focusing on individuals’ strengths as opposed to framing problems in a biomedical disease framework; users have input into their own recovery programs; working in partnership with professionals; renewing a sense of possibility; and engagement and participation in life.

Recovery as a process is often presented as a reaction against the concept of recovery as an outcome. Recovery as a process is defined partly by its opposition to biomedical and outcome-based conceptions of recovery. Definitions of recovery as a process include expositions of what recovery does not entail, as well as what it does. Such definitions rely on the use of contrasting
dichotomies to highlight differences. Some of aspects of recovery as a process which differ from recovery as an outcome are outlined here. For example, recovery as a process is not measurable. Recovery as a process is not necessarily reliant on professionals’ authority and expertise, or on users’ adherence to prescribed interventions. Its proponents also argue that when discussing recovery, an illness model or a deficit model should not be employed.

In many of the analysed papers, users and critical researchers have highlighted problems which they associate with a biomedical mental health system. In order to highlight these problems, dichotomies between two approaches have been constructed in many of the analysed papers. Strongly contrasting dichotomies emphasise the differences between two perspectives on recovery (e.g. recovery as a process vs. recovery as an outcome). This may be interpreted to be a rhetorical device which attempts to achieve political ends such as policy-change.

Power relations are an overarching theme found in definitions of recovery as a process, although this theme of power is often stated implicitly. Power in any sphere of life relates to the perceived or real influence that one person or group has over another person or group. Those who define recovery as a process argue that users should have greater input into their own recovery programs. In the analysed conceptualisations of recovery as a process, terms employed in relation to increasing the power or input of SUs included “empowerment”, “agency”, and “choice”. According to this emphasis on user input, which is evident in some conceptualisations of recovery as a process, users and professionals should work in partnership as part of the recovery process instead of relying solely on prescriptions or solutions offered by the professional expert.

One paper (Ng et al., 2008) provides a refutation of the general consensus outlined above. Ng et al. (2008) carried out interviews with eight service-users of Chinese ethnicity. In contrast to other the other accounts analysed, Ng et al. (2008) reported that SUs defined recovery as consisting of cessation of antipsychotic medication and disappearance of symptoms, as well as employment, good familial relationships, and independent living. This description of what recovery means for these SUs is broadly in line with the biomedical definitions of recovery outlined previously. In
particular, “disappearance of symptoms” is an outcome associated with biomedical definitions of recovery, but these SUs see it as an integral part of recovery for them. This may be due to cultural differences between Chinese and English-speaking populations. However, it may also be due to the type of service-user who is asked for their definition of recovery. A SU like Deegan (2005) for example, who is a successful academic, may not be representative of SUs as a whole. Her priorities and experiences may differ from other SUs. Deegan (2005) does also refer to outcomes related to symptoms and illness when describing the goals of the recovery process: “to raise self-esteem, decrease symptoms, and avoid unwanted outcomes such as hospitalization”, although cessation of symptoms is not presented as being an essential part of recovery.

Another contested area within the analysed definitions of recovery as a process revolves around their operational specificity. Bellack (2006) and Hopper (2007) criticise the lack of operational specificity observed amongst definitions of recovery as a process. Similarly, Corrigan (2006) states that these process definitions are concerned with “nebulous issues of purpose and vision”, although it is pointed out that definitions of recovery as an outcome also encounter methodological problems regarding specificity and measurement. Ridgway (2001) also points out that an exact formulation of the recovery process is not possible: “*the multi-faceted recovery process remains too complex to be operationalized in any simple manner*” (p.341).

### 2.4.3 Recovery as a program of care

The individual conceptualisations presented in this section represent the second order constructs of each analysed paper. The final third order construct of recovery as a program of care was subsequently identified after having compared, contrasted and amalgamated various proposed “program of care” conceptualisations.

Recovery has also been conceptualised by some authors as being a program of care. In other words, recovery may be seen as a particular approach to structuring care programs. This definition of recovery covers all the aspects that a recovery-oriented service might include. The
concept of recovery as a personal process is heavily influenced by user-led conceptualisations of how recovery should be defined. In this synthesis, most papers which have identified their preferred components of a program of care promoting recovery have identified components similar to those of the user-led movement. However, there also appears to be differences between these two perspectives. User-led recovery tends to see recovery as a personal process, and focuses on aspects of personal experiences. On the other hand, those who see recovery as a program of care, apply many of these user-led concepts to structuring programs of care with the intention of promoting recovery from psychosis. Recovery as a program of care is often a set of practices framed and delivered by professionals, and not always led by users’ definitions.

Spaniol et al. (2002) suggest four frequently proposed “elements of a comprehensive mental health system that may also be essential for promoting recovery among individuals with schizophrenia. These elements include: (1) integrated mental health and substance abuse services (Drake et al., 1998; Mueser et al., 1998); (2) provision of a level of resources that allow for a lifestyle above the poverty level (Saraceno & Barbui, 1997; Alverson et al., 1998); (3) access to effective medications; and (4) ongoing flexible services offered within a structure and timeframe that recognizes the variety of patterns that the individual course of recovery may take (Anthony, 2000)” (p.335).

Bellack (2006) presents an example of what recovery-oriented programs of care might consist of. In this case, the Substance Abuse and Mental Health Services Administration (2005) identified ten essential characteristics of effective recovery-oriented services. They are heavily influenced by user-led conceptions of what recovery entails:

1. “Self-Direction: Consumers lead, control, exercise choice over, and determine their own path of recovery.
2. Individualized and Person-Centred: There are multiple pathways to recovery based on the individual person’s unique needs, preferences, and experiences.
3. Empowerment: Consumers have the authority to exercise choices and make decisions that impact their lives and are educated and supported in so doing.
4. **Holistic**: Recovery encompasses the varied aspects of an individual’s life including mind, body, spirit, and community.

5. **Nonlinear**: Recovery is not a step-by-step process but one based on continual growth with occasional setbacks.

6. **Strengths-Based**: Recovery focuses on valuing and building on the multiple strengths, resiliency, coping abilities, inherent worth, and capabilities of the individual.

7. **Peer Support**: The invaluable role of mutual support in which consumers encourage one another in recovery is recognized and promoted.

8. **Respect**: Community, systems, and societal acceptance and appreciation of consumers—including the protection of consumer rights and the elimination of discrimination and stigma—are crucial in achieving recovery.

9. **Responsibility**: Consumers have personal responsibility for their own self-care and journeys of recovery.

10. **Hope**: Recovery provides the essential and motivating message that people can and do overcome the barriers and obstacles that confront them” (p.436).

Roberts and Wolfson (2004) highlight eleven key aspects of what a recovery-orientated program of care might look like:

1. A shift of professional role from authority to coach.
2. A focus on the core significance of hope and optimism.
3. The timing of professional responses is important, e.g. “working with psychotic symptoms may be more helpful than attempting to demonstrate their falseness” particularly in the first six months of the illness (p.42).
4. Taking medication should be based on well-informed choice and negotiation, not compliance.
5. The right to failure and the dignity of risk should be embraced.
7. Hospital should be a “springy safety net” which does “not necessarily lead to long-term involvement and monitoring” after a crisis has been resolved (p.43).
8. The patient is an expert in their own experience.
9. Value ethnicity and diversity.
10. Make supported employment schemes available.
11. Doctors should communicate in accessible language. Diagnostic caution is commendable, but it carries with it the risk of diagnostic avoidance. “There should no longer be a single account of the illness experience, refracted through a medical perspective” (p.45).

Resnick et al. (2005) outline four domains of recovery which can be used to empirically measure recovery as a process. As outlined previously, these four domains are empowerment, hope/optimism, knowledge about one’s illness and about the system, and life satisfaction. Recovery as a process is then linked to recovery as a care program through the use of the measure they created as a “tool for assessing interventions for their ability to assist practitioners and consumers in fostering recovery” (p.125). Resnick et al. (2005) suggest that supported employment may promote empowerment; peer supported services may help to foster hope; while life satisfaction may be improved through assertive community treatment which may help consumers maximise their housing opportunities, and through family psychoeducation. These interventions would need to be tested for efficacy. Thus, evidence-based practice has the potential to provide the missing “how” - in terms of “how states, mental health services and professionals can cultivate a recovery orientation” (p.126).

Ramon et al. (2007) report that there is an emphasis on the application of optimism, hope and user-led recovery principles to program design in the Australian national guidelines for the treatment of schizophrenia (McGorry, 2005). Recommendations included: early and active use of medications, psychosocial interventions, and attending to individuals’ social and cultural environments. Ramon et al. (2007) notes that this approach to recovery as a program of care “remains more a set of exemplary practices framed and delivered by professionals, albeit within a high quality and innovative clinical setting, rather than one led by users’ definitions of their recovery goals and related journeys” (p.116). Ramon et al. (2007) also mentions that a proposed recovery-based model of care originating from the UK includes hope-inducing interventions.
However, an obstacle to the implementation of user-led recovery principles in UK care programs is that the “service system is built on programmes aimed at user populations, rather than at the provision of individualised packages” (p.118).

Corrigan (2006) suggests that evidence-based biomedical and psychosocial interventions could be implemented as part of care programs aiming to stimulate recovery. Suggested interventions include strategic medication management, illness management, supported employment, assertive community treatment, services to families, and services for people with dual diagnoses.

Farkas et al. (2005) outline what “recovery-oriented programming” entails. This is an example of recovery as a program of care, where aspects of the “user-led recovery” concept and the “recovery as a process” concept are applied to a care program: “First person accounts of recovery and empirical research have led to a developing consensus about the service delivery values underlying recovery” (p.141). Farkas et al. (2005) identify four key recovery-oriented values from a user-led perspective (person orientation, person involvement, choice, growth potential) which can be applied to the structural components of care programs. These values can be applied to the organisation and administration of programs in the following areas: mission, policies, procedures, recordkeeping, quality assurance, physical setting, and network. Such values can also be applied to the selection, training and supervision of staff.

Deegan (2005) also recommends the application of user-led recovery concepts to care programs. “When treatment plans support the personal medicine, resilience, and self-assessed health resources of the people who come for help, then clinicians become more effective partners in the journey toward health” (p.35).

Hopper (2007) presents a capabilities approach to recovery. This approach measures quality of life by the valued things people are able to do or to be (their capabilities) as a result of having resources, rather than measuring quality of life simply by the resources people have. Hopper (2007) recommends applying this capabilities approach to contemporary practice: “transforming
what is now a coopted, near-toothless gospel of hope into workable guidelines and tools” (p.874). Thus, recovery as a process or as potential capabilities would become recovery as a program of care.

Ridgway (2001) notes that “helping systems can either amplify resilience and support recovery, or suppress these processes and induce chronicity” (p.342). The author recommends avoiding “socially segregated programs” because they “frequently serve as entrapping niches that reinforce social stigma, reduce access to normative feedback and resources, encourage passive adjustment, and solidify social withdrawal” (p.342).

Lester et al. (2005a) highlight the tension between the approaches of primary care health care professionals to psychosis treatment compared to the expressed views of SUs. Most primary care health professionals interviewed in the study viewed psychosis as a “chronic lifelong condition” (p.4) requiring continuous treatment. However, SUs who were interviewed in the study emphasised elements of care which might promote recovery. Such elements included: “enabling patient choice in treatments, offering talking and alternative therapies as well as medication, and discussing future educational and work opportunities...support from other family, friends, and other patients” (p.4).

The following five papers do not present definitions or conceptualisations of recovery as a program of care: Davidson et al. (2008), Ng et al. (2008), McCabe et al. (2007), Harrison et al. (2001), and Harrow et al. (2005).

**Translational synthesis**

The individual conceptualisations presented above represent the second order constructs of each analysed paper. The final third order construct of recovery as a program of care was subsequently identified after having compared, contrasted and amalgamated various proposed “program of care” conceptualisations.
Definitions of recovery as a program of care may be categorised into three different types. The first type of definition applies biomedical and psychosocial interventions to programs of care which are aimed at stimulating recovery. Evidence-based practice tends to be invoked as a validation of such interventions. Spaniol et al. (2002), Resnick et al. (2005), and Corrigan (2006) propose the application of interventions to recovery programs. These interventions include supported employment, peer-supported services, assertive community treatment, services for dual diagnoses, access to effective medication, above-poverty lifestyles, family psycho-education, and illness management skills. Ramon et al. (2007) report Australian national guidelines for recovery-based care programs recommend early and active use of medications, psychosocial interventions, and attending to individuals’ social and cultural environments. Ramon et al. (2007) also note that this approach “remains more a set of exemplary practices framed and delivered by professionals, albeit within a high quality and innovative clinical setting, rather than one led by users’ definitions of their recovery goals and related journeys” (p.116).

The second type of definition portraying recovery as a program of care places its emphasis on user-led concepts. User-led concepts of recovery are applied to programs or services, but tend not to specify particular interventions. Rather, it is the general attitude of those providing the service that is important here. Bellack (2006), Deegan (2005), and Roberts and Wolfson (2004) present this type of definition, where user-driven and relatively vague terminology is employed without specifying exactly how these concepts might be applied to programs of care, e.g. “holistic”, “respect”, “responsibility”, “self-direction”, and “hope”.

The third type of definition is exemplified by Farkas et al. (2005). Here, user-led concepts of recovery are applied to care programs, but specific recommendations are also made regarding how these concepts might be incorporated into how care programs are structured. The user-led values of person orientation, person involvement, choice, and growth potential are applied to the organisation and administration of programs in the following areas: mission, policies, procedures, recordkeeping, quality assurance, physical setting, and network, as well as to the selection,
training and supervision of staff. Personal involvement in directing care programs is an important element of care programs. Lester et al. (2005a) propose the following interventions based on the reported desires of SUs: “enabling patient choice in treatments, offering talking and alternative therapies as well as medication, and discussing future educational and work opportunities…support from other family, friends, and other patients” (p.4). However, Ramon et al. (2007) points to failed attempts to implement recovery-based care programs in the UK because the “service system is built on programmes aimed at user populations, rather than at the provision of individualised packages” (p.118). To summarise, recovery may be conceptualised as a program of care. The particulars of how this care program might be structured, varies from author to author. Recovery programs may consist of biomedical, psychosocial or user-led interventions.

2.5 Overall Synthesis Output

A first order construct refers to the basic conceptualisations or the everyday understandings held by ordinary people. For example, the way that service-users or professionals conceptualise their own first-hand experiences of recovery would represent first order construct. However, most of the analysed papers were theoretical, and did not include empirical data. Nonetheless, first order constructs were evident in the way in which indicators of recovery were viewed.

Much of the data analysed for the current synthesis was composed of second order constructs as opposed to the first order constructs of lay people. A second order construct refers to conceptualisations created by social scientists and other theorists. The conceptualisations of “recovery” presented by the authors in the 16 analysed papers are second order interpretations. Each of these papers present their own second order constructs of recovery and of related notions. Some of these second order interpretations were created based on the empirical evidence provided by the primary data (i.e. first order constructs) of those same studies. Second order constructs were then compared, contrasted and amalgamated where possible, through the application of a critical interpretive synthesis.
“Third order constructs” (Noblit & Hare, 1988) or “synthetic constructs” (Dixon-Woods et al., 2006a) were the products of this synthesis. They form a coherent theoretical framework for presenting the various meanings of “recovery”. These “third-order” or “synthetic constructs” form the output of the critical interpretive synthesis. However, it should also be noted that the CIS method does not require the creation of third order constructs per se. Third order constructs are part of the meta-ethnography approach to synthesis. Rather, according to Dixon-Woods et al. (2006a), the outcome of the synthesis should be a synthesising argument which “integrates evidence from across the studies in the review into a coherent theoretical framework comprising a network of constructs and the relationships between them. Its function is to provide more insightful, formalised, and generalisable ways of understanding a phenomenon” (p.5).

The output of the synthesis may be organised into the three constructs described in the preceding sections - recovery as an outcome, recovery as a personal process, and recovery as a program of care. The output is illustrated in Appendix 4. These three conceptualisations of recovery from psychosis have parallels in three general approaches to mental health services. These three corollaries are the biomedical, psychosocial rehabilitation, and user-led approaches respectively. The first three conceptualisations (recovery as an outcome, recovery as a personal process, and recovery as a program of care) focus on specific ways of defining recovery, whereas the later three approaches to recovery (biomedical recovery, user-led approaches, and psychosocial rehabilitation) are indicatory terms which help to situate the former three conceptualisations in their respective underlying theoretical frameworks. However, the parallels between the two sets of conceptualisations are not complete. For example, when recovery is conceptualised as a program of care, care programs tend to be heavily influenced by psychosocial rehabilitation interventions. However, the care program may also consist of either biomedical or user-led interventions. Thus, these three corollaries serve only as general guides, and are not exact parallels of the three main recovery conceptualisations which are focused on here.

Due to the lack of distinct boundaries sometimes evident between the three conceptualisations
identified (recovery as an outcome, recovery as a program of care, and recovery as a personal process), and due to the eclectic theoretical approach of some papers to recovery from psychosis, it is suggested that the many and varied theoretical conceptualisations presented here may be positioned along a continuum or spectrum. According to this approach, a single continuum replaces the trichotomy of discrete conceptualisations. This continuum approach would obviate the need to artificially force or “shoe-horn” some of the analysed papers’ second-order constructs into one of the three third-order categories, when they do not obviously subsume into any one specific third-order construct.

2.6 Discussion

One method of scrutinising conceptualisations of recovery is to examine such conceptualisations through the lens of social constructionism. Social constructionism posits that “reality is not self-evident, stable and waiting to be discovered, but instead it is a product of human activity” (Rogers & Pilgrim, 2005, p.15). According to this theory, conceptualisations of recovery may be examined in order to consider the influence of who creates them, as well as the influence of where and when they are created. Meta-synthesis is a method which is concerned with deconstructing concepts such as “recovery” in order to subsequently reconstruct new concepts (Thorne et al., 2004). Deconstruction and reconstruction of “recovery” conceptualisations is also employed here with this CIS. The “who, where and when” of recovery conceptualisations are examined below, under the headings of personal identity/professional socialisation, cultural context, and temporal context. Each of these influences on recovery conceptualisations will be examined.

Influence of personal identity and professional socialisation

How recovery from psychosis is conceptualised appears to be influenced by the experiences and background of the authors (see Appendix 4). Conceptualisations of recovery which focused on outcomes tended to originate from papers written by professionals who have been exposed to
training of a biomedical orientation. Two studies employing an outcome-based conceptualisation of recovery here were Harrison et al. (2001) and Harrow et al. (2005). The primary investigator in the former study was a psychiatrist, while the latter was carried out by three clinical psychologists and a GP. It may be argued that the influence of professional training was evident here, in that some beliefs of individual professionals may have been created through a process of socialisation into particular professional groups. Socialisation refers to the process of learning one’s culture and the appropriate ways of living within it, as well as to the “means by which social and cultural continuity are attained” (Clausen, 1968, p.5). This culture may be a professional culture, such as the culture of medical doctors. Socialisation has been shown to have wide-ranging effects on the social roles, language, norms, values and attitudes of medical doctors (Sinclair, 1997). Biomedical perspectives are impressed upon medical doctors throughout their preclinical and clinical training. As a result of this, medical students and qualified doctors tend to show a preference for knowledge which is based on concrete physical referents (i.e. materialism or biological reductionism). Doctors’ attitudes regarding what constitutes “proper” knowledge, also includes a tendency to view the disciplines of Psychiatry, Psychology and Sociology in a negative light (Furnham, 1986). Sinclair (1997) argues that this collective professional distaste for such disciplines is due to training and socialisation as students. In order to successfully progress upwards though the medical professional hierarchy, certain attitudes are expected and rewarded by superiors, thus possibly perpetuating a negative attitude towards the treatment of mental illness in general, and recovery from psychosis. Sinclair (1997) describes this negative attitude of medical students towards psychiatry in general: “Students find that psychiatrists lack responsibility for the patients in terms of both ownership and action: not only are there ‘multi-disciplinary teams’ including many non-doctors, but nearly all psychiatric treatment is negotiated, and much treatment is talking, hardly action at all” (p.245).

It is interesting to note that medical students tend to hold a negative view of treatment negotiation (Sinclair, 1997). Treatment negotiation is a central tenet of user-led “recovery” conceptualisations, so there is a conflict here between conceptualisations of recovery informed by a biomedical framework (e.g. recovery as an outcome such as absence of symptoms) compared
with those of stemming from a user-led approach (e.g. recovery as a personal process). Medical students believed that negotiating treatments with psychiatric patients was an indicator of the uncertainty of psychiatric knowledge. This uncertainty contrasts with the more certain and “scientific” knowledge-base of other areas within Medicine, which were held in higher esteem. These attitudes are often created through the socialisation process which creates an “exclusive professional identity” (Sinclair, 1997, p.321).

The analysed papers which had contributions from SUs unsurprisingly supported user-led conceptualisations of recovery as a personal process, e.g. Lester et al. (2005a), Deegan (2005), Ridgway (2001), Farkas et al. (2005). This highlighted the influence of a person’s experience on their conceptualisation of recovery from psychosis. However, many of the analysed papers written by mental health professionals (both psychiatrists and clinical psychologists) also supported user-led definitions of recovery, e.g. Davidson et al. (2008), Bellack et al. (2006), Spaniol et al. (2002), Roberts & Wolfson (2004), Resnick et al. (2005), Ramon et al. (2007), Ng et al. (2008), McCabe et al. (2007). Similarly, Lester et al. (2005a) advocated an approach to structuring programs of care based on what SUs would like. This indicates that many psychiatrists, clinical psychologists, and GPs are far from being primarily influenced by their training and socialisation. The article written by a social scientist - Hopper (2007) - advanced views in support of a psychosocial conceptualisation of recovery, again possibly indicating a discipline-related bias. Although there are examples available which contradict the argument that an author’s professional background or discipline always effects their conceptualisations of recovery from psychosis, there is also evidence to support a claim that professional backgrounds may sometimes effect such conceptualisations.

Research into recovery from psychosis has been conducted almost exclusively in the context of secondary care. There is a lack of evidence available in the literature generally regarding recovery from psychosis in a primary care context, as evidenced by the systematic literature review carried out previously. The reason for this apparent lack of research interest regarding recovery from psychosis in a primary care context is unclear. Health research into particular
health specialities is generally carried out by specialists in each particular field. Most mental health research is carried out by psychiatrists, psychologists and allied professionals. The role of the GP is not specifically geared towards psychosis-related problems. Critically, GPs themselves do not see their role as being an important to SUs’ recovery from psychosis, as reported by Lester et al. (2005a): “Most health professionals felt that the care of people with serious mental illness was too specialised for primary care” (p.1122). This may help to explain the lack of research into recovery from psychosis in a primary care context.

In terms of this PhD’s empirical investigations, the CIS informed the PhD by highlighting the need to carry out further research regarding how GPs and SUs conceptualise recovery from psychosis, particularly in a primary care setting.

**Influence of temporal context**

The way in which recovery from psychosis is conceptualised also seems to depend on the temporal or historical context in which each particular conceptualisation is produced. Conceptualisations of recovery from psychosis change over time.

During the closing years of the 18th century the first humane method of treating the mentally ill was applied at the York Retreat, in Britain. The retreat was opened in 1796 by William Tuke, a Quaker and a coffee merchant with no medical background. It was not like other mental health institutions of its day because it was not run like a hospital or an asylum. Instead, it was created as a reaction against the ill-treatment of inmates found in asylums at the time. In the nearby York Asylum, a Quaker called Hannah Mills had died of neglect prior to the opening of the Retreat. The Asylum was reported to be filthy, with excrement on the walls, and the flogging of inmates was routine (De La Rive, 1814). The York Retreat represented a new, humane approach to promoting recovery, whereas for The York Asylum, the idea of recovering from psychosis was not even an issue.
A number of factors at the end of the 18th century led to a reappraisal of what constituted the essential condition of the person with psychosis, and provided the impetus for the movement towards moral treatment. For example, the Enlightenment led to an appraisal of psychosis through its promotion of ideas such as rationality, secular humanism, progressive individualism, liberty, quality, and fraternity. This enlightenment ideology was particularly prevalent in England and France. These were also the two countries where humane “moral treatment” originated, a treatment which had the intention of aiding people in their recovery from psychosis (Warner, 1994).

Similarly, the Industrial Revolution stimulated an increased drive to aid people in their recovery from psychosis. The Industrial Revolution at the turn of the 18th century in England caused a labour shortage. It has been argued that this shortage led to an increased desire to rehabilitate the mentally ill, in order to enable them to rejoin the labour market as productive agents (Warner, 1994). Thus, increased rates of rehabilitation from mental illness were a function of a societal need for extra labour in that particular temporal context. This need for extra labour on the part of English industrialists meant that there was an emphasis on the “moral treatment” of insane inmates, and their recovery to functionality.

Throughout the 19th century, doctors took over the stewardship of many such madhouses. This process involved the enactment of a succession of Laws of Parliament which strengthened this stewardship – The County Asylums Act (1808), The Lunacy Act (1845), The County Asylums Act (1845), The Lunacy Act (1890) and The Lunacy Act (1891). The County Asylums Act of 1808 stated that institutions would be set up to cater for the poor and for the criminally insane mental health patients. This led to an increasing medicalisation of what we now term psychosis, as well as recovery from psychosis.

In 1896, German psychiatrist Emil Kraepelin first popularised the diagnostic category of dementia praecox. Dementia praecox referred to a chronic, inherited, deteriorating psychotic disorder characterized by cognitive disturbances. Dementia praecox was seen as a progressively
degenerating disease, and recovery was deemed not to be possible. Kraepelin’s prognosis for those with dementia praecox was extremely negative – it was chronic, and deteriorated over time. There was little chance of recovery, so any therapeutic intervention would have been ultimately futile. Only 13% of Kraepelin’s patients were rated as having completely recovered (Kraepelin, 1919). This represented a reversal in a trend prior to this, where the idea of recovery from psychosis had been gaining greater emphasis.

In one of the papers under analysis here, Hopper (2007) presents the following historical notions of “social recovery” (p.869):

1. “cure with defect” or “healing with scarring” (Bleuler, 1911, p.163).
2. “healthy people, if eccentric or moody; but they had purchased provisional stability by lowering the level of aspirations with regard to their accomplishments and claims on the world” (Bleuler, 1911, p.163).
3. “adjustment at a social level...getting along quite well in simple life situations” (Strecker & Willey, 1928, p.428-430).

These historical conceptualisations of social recovery are similar to aspects of widely-accepted present-day conceptualisations of social recovery. Bleuler’s therapeutic optimism was the continuation of a tradition which emphasised the importance of humane care (e.g. the York Retreat) for those with mental health problems, which again represented a reversal of the less optimistic attitudes towards recovery from psychosis which were espoused by Kraepelin. Bleuler aimed to minimise institutional care and to avoid unnecessary hospitalisation. Active community rehabilitation was promoted, with Bleuler considering it an established rule that “earlier release produces better results” (Bleuler, 1911, p.475).

The temporal context was also important to conceptualisations of recovery from psychosis during the 1950’s and 1960’s. During this period, there was a growing concern with civil liberties and social freedoms in general society. In the 1950’s, the treatment of mental health patients began to be seriously criticised by the establishment for the first time. The National Council for Civil Liberties targeted cases where people had been wrongly certified and detained in mental health
institutions, publishing “55000 Outside the Law” in 1951. This opened up mental health practice to greater public scrutiny, and a new discourse regarding the civil rights of mental health patients was established, which was developed and popularised with the advent of the “anti-psychiatry” movement during the 1960’s. According to Crossley (2006), the “anti-psychiatry” movement set a precedent for psychiatrists who became internal critics of the flaws of the biomedical approach as they saw it.

The influence of SUs’ views regarding what constitutes recovery from psychosis has also changed over time. Gradually, throughout the last three decades of the 20th century, more and more attention was paid to the views of mental health SUs by service providers. The “People Not Psychiatry” group was set up in 1969 to campaign for the rights of patients within the mental health system. The National Schizophrenia Fellowship (later to be renamed “Rethink”) was founded in 1972 to raise awareness of schizophrenia-related issues amongst the wider public. During the same period, the National Association of Mental Health changed its name to MIND and its outlook became much more radically user-oriented. For MIND, schizophrenia was a label which could cause problems in and of itself. MIND also believed that psychiatric paternalism should be challenged (Crossley, 2006).

It may be argued that all conceptualisations are social constructions, and thus depend on their temporal and spatial contexts. As the years have progressed, Western society has in some ways become more influenced by progressive, enlightened and liberal attitudes. One example of societal attitude change over time is the increased secularism and tolerance which has become a trait of European countries in recent years (European Commission, 2005). This trend could be expected to bring about further positive changes in attitudes among future generations regarding what constitutes mental health, recovery and normality. Approaches to recovery can also be seen to differ historically. What once looked like a minority discourse or trend (e.g. York Retreat) is now becoming a dominant discourse adopted by policy makers and mainstream mental health services. To quote from a lecture given by the former UK Prime Minister Gordon Brown at the University of Westminster: “Nor should we succumb to an excessively Whig-like interpretation...”
of history that assumes an inevitable stage-by-stage progress” (Brown, 2007). Although this warning against a particular type of historical interpretation was given in a different context (security-related issues rather than health issues), the sentiment may be applied to interpretations of how conceptualisations of recovery from psychosis have developed over time.

Conceptualisations of recovery have not strictly followed an ever-increasing tendency towards liberality. By examining the examples of historical contexts outlined above, attitudes to recovery from psychosis alternated from seeing psychosis as a type of crime (pre-Enlightenment asylums), to treating people more humanely (post-Enlightenment York Retreat), back to increasing therapeutic pessimism and chronicity (the rise of psychiatry and Kraepelin), followed by an emphasis on optimistic rates of recovery (Blueler) and an acknowledgement of service-users’ rights and civil liberties (1950’s and 1960’s). It is not clear that more recent trends will necessarily continue in a unidirectional and progressively tolerant manner. This uncertainty is highlighted by the findings of the UK’s Office for National Statistics (ONS) who recently published their “Attitudes to Mental Illness 2008 Research Report”. For example, over recent years there has been a significant decrease in the percentage of British people who agree with the following statements (p.4):

- “We have a responsibility to provide the best possible care for people with mental illness” – 95% agreeing in 2000, down to 89% in 2008
- “We need to adopt a more tolerant attitude towards people with mental illness” – 92% agreeing in 1994, 90% in 2000, and down to 83% in 2008.

Other areas covered by the survey, did show increases in understanding and tolerance of people with mental illness, including an increasing belief that people with mental illness deserve sympathy (ONS, 2008). However, a definite trend indicating ever-increasing public tolerance towards mental illness is not clearly distinguishable.

**Influence of cultural context**

A critical examination of conceptualisations of recovery may be carried out based on the idea that these conceptualisations rely on assumptions which are specific to a particular cultural context.
These Western cultural assumptions are not universally accepted, and do not always translate into non-Western contexts. Western biomedical conceptualisations of recovery presented here have included requirements such as engaging in work or school and living independently in terms of housing. However, the study carried out in a Chinese context (Ng et al., 2008) showed that for people who do not live in a Western society, these requirements do not constitute signifiers of recovery. For example, Chinese participants did not consider living independently from parents to be a necessary requirement of mature adulthood or recovery (Ng et al., 2008). This highlights the fact that biomedical conceptualisations of recovery are based on cultural norms created by Western societies. These norms may not translate into other societal contexts outside the West. Indeed, many people living within Western societies may also disagree with the norms upon which biomedical conceptualisations of recovery are based. Not only are there conceptual differences between Chinese SUs and Western biomedicine, there are also differences between how Chinese SUs and Western SUs conceptualised recovery. Ng et al. (2008) reported that Chinese SUs defined recovery as consisting of cessation of antipsychotic medication and disappearance of symptoms, as well as employment, good familial relationships, and independent living. This conceptualisation is actually quite similar to a Western biomedical conceptualisation of recovery, but diverges significantly from how many Western SUs conceptualise recovery. This highlights the important influence of one’s culture and society as well as one’s personal theoretical perspective when recovery from psychosis is being defined or conceptualised.

**Summary**

This discussion section has outlined three different factors which may influence how recovery from psychosis is conceptualised. A social constructionist approach has been adopted in order to examine how conceptualisations of recovery may be the product of human activity. According to this approach, conceptualisations of recovery may be examined in order to consider the influence of who creates such conceptualisations, as well as the influence of where and when they are created. In other words, the “who, where and when” of recovery conceptualisations are scrutinised. Conceptualisations are informed by the personal identity/professional socialisation of
those who create them, as well as by the period in history when they were proposed and by the cultural and geographical environment in which they were produced. Each of these factors may influence how recovery from psychosis has been conceptualised, as evidenced above.

2.7 Conclusion

The output of the synthesis was used to inform the next chapter of the PhD – the conceptual framework. The CIS facilitated the development of a more robust conceptual framework for the study. For example, the synthesis identified the central importance of context when examining how recovery conceptualisations were constructed. For this reason, social constructionism was seen to provide a way of understanding how context influences meanings and values, including how recovery from psychosis might be constructed in a primary care setting.

Three additional theoretical approaches were identified following the CIS – postpsychiatry, positive psychology, and the autonomy enhancement approach. One consequence of carrying out the CIS was that it highlighted the contested nature of recovery as a concept. It highlighted the idea that recovery could not necessarily be defined solely by healthcare professionals, or solely in an objective and measurable modernist manner. This resonated with the postpsychiatry approach, and the author felt that such an approach might also be usefully applied to an analysis of recovery in primary care settings. The autonomy enhancement approach also challenges notions of expertise, particularly with regard to who should have priority in defining recovery, from an ethical point of view. The decision to include the positive psychology approach in this PhD’s conceptual framework also stemmed from the findings of the CIS. The findings questioned the idea that there is a consensus “disease model” approach to understanding psychosis and recovery from psychosis, and this resonated with the positive psychology approach. Each of these strands of the conceptual framework will be outlined in Chapter 3.

The output of this synthesis will also be used to inform the collection of empirical data. The three recovery conceptualisations will be explored further by carrying out interviews and focus groups
with GPs and SUs. This research will investigate how individual GPs (including those with a special interest in mental health, as well as those without a special interest) and SUs conceptualise recovery from psychosis, with a particular emphasis on recovery in a primary care context. The opinions of GPs and SUs will be sought regarding their views on recovery. An exploration will be undertaken regarding whether recovery in primary care is conceptualised as an outcome, a program of care, a personal process, or as something else. Each one of the three main strands of recovery conceptualisations identified during the CIS encompasses a variety of ways of defining recovery. The empirical work will focus on the many nuanced ways in which recovery may be conceptualised.

An exploration of potential interventions which might facilitate recovery in primary care will be undertaken. An awareness of the differing conceptualisations of recovery from psychosis might prove important in a primary care context. Potential interventions might indicate the opinions, personal experiences, and preferences of GPs and SUs regarding which recovery conceptualisations they find most useful in a primary care context.
Chapter 3

Conceptual Framework
Introduction

This chapter presents the conceptual framework which underpins the PhD. The philosophical underpinnings of the PhD include social constructionism, positive psychology, postpsychiatry, and autonomy enhancement. The importance of each of these approaches to the PhD’s conceptual framework was identified following the critical interpretive synthesis. The output of the synthesis highlighted the importance of context regarding how recovery might be conceptualised in primary care. This chapter will examine how each of these strands of the conceptual framework guided and informed the empirical research and its methodology.

3.1 Social Constructionism

Broadly speaking, social constructionism could be said to be an approach to the study of human thought and behaviour which is informed by the social, cultural, historical and linguistic contexts in which such thoughts and behaviours have developed. However, a singular definition of social construction does not exist as it is a conceptual or meta-theoretical framework rather than a clearly delineated theoretical model (Harper & Spellman, 2006). Although social constructionism is most commonly used by psychologists, many of its assumptions are fundamental to sociology, and social constructionism has been heavily informed by this discipline (Craib, 1997). Social constructionism developed as a radical “critique of the mainstream approaches in western psychology which were seen as individualistic and ignoring the importance of historical and cultural context” (Harper & Spellman, 2006, p.98). A variety of theoretical approaches are underpinned to some extent by social constructionist beliefs, including critical psychology, discursive psychology, discourse analysis, deconstructionism, and post-structuralism. As with postmodernism, social constructionism takes a questioning attitude towards the fundamental philosophical assumptions of modernism and the Enlightenment, such as the search for objective truth. Social constructionism is also related to symbolic interactionism, as both share a view that people construct their own identity and the identity of others through everyday social interactions with one another (Burr, 2003).
Social constructionism as a conceptual framework is founded upon a number of related assumptions which were initially outlined by Gergen (1973, 1985), and further elaborated upon by Burr (2003). According to social constructionism, taken-for-granted knowledge should be critically examined and questioned. Knowledge is assumed to be culturally, socially, and historically specific. Knowledge is sustained by social processes, rather than being fundamentally dependent on empirical validity. Descriptions and theories are not neutral, but rather are social actions which serve to sustain certain viewpoints to the exclusion of others. Theories which attempt to explain phenomena in an ahistorical or culture-free manner are flawed. Social constructionism takes a critical approach to realism by assuming that one cannot directly perceive a naively objective truth and that “reality” as we know it is socially constructed.

Epistemology concerns the question of what is knowledge or how is knowledge acquired. In terms of its epistemology, social constructionism is anti-essentialist. Anti-essentialism involves a belief that any given phenomenon or entity cannot be defined in terms of specified characteristics, which that phenomenon must have in order to be defined as that phenomenon. Social constructionism resists searching for innate discoverable psychological essences like “personality”, “cognitions”, or “emotions”. At the same time, it does not claim that such essences or constructs do not exist in any form.

Social constructionism also emphasises the importance of language. Language is assumed to be central to how humans view the world. Language is not merely descriptive, but rather is a social action and is constitutive. Through the use of certain words, constructs are brought into existence, and become a particular way of viewing phenomena.

There are two broad forms of social constructionism. These have been labelled as a ‘micro’ and ‘macro’ social constructionism by Burr (2003) or alternatively as ‘light’ and ‘dark’ social constructionism by Danziger (1997). Micro social constructionism emphasises the micro structures of language in interaction, where people are seen as being able to construct themselves
and each other. This has been perceived as being a more hopeful analysis in terms of the agency of individuals, hence the label of “light” social constructionism. This form of social constructionism is often present in discursive psychology, such as that described by Gergen (1999). On the other hand, macro social constructionism places a greater focus on the role of macro linguistic and social structures which influence our social and psychological life. This approach is evident in Foucauldian discourse analysis, for example in Foucault (1972) and in Rose (1990). It should be noted that these two forms of social constructionism are not mutually exclusive and may be employed in conjunction with one another as part of an analysis which includes both micro and macro elements. Wetherell (1998) has called for a synthesis of the two approaches as this would address both the situational and institutional elements at work during the construction of accounts.

Danziger (1997) has highlighted a limitation of social constructionism. It originated as a radical critique of mainstream psychology, and it paradoxically requires the continued existence of mainstream psychology in order to maintain a critique of some of the discipline’s perceived shortcomings. There is a tension regarding whether social constructionism should continue its attacks and subversions of mainstream psychology from the margins, or if it has the ability to generate its own independent theoretical and research programmes.

Social constructionism informed two elements of this PhD: the CIS and the empirical methodology. In the previous chapter, the way in which different conceptual frameworks affect definitions of recovery from psychosis was explored. The CIS outlined different factors which may influence how recovery from psychosis has been conceptualised. The CIS concluded that a social constructionist approach provided a potentially helpful way of understanding the influence which the person who creates the conceptualisation has on the conceptualisation itself. It also focused the investigation of conceptualisations on the context of where and when the conceptualisations were created. According to social constructionism, conceptualisations may be informed by the personal identity or the professional socialisation of those who created them, as well as by the period in history when they were proposed and by the cultural and geographical
environment in which they were produced. Thus, the “who, where and when” of recovery conceptualisations were identified as being considerations of great importance. In addition, social constructionism informed this PhD’s empirical methodology. Social constructionist grounded theory (Charmaz, 2006) guided how interview data was sampled and analysed. This is discussed in greater detail in Chapter 4 which outlines the methods used during the empirical research.

3.2 Postpsychiatry

This PhD is also informed by postpsychiatry (Bracken & Thomas, 2005), a term first used by Campbell (1996). Postpsychiatry is a postmodern critique of mainstream psychiatry. As with social constructionism, postpsychiatry is neither a model nor a theory. Rather, postpsychiatry is a critique. It shares many assumptions with social constructionism such as an emphasis on the importance of the social, cultural and historical contexts which frame mental health problems. While social constructionism tends to focus its criticisms on the failings of mainstream psychology, postpsychiatry focuses more on the failings of a related discipline - mainstream psychiatry. However, it should be noted that postpsychiatry also casts a critical eye over CBT approaches utilised in clinical psychology and psychotherapy. For example, Bracken and Thomas (2005) invoke the argument of Proctor (2002) that CBT interventions do not pay enough attention to the power dynamics which exist between the SU and the therapist, as well as arguing that the therapist’s power is derived from the contestable assumption that they are able to objectively decide what is best for the SU due to the therapist’s access to science and rationalism. According to postpsychiatry, the CBT therapist views SUs’ understanding of themselves and the world as potentially flawed and in need of rectifying.

Modernism is defined by Bracken and Thomas (2005) as “a belief that science and technology are the main way forward” (p.5). Postpsychiatry argues that managers and professionals are often keen to assert modernism in mental health services, with a resultant emphasis on the expertise of professionals, the application of technologies and technological language to mental health and emotional problems, and an individualistic decontextualised approach to mental health.
Postpsychiatry argues that when responding to psychosis, ethics should be given precedence before pharmacological or psychological interventions. Any coercion accompanying interventions should be minimised, and interventions should be directed by values and meanings as with the values-based practice described by Fulford (2004).

Postpsychiatry emphasises the need for greater SU involvement in the planning and development of services. It also emphasises the importance of the critical professionals’ movement in bringing about a change in the level of SU involvement, and is cautiously optimistic about the further growth of a critical professionals’ movement into the future.

“The winds of change are also beginning to blow through the professional sector. Many mental health nurses, psychologists, occupational therapists, managers and social workers, who have long argued for user involvement in the planning and development of services, are now being joined by a growing number of psychiatrists who are waking up to the positive benefits of working in collaboration with users and carers, and are joining the call for change” (Bracken & Thomas, 2005, p.1).

Postpsychiatry’s views on SU involvement in service development, as well as its views on the growth of a critical professionals’ movement form a key part of the conceptual framework upon which this PhD is constructed. This PhD will apply a postpsychiatry framework to the setting of primary care, and will explicitly aim to ascertain the views of SUs regarding how they believe recovery from psychosis might be promoted in primary care. This PhD will also involve the collection of GPs’ views and experiences, including those of some GPs’ who may be critical of the present system, and are advocates of greater collaboration with SUs. According to postpsychiatry, these critical GPs may play an important role in increasing the involvement of SUs generally in setting their own recovery agendas.

3.3 Positive Clinical Psychology
Clinical psychology as a discipline has traditionally placed more of its academic and clinical focus on negative aspects of human nature rather than on the wider spectrum of human attributes. An analysis of the number of positive versus negative subjects in all psychology publications available in the PsycINFO database from 1872 onwards established that twice as much psychological research has focused on negative terms such as sadness, hopelessness and pessimism in comparison to their positive dialectic equivalents such as happiness, hope and optimism (Rand & Snyder, 2003). Positive clinical psychology is a relatively new branch of psychology (Seligman, 1999) which aims to redress this imbalance by focusing on positive strengths and qualities in addition to psychopathology and deficits. At first glance, this would appear to be a simple idea, but it has been frequently neglected within clinical psychology. According to Maddux et al. (2004), the discipline of psychology had three main aims prior to World War II: helping all people to lead fulfilling and productive lives, identifying and encouraging talent, and treating mental illness. However, in post-war America, psychology tended to focus primarily on the third of these three aims. The Veterans Administration and the National Institute of Mental Health were set up in 1946 and 1947 respectively, and psychology began to follow a disease model, using the language of illness.

Positive psychology shares some implicit commonalities with one of its antecedents - humanistic psychology. This approach focused on self-actualisation and on realising the potential of people (Rogers, 1961; Maslow, 1968). In fact, Maslow identified psychology’s prioritisation of disorder many decades before the establishment of positive psychology as a coherent approach to psychology:

“The science of psychology has been far more successful on the negative than on the positive side. It has revealed to us much about man’s shortcomings, his illness, his sins, but little about his potentialities, his virtues, his achievable aspirations, or his full psychological height. It is as if psychology has voluntarily restricted itself to only half its rightful jurisdiction, and that, the darker, meaner half” (Maslow, 1954, p. 354).
A positive psychological approach to the discipline of psychology (and, by extension, to other areas such as primary care mental health) argues that research and its clinical applications should focus on “understanding the entire breadth of human experience, from loss, suffering, illness, and distress through connection, fulfillment, health, and well-being” (Linley et al., 2006, p.6).

Traditional psychology focuses primarily on distress, disorder, and dysfunction. Positive psychology argues that we should also focus on wellbeing, health, and optimal functioning. However, the aim of positive psychology is not to deny the existence of negative experiences, but rather to achieve a synthesis of both approaches. This balanced synthesis of the positive and negative aspects of experience has been described as follows:

“The integration and resolution of these dialectics, thus evolving into ‘simply psychology’, with a focus that spans the whole of the human condition, from disorder and distress to well-being and fulfillment” (Linley et al., 2006, p.6).

Positive psychology has been conceptualised by its founders as existing on three levels: the subjective, the individual, and the group:

“The field of positive psychology at the subjective level is about valued subjective experiences: well-being, contentment, and satisfaction (in the past); hope and optimism (for the future); and flow and happiness (in the present).

At the individual level, it is about positive individual traits: the capacity for love and vocation, courage, interpersonal skill, aesthetic sensibility, perseverance, forgiveness, originality, future mindedness, spirituality, high talent, and wisdom.

At the group level, it is about the civic virtues and the institutions that move individuals toward better citizenship: responsibility, nurturance, altruism, civility, moderation, tolerance, and work ethic” (Seligman & Csikszentmihalyi, 2000, p. 5, emphasis added).

The argument for the positive psychology approach is not based on wishful thinking or nebulous positivity. Evidence exists to show that the absence of positive characteristics predicts the onset
of disorder. People low on positive well-being are up to seven times more likely to meet criteria for depression 10 years later, and this effect persists after controlling for the presence or absence of negative characteristics like neuroticism (Wood & Joseph, 2010). Positive characteristics have also been shown to provide resilience to the effect of negative life events and negative characteristics on psychotic symptoms (Johnson et al., 2010).

As a strand of the conceptual framework, positive clinical psychology has influenced this PhD by expanding the research focus to encompass interview questions which may stimulate participants to discuss positive elements of recovery from psychosis in primary care, and how recovery might be promoted in primary care. Interview questions will not demand a focus on positive psychological experiences and traits, but will implicitly encourage this by asking participants to explore what factors they feel promote recovery (as well as asking about the barriers to promoting recovery). Interviews will encourage an exploration of positive subjective experiences and outcomes such as well-being, hope, optimism and happiness, as well as the personal strengths and resilience of those who have experienced psychosis. Interviews will encourage the exploration of how communities and institutions (such as primary care health services) can promote recovery from psychosis. Positive psychology has influenced the practising of innovative positive approaches to CBT which as a therapeutic approach has traditionally focused on threats, negative experiences, negative mental states, negative emotions and negative cognitions (Tarrier, 2010). Positive psychology has also influenced the practising of strengths-based interventions in social work (Noble et al., 2000). This PhD will investigate whether a strengths-based positive psychology approach can also be applied to primary care and the promotion of recovery from psychosis in that setting.

3.4 Autonomy Enhancement

Clinical psychologist Richard Bentall (2009) has proposed an approach to mental health care called the “recovery-orientated, autonomy-enhancing approach”. This approach to care is underpinned by a belief in the SU led conceptualisations of recovery previously discussed in
Chapter 2 of this PhD. Bentall (2009) describes his understanding of the “recovery approach” as follows:

“These services typically encourage optimistic expectations in their own treatment goals. Services of this kind prioritise the fostering of close, collaborative relationships between clinicians and service users” (p.266).

In addition to being informed by SUs’ conceptualisations of recovery, the autonomy-enhancing approach emphasises the need for mental health professionals to relinquish decision-making powers to SUs. Bentall (2009) argues that the psychological well-being of SUs would be promoted if they were to have more authority and autonomy in relation to their own treatment and care plans. In addition, the autonomy-enhancing approach considers the rise of an organised SU movement as the “greatest force for good in modern mental health care...empower(ing) patients to pursue avenues of recovery chosen by themselves” (p.287).

The autonomy-enhancing approach posits that respect for autonomy is an inherent part of medical ethics (Gillon, 1985). Thomas Szasz (1960) argued that the autonomy of SUs was desirable based on libertarian and human rights reasons (i.e. deontological reasoning based on universal moral laws). In addition to this deontological reasoning, the autonomy-enhancing approach argues for autonomy because of the increased well-being that it brings to as many people as possible (i.e. utilitarian reasoning).

The autonomy-enhancing approach of Bentall (2009) defines autonomy in a broad sense – “the absence of coercion” (p.273). The denial of autonomy due to the paternalism and coercion sometimes employed by mental health professionals is criticised by Bentall (2009) for the four reasons summarised here:

1. Coercion is only justifiable if professionals reliably know what is in SUs’ best interests, which is not always the case.
2. Coercing SUs to undergo treatment is wrong if the treatment is ineffective.
3. Coercion reduces self-empowerment and self-efficacy, and is intrinsically damaging to mental health.
4. Coercion damages the therapeutic relationship between the professional and the SU.

The autonomy-enhancing approach informs this PhD by providing a conceptual framework which envisages an alternative approach to future mental health services. The autonomy-enhancing approach is not specific to secondary services provided by psychiatrists and clinical psychologists. It is also applicable to treatment and care provided by GPs in primary care settings. The empirical research will not explicitly ask questions pertaining to an autonomy-enhancing approach to psychosis in primary care, as such questions would be too leading. Rather, the research will investigate whether an autonomy-enhancing approach will be mentioned by GPs and SUs independently and of their own accord. If GPs and SUs deem autonomy to be important, we will also investigate the ways in which GPs might be able to provide such autonomy in primary care for SUs who have experienced psychosis.

**Summary and Synthesis**

This chapter presented four approaches which constitute the conceptual framework. They provide a philosophical basis for this PhD, as well as informing the empirical research investigation. The philosophical underpinnings of this PhD include social constructionism, positive psychology, postpsychiatry, and autonomy enhancement. Each of these strands of thought has its own specific origins and particular emphases. However, they also share a critique of current mainstream mental health services in general.

A synthesis of these four strands involves taking aspects of each approach and applying them in a coherent form to a primary care setting. This synthesis takes social constructionism’s critique of mainstream psychological and postpsychiatry’s critique of mainstream psychiatry and applies them to how GPs promote recovery from psychosis in primary care. For example, is the imposition of psychiatric medications and psychological technologies in primary care the most
appropriate course of action for GPs to take, particularly if social, historical, and ethical considerations are not given priority? Along with these two critiques, the synthesis also applies the strengths-based approach of positive psychology and the autonomy-based approach of the autonomy enhancement model of recovery to a primary care setting. This synthesis has been brought together to underpin the overall conceptual framework of this PhD.

This synthesised conceptual framework involves a critique of applying the modernist project to mental health services without taking account of the following factors: ethical considerations, respect for autonomy of SUs, the values and meanings of SUs, the strengths and potentials of services users, and the social, cultural, historical and linguistic contexts within which mental health is constructed. This synthesised conceptual framework will be used to inform this PhD by providing sensitizing concepts which will guide and orientate the empirical research.

An important consequence of the conceptual framework adopted was the way in which it informed the choice of empirical research methods. Social constructionism formed a key element of modified grounded theory, and it was this approach which was subsequently chosen as the central method of the empirical work undertaken. The use of modified grounded theory as an empirical method will be discussed in the next chapter, as will other aspects of the methodology.
Chapter 4

Methodology
Introduction

This chapter consists of three sections. In section 1, the theoretical background to the methodologies employed in the interviews and focus groups is discussed, including a justification for the use of a qualitative approach to data collection for this research study and a discussion of the critical incident technique. The possible impact of the interviewer’s background and training on the research is examined as well as issues of reliability and validity.

In section 2, the empirical methodology is described in detail, with reference to access to and recruitment of participants, methods of sampling, the creation of topic guides, collection of demographic information, and the carrying out of interviews.

In section 3, the approach to data analysis is described, along with the stages of the analysis. The stages of data analysis include familiarisation with the data, indentifying codes and manual coding, formulation of a thematic framework, nVivo coding, finding associations between codes, and building a consensus amongst the three investigators in each stage of the process. The iterative process is discussed, including where the analysis led to the inclusion of further questions and topics in subsequent interviews and focus groups.

4.1 Theoretical background of the methodology

4.1.1 Using a qualitative approach

Qualitative research is generally defined by its study of phenomena in natural or non-experimental settings, and by not primarily seeking to answer research questions in a quantifiable manner (Miles & Huberman, 1994). The strengths of qualitative methods lie partly in their ability to study meaning as well as causes, and to study process as well as outcome (Hammersley, 1992). Qualitative research methods were chosen for the collection and analysis of data for a number of reasons. The central research questions were exploratory – examining what recovery from psychosis meant to GPs and SUs, and exploring their personal experiences of recovery. Qualitative methods are more suitable than quantitative methods when the research question is
exploratory. Qualitative approaches attempt to understand the unique worldviews of research participants, to discover the different meanings which participants ascribe to the phenomena being researched, and to explore the details of participants’ lived experiences (Neale, Allen & Coombes, 2005). Indeed an investigation of the wide range of complex personal attitudes, beliefs and behaviours might be inaccessible to quantitative research methods, especially in an exploratory study (Pope & Mays, 1995; Sinclair & Green, 2005).

Qualitative methods were also chosen due to their greater ecological validity. When a study possesses ecological validity, the setting, materials and methods of the study approximate the real-life situation under investigation (Brewer, 2000). The study is undertaken in a more naturalistic setting than is the case with experimental research designs. This naturalistic context also allows for richer data to be collected. Unlike rigid pre-defined experimental designs, qualitative methods also allow for a degree of flexibility as to how the research is carried out with each participant. This is particularly useful when the research topic is not yet well understood, and reflexive and iterative hypothesis-generating methods may be more appropriate (Britten et al., 1995).

Exploratory research in this area was also required in order to inform future theory. This research study attempts to generate hypotheses not test them, and is thus amenable to qualitative inquiry. Qualitative methods are employed when hypothesis generation is the goal. Such methods enable the development of explanatory concepts which may help us to understand phenomena related to recovery in primary care. Rich descriptions of complex circumstances can be built through the application of qualitative research methods (Marshall & Rossman, 1999).

### 4.1.2 Semi-structured interviews

Semi-structured interviews were employed as a method in the first round of data collection. Interviews were semi-structured in that a specific topic guide was created beforehand, but this topic guide was brief, general, and flexible. The semi-structured interviews had a certain number of pre-defined topics of interest that all participants were asked about. However, these scheduled, exploratory, open-ended questions were supplemented with further relevant, probing questions
The interview topic guides (see Appendix 5) allowed for new questions to be brought up during the interview as a result of what participants said. The initial topic guide was planned in advance so that the core topics of importance could be explored in each interview. This topic guide was a “grouping of topics and questions that the interviewer can ask in different ways for different participants” (Lindlof & Taylor, 2002, p. 195). The topic guides were used to prompt participants to talk about particular experiences and incidents in their life, while allowing flexibility in terms of the kind of information that participants chose to offer (Sinclair & Green, 2005). This enabled the interviewer to focus on topics during the interview without constraining them to a particular format, whilst being able to tailor questions to the particular interview context and to the individual participants (Lindlof & Taylor, 2002).

The semi-structured interviews were used as a means of investigating the definitions that each of the participants had for the concept of recovery from psychosis in primary care. This allowed for the individual lived experience of each of the GPs and SUs to be documented. Strauss and Corbin (1998) described such research in the following way: “Although we do not create data, we create theory out of data. If we do it correctly, then we are not speaking for our participants but rather are enabling them to speak in voices that are clearly understood and representative” (p.56).

Additional topics were added to the topic guides as the number of interviews undertaken increased. This was an essential part of the iterative process, whereby topics unexpectedly introduced and discussed by a participant in one interview could then be explored further in subsequent interviews with other participants. Thus, the data-gathering process was responsive to emergent data (Charmaz, 2006).

Interviews incorporated a technique called the “critical incident technique”. This technique was invented by an American Air-Force psychologist during World War II in order to ascertain exactly why pilots failed training (Flanagan, 1954). In its original application, the critical incident technique was employed in an interview schedule which asked the pilots’ instructors to cite specific incidents where a trainee pilot had been particularly effective or ineffective. The core characteristic of this technique involves asking participants to cite particular instances or events.
By focusing participants’ attentions on certain events, the participant’s recall of specific details is aided, and vague generalisations are reduced. At the same time, questioning should be open-ended and unprompted so as to avoid deductively categorising the data into pre-existing theories. The incidents that are asked about in this study are “critical” in the sense that they are consequential or meaningful for the topic under study, i.e. recovery from psychosis in primary care. The critical incident technique works particularly well when it is employed in the exploration of a dichotomy, i.e. a good experience versus a bad experience (Bradley, 1992). As well as being a method for collecting data, the critical incident technique may also be used as a method for analysing data, although it was not used for the latter purpose in this PhD. It has been noted that the critical incident technique does not consist of a set of structured rules regarding its application; rather it is flexible and modifiable according to the specific needs of a particular study (Flanagan, 1954). The critical incident technique has previously been used in research into primary care service provision for patients experiencing serious mental health problems (Lester et al., 2005a).

When the critical incident technique was applied to this PhD, participants were asked to recall an incident (in this case an episode of psychosis) where they felt they recovered well (SUs) or facilitated recovery well (GPs). They were then asked to recall an occasion where they felt they did not recover well (SUs) or did not facilitate recovery well (GPs). This technique allowed the participants to define recovery themselves, without being presented with preconceived definitions of what recovery entails. The participants’ perspectives on recovery unfolded as the participant saw it, not as the interviewer saw it. This open-ended approach allowed for clusters of themes and factors to be identified inductively after analysis, without reference to pre-existing theories.

Questions for the interview topic guides were generated through the author’s exposure to different accounts of recovery from psychosis which were encountered during the Critical Interpretive Synthesis. It was apparent from reading the literature that there were many different definitions of recovery in existence. This lack of coherence between different individuals’ accounts led to the inclusion of the first two questions in the topic guide. These questions investigated the meaning of recovery for participants, as well as participants’ views on the processes involved in recovery and in lack of recovery.
A pilot interview with a SU was undertaken before the main study took place to ascertain if there were any problems with the interview process which needed rectifying. The length of the initial pilot study interview was deemed to be too long at almost two hours, so the number of probing questions was reduced in the subsequent main study for both SUs and GPs. The first two GP interviews were used to assess whether or not there was a need to significantly alter the interview process as originally planned for GPs. Significant alterations were not required, although the topic guides continued to be modified slightly throughout the main study interview process. This was particularly the case as new topics emerged with the first group of GP interviewees – those GPs with a specialist interest in mental health. Topic guides for interviews with SUs were also modified slightly throughout the main study interview process, as new topics emerged during interviews.

4.1.3 Focus Groups

Focus groups were used in this PhD, as the second part of a two-pronged research strategy. The focus group is most commonly used for “an in-depth exploration of a topic about which little is known” (Stewart & Shamdasani, 1990, p.102). Focus groups are used not for generalising or making inferences, but for understanding such things as individual personal perceptions and experiences (Krueger, 1994).

In a focus group discussion, participants are encouraged to talk about specific topics so that underlying beliefs and experiences may be uncovered which are common to all or some participants (Bloor et al., 2001). The major epistemological reason that focus groups were chosen for collecting data was that it allowed for an investigation of participant commonality (Parker & Tritter, 2006). In this PhD, participants were invited to the focus groups because they had something in common with each other (i.e. either having experienced psychosis personally, or having dealt with psychosis professionally in a primary care setting). Thus, psychosis and recovery from psychosis in a primary care setting was the common “focus” of the focus groups. Focus groups also allow participants to discuss the contributions of others, thus expanding on
points that might have been left undeveloped in the semi-structured interviews (Powell & Single, 1996).

Focus groups differ from group interviews. The two differ regarding the role of the researcher, and regarding the researcher’s relationship to what is being researched (Smithson 2000). In focus groups, the researcher is a “moderator” or “facilitator” of the discussion between the participants. The researcher takes a peripheral role so that their effect on the dynamics and the interactions between the participants is kept to a minimum. Conversely, in group interviews, the researcher controls the group dynamics by investigating particular topics with specific participants. In group interviews, the researcher is an “investigator” asking questions and receiving answers directly from respondents, without a group discussion necessarily taking place between participants.

In this PhD, the focus groups allowed GPs and SUs to meet and interact in mixed groups, elaborate on pertinent aspects of recovery from psychosis in primary care, and discuss complex aspects of recovery which were explored in the individual semi-structured interviews. The focus groups also provided a useful forum for SUs and GPs to share their experiences with each other, possibly providing new insights for both groups of participants.

A number of broad, open-ended questions were selected for the topic guide (see Appendix 5). These questions were chosen in a similar fashion to those for the interview topic guides. The initial focus group topic guides were preliminary in nature, and were altered prior to the first focus group based on the findings of the semi-structured interviews.

A disadvantage of using focus groups can be that participants may find it difficult to disclose sensitive personal information in a group situation. Some participants may feel more inhibited than others and contribute relatively less to the discussion. In order to limit this possibility, one of the roles of the facilitating moderator is to encourage universal participation within the group, with the goal of all participants contributing synergistically to the discussion (Kitzinger, 1994). In this PhD, two moderators (SR and HL) were present to facilitate both of the focus groups, which lasted approximately one and a half hours on each occasion. One of the moderators was primarily
responsible for facilitating discussion between participants, while the second moderator was primarily responsible for manually recording supplementary observational data.

4.1.4 Interviewer’s background and training

It has been noted that the qualitative research process can result in a focus on particular phenomena and questions at the expense of others (Morse, 2003). This particular focus may be interpreted negatively as possibly leading to an incomplete representation of the phenomena being investigated. Conversely, this prior research focus has also been interpreted in a different light by Blumer (1969). He described such initial research interests, ideas, and concepts as “sensitizing concepts” which provided a loose framework with which the researcher pursued particular research questions. This biased or sensitised focus may be due to a range of factors including the background of the researcher. It is important that this is recognised as part of the research process. The interviewer’s personal biography, gender, ethnicity, age, social status and experience can all affect the research process, including the data collection and the analysis (Burgess, 1977). For transparency purposes, basic biographical information about the interviewer in the case of this PhD is provided here. The interviewer (SR) is male, Irish, and born in 1984. SR has previously worked or volunteered for organisations that provide services to people with a range of difficulties including mental health problems such as psychosis, depression, and anxiety (Self-Help Services Manchester, Anxiety UK, and Pennine Care NHS Foundation Trust). SR holds a bachelor’s and a master’s degree in Psychology, which included basic training in interviewing for research purposes. However, this previous training in Psychology focused primarily on quantitative research methods. Before data was collected for this PhD, further training was provided to the interviewer in interviewing techniques and focus group facilitation by the School of Social Science. In addition, the interviewer’s primary supervisor (HL) provided support and detailed information about interviewing techniques and focus group facilitation.

In order to limit bias, Morse (2003) suggests that a variety of standpoints and approaches should be used to examine the phenomena under research. The Psychology background of the interviewer (SR), along with the GP/Medicine background of the main supervisor (HL), and the
Sociology background of the second supervisor (AR) provided a multi-disciplinary, diverse and balanced approach to the research process which helped to reduce “conceptual blindness”.

4.1.5 Reliability

Reliability has been defined as the degree to which different observers agree on which instances are assigned to the same category. Reliability also refers to the degree to which the same observer agrees about which category to assign an instance to on different occasions (Hammersley, 1992). In other words, it refers to the consistency of research observations. It has been argued by some qualitative social scientists that reliability is a concept more suitable for quantitative research, as reliability is viewed as being irrelevant in a subjective and socially constructed world (Marshall & Rossman, 1989). On the other hand, some contend that the value of qualitative research should be measured by its reliability (Kirk & Miller, 1986). However, it has been acknowledged that the complexities of field relationships are not easily reconciled with standardisation or replication (Booth & Booth, 1994).

One method of ensuring reliability is through the assessment of inter-rater reliability. Different researchers code the data initially and compare their results. In this PhD, three researchers were involved in independently coding the data, and a consensus position was then subsequently agreed upon as part of the triangulation process (Armstrong et al., 1997).

A second method of ensuring reliability in qualitative research is through the use of note-taking during the data collection phase. Field notes can be used to complement the recorded interviews and their transcripts. Note taking may take different forms depending on the preferences of the researcher. This PhD used a modified version of the note-taking method outlined by Spradley (1979). This modified method did not involve taking notes during the actual interviews, as it was felt that this might lead to an atmosphere of increased formality during the interviews which might in turn affect the level of personal disclosure forthcoming from the interviewees. Booth and Booth (1994) argue that note taking during the interview is intrusive and should be avoided: “It comes between the interviewer and the informant; it is just as intrusive as recording; and it diverts attention from the transactional side of the interview process” (p.419).
Instead of making notes during the interview, field notes were made immediately after each interview, alongside notes on problems and ideas that arose during the research process.

4.1.6 Validity

Validity has been defined as the accuracy with which an account represents the phenomena to which it refers (Hammersley, 1990). As with the issue of ensuring reliability, ensuring the validity of semi-structured interview data can be more difficult than when dealing with more structured data. Neill (1999) refers to the necessary “trade-off” inherent in the choice of data collection methods. One the one hand, structured data collection methods may provide greater precision in measurement, reliability and validity. Conversely, semi-structured interviewing may provide a fuller, richer, more in-depth understanding of the topic under investigation (Gardner, 2010).

Not only is the validity of qualitative research difficult to assess, but the relevance of the concept of validity to this type of research has been challenged. The researcher cannot verify the accuracy of an interviewee’s account, as it is impossible to have independent access to the interviewee’s inner world of experience (Booth & Booth, 1994).

Five methods for checking the validity of the data analysis were employed in this PhD - counting the frequency of themes, triangulation, respondent validation, searching for disconfirming evidence, and the intuition of a feeling human observer. Each method will be briefly outlined.

*Counting the frequency of themes:*

Qualitative research does not necessarily mean that the research should not include quantitative elements. Counting the frequency with which particular themes arise in the data is one method of providing a survey of the whole data set (Silverman, 1993). It allows the researcher to decide if data fragments (in the form of quotes) taken from an interview are representative of the entire data set.

*Triangulation:*
Triangulation was used to increase validity, by employing two different methods (interviews and focus groups) in order to compare the results. Different methods provide different avenues for data collection, as well as allowing participants to present their experiences and representations in different temporal, spatial and social contexts. Triangulation facilitates validation of data through cross verification from multiple sources (Bogdan & Biklen, 2006).

**Respondent Validation:**
When the researcher presents their analysis of the initial data back to the informant, this is known as respondent validation. It allows the researcher to check the validity of their analysis with the informant. Respondent validation was carried out in this PhD by recycling the evidence gleaned from informants during the interview stage back to the informants in the later focus group stage. This checks with the participants that they are in agreement with the researcher’s interpretation of the data (Lincoln & Guba, 1985).

**Disconfirming evidence:**
Searching for disconfirming evidence is another method of increasing validity. This involves searching for data that doesn’t fit the theory proposed in the analysis. This search may lead to an appropriate reformulation of hypotheses in the light of conflicting evidence. Validity is increased by researchers seriously attempting to falsify their theories (Silverman, 1993).

Here is an example from the present study where data was used as disconfirming evidence, thus leading to a reformulation of a hypothesis. An initial theory was formulated which proposed that if there was a lack of supportive social networks available, GPs generally believed that this hindered the recovery of SUs. Furthermore, social support was seen by GPs as being provided most frequently by family members of SUs. This initial theory was based on the finding that a majority of GPs felt families played a very important role in providing social support. However, disconfirming evidence was also found, with two GPs reporting that the support of family members had in fact led to a deterioration in the condition of those SUs whom the families were intending to support. The initial theory was then modified to incorporate this data. The modified theory proposed that GPs generally believed recovery was hindered by a lack of supportive social networks, with this social support being most frequently provided by family members of SUs.
However, the theory also proposed that when family support led to an unwanted reduction in SU independence or an increase in SU anxiety and family tension, then social “support” provided by the family was not seen as helpful by GPs.

Researcher’s observation and intuition:
The final approach to ensuring validity in this PhD was not a technical check of the data. Booth and Booth (1994) suggest that the intuition and the feeling of the researcher as a human observer are important in how the researcher determines the validity of the data:

“The validity of the data is the stuff of the relationship between the interviewer and the informant...It is through close personal contact that researchers slowly learn whether to believe what they are told. The first requirement here is time spent with the informant” (p.421).

In order to achieve validity in this way, the researcher spent time observing and getting to know the majority of participants before undertaking interviews. For example, weekly psychosis support groups were attended for over a year, during which time the researcher got to know most of the SU participants before interviews took place. Similarly, the researcher spent two days and nights getting to know GPwSIs during educational sessions for their Masters course and during informal leisure activities outside of the educational sessions. In this way, the requirement of “time spent with the informant” was achieved, and the validity of the data was increased. Apart from increasing validity, this approach also helps to build trust and achieve disclosure.

4.2 Empirical Methodology

4.2.1 Recruitment Strategy

GPs were initially recruited through the charity “Primary Care Mental Health and Education” which runs a Masters course at Staffordshire University for GPs with a special clinical interest in mental health. This group of GP participants were targeted in the first phase of data collection because they had already demonstrated their interest in mental health issues by selecting themselves for the “Primary Care Mental Health and Education” course. These GPs who had a special interest in mental health were expected to provide information-rich and experience-rich
data on recovery from psychosis in primary care. This initial group of participants provided a particular set of data, which was then developed in subsequent interviews with GPs who did not necessarily have a special interest in mental health. This theoretical sampling (Glaser & Strauss, 1967) did not aim to be representative of the entire population as probabilistic sampling does but was employed in order to better understand the particular issues of interest and to help develop a conceptual framework for recovery from psychosis in primary care.

The sampling framework for GPs aimed to include individuals who had potentially diverse views on recovery from a primary care perspective. The initial interviews were carried out with GPwSIs. It was anticipated that this subset of GPs would have a greater interest in psychosis, and were likely to have more experience and knowledge of working within this particular area of primary care. GPwSI interviewees were recruited from a group of GPs who were participating in a master’s degree program at the University of Staffordshire entitled “Practitioner with a Special Interest in Mental Health”. The 17 participants were invited from a total available pool of 22 GPs who were enrolled on the course.

GPwSIs (without a special interest in mental health) were subsequently interviewed once the interviews with GPwSIs had been completed. The additional interviews with GPwSIs were undertaken in order to provide a wider range of GP experiences, interests, and views regarding recovery from psychosis. GPwSIs were recruited from two NHS PCTs – Manchester PCT and Stockport PCT. A letter was sent to every GP in these two trusts explaining the purpose of the study and inviting them to participate. A total of 148 GPs (99 in Manchester, 49 in Stockport) were contacted.

Recruitment of further GPs ceased once it was agreed that theoretical saturation had been reached, and additional new and relevant information regarding recovery from psychosis was not being provided by each subsequent interview. Theoretical saturation is said to be reached when no new properties or theoretical insights are added to the emerging grounded theory or the developing conceptual framework following each additional interview (Charmaz, 2006).
A decision was made not to recruit SUs who were currently experiencing a psychotic episode or who were engaged with in-patient services, as it was felt that a coherent narrative about recovery may not have been obtainable due to their current problems. Incoherent speech is commonly seen as one of the defining characteristics of current psychotic experience (Reischel & Shih, 1999). It was also deemed inappropriate to discuss experiences of recovery with this group of SUs as they may not have felt particularly recovered at the time. Only SUs engaging with out-patient services, with community services, or with no services were recruited.

Recruitment of SUs posed problems, as there may be a self-selection bias whereby a particular subsection of the SU population would be more likely to put themselves forward for participation compared with other SUs. This subsection may comprise those SUs who have the ability, the competencies, and the interest to respond to research participation advertisements. Some SUs experiencing particularly severe mental health problems may feel that they do not have the capacity, the confidence, or the social skills to participate, and thus exclude themselves from participation by not responding to recruitment advertisements (Figueroa et al., 2004). It was felt that the best approach to advertisement of the research was direct and personalised face-to-face requests to participate. Gilliss et al. (2001) found that face-to-face recruitment produced the highest yield of eligible and willing research participants amongst hard-to-reach populations.

The sampling framework for SUs was purposeful in terms of age and gender. It also aimed to recruit participants who were at different stages in their recovery process – some SUs were living independently, while others were living in supervised accommodation. Interviewees had diverse experiences of the recovery process, and had potentially wide-ranging views on recovery from psychosis in primary care.

Participants were recruited through six different sources in Manchester to help ensure a variety of viewpoints. 20 SUs were recruited through four local mental health voluntary sector organisations which held weekly peer support groups or activities – Anne Lee Centre, Blue Sci, Self-Help Services, and St. Luke’s Art Project. Participants were also recruited through two supervised housing organisations catering for those with mental health needs – Norton Group (Brook House) and Imagine Act Succeed (Highfield Road). Recruitment of further SUs ceased.
once it was agreed that theoretical saturation had been reached, and additional new and relevant information regarding recovery from psychosis was not being provided by each subsequent interview.

GPs and SUs who agreed to take part were contacted in order to arrange suitable times for the interviews to be carried out. Participants were informed two weeks beforehand that they were going to be asked about critical incidents, i.e. their experiences of accessing services or of recovery which they found most or least useful in line with the best use of the Critical Incident Technique. This forewarning allowed participants to recall and prepare their stories more fully (Flanagan, 1954). On the day of the interviews, participants were reminded of what the research entailed and were provided with an information sheet. Participants were then asked to read a consent form and sign it if they chose to take part. Interviews generally lasted between thirty minutes and one hour each, and were carried out in a variety of locations. Interviews with GPs took place at Manchester University, Staffordshire University, GPs’ practices, GPs’ living rooms, a pub, and a cafe. Interviews with SUs took place in cafes, SUs’ living rooms, SUs’ gardens, and private rooms attached to community drop-in centres. Participants were always asked for their preferred location, and this was where each interview took place. The confidentiality of participants was ensured by undertaking the interviews in private rooms, or in quiet areas of public spaces.

All interview participants were also invited to participate in the subsequent focus groups. In total, 10 of the 44 interview participants subsequently took part in the focus groups. This was a suitable number of participants for the two focus groups. Two focus groups was the number of groups which had been envisaged prior to the invitations having been sent out. More than 10 participants expressed interest in taking part in the focus groups, however not all of these participants were able to agree upon times that would suit everybody in the proposed group. Times that suited as many participants as possible were decided upon. In addition, interviewees who did not express an interest in participating, either by not responding to the invitation, or by declining the invitation due to other commitments, were not pursued further.
Five of the 24 GPs and five of the 20 SUs who had been initially interviewed took part in the subsequent mixed focus groups. In the first focus group there were six participants - two GPwSIs (both male), one GPS (female), and three SUs (two male, one female). In the second focus group there were four participants - one GPwSI (female), one GPS (male), and two SUs (both male). These groups were designed so as to have an equal balance of GPs and SUs in each. Also, the members of each group were relatively representative of those interviewed previously. For example, there was at least one GPwSI and one GPS in each focus group.

All the participants’ expenses were reimbursed (locum fees, travel costs, time) and lunch was provided before the focus groups in order to incentivise participation and increase the chances of successful focus group recruitment (Bloor et al., 2001). The focus groups were conducted in a seminar room at the University of Manchester. All participants were seated around a boardroom-style table. Participants were asked to sit in such a way as to have a mix of SUs and GPs sitting beside one another.

4.2.2 Ethical Issues

Consent forms, interview tapes, and interview transcripts were coded using numbers rather than names in order to ensure the participants’ confidentiality. The option of withdrawing from the research at any point before, during, or after participation was made clear on the participant information sheets and on the consent forms (see Appendix 6). Due to the sensitive nature of the topics under discussion, and the potential for emotional issues to arise during the course of the study, all participants were provided with contact details for local organisations that could provide help or support with such issues if required. It was made clear that consent forms and data would be held, under the responsibility of the principle investigator, for five years following the publication of data from the study in a scientific journal. It was also made clear that data would be stored within a lockable file and would then be destroyed via a shredder. Ethical approval was received from the North Manchester NHS Research Ethics Committee, on behalf of the Greater Manchester Primary Care Research Governance Partnership.

4.3 Analysis
4.3.1 Grounded Theory: Its historical background

A modified version of grounded theory, as described by Charmaz (2006), was chosen as a set of qualitative methods to be used in this study. It has been defined by Charmaz as follows:

“Systematic, yet flexible guidelines for collecting and analyzing qualitative data to construct theories ‘grounded’ in the data themselves...Data form the foundation of our theory and our analysis of these data generates the concepts we construct” (p.2).

Grounded theory was first described as a method by Glaser and Strauss (1967) in their book entitled “The Discovery of Grounded Theory”. This research method was developed by these two sociologists during their research on seriously ill and dying patients in hospitals during the 1960’s. Before the development and promulgation of grounded theory as a research method, there had been an increasing tendency in sociology and in health service research to use only quantitative research methods which could test the veracity of hypotheses, and which were founded upon a positivistic approach to scientific investigation. At that time, qualitative approaches to research were often ignored because they were viewed as unsystematic, impressionistic, and biased. These qualitative methods did not share the positivists’ assumptions about science such as replicable experiments, operationalised concepts, and logically deduced hypotheses which could be confirmed with evidence (Charmaz, 2006, p.4).

The publication in 1967 of Glaser and Strauss’s “The Discovery of Grounded Theory” altered this situation. They critiqued the epistemological foundations of the positivistic approach to research, and contested the methodological consensus of the time. This was done by challenging assumptions such as that qualitative research could not generate theory, that research and theory are separate, that data collection and data analysis are separate, and that qualitative methods are unsystematic and biased.

Glaser and Strauss (1967) also put forward practical and systematic strategies for carrying out qualitative research, which was further added to in a subsequent book by Glaser published in 1978 called “Theoretical Sensitivity”. This explicit approach to grounded theory involved
collecting and analysing data simultaneously, while not conducting a literature review until after the analysis had been carried out. The sampling of participants did not attempt to adhere to population representativeness; rather sampling was aimed at developing theory. Grounded theory involved the construction of codes and categories during analysis. Codes were sourced from the data, not from prior deduction, and these codes were used to develop theory. Each stage of the analysis involved the making of constant comparisons. For Glaser and Strauss, memo-writing could be used as a tool for examining the specifics of categories, and the relationships between categories. In this way, grounded theory merged the empiricism and the systematic codified approach of positivism with notions such as socially constructed meanings, subjective meanings and emergent processes.

Strauss and Corbin (1998) subsequently outlined further technical procedures such as techniques to aid verification, and added these to the original grounded theory approach. This increased the rigour and the positivistic assumptions of the method. They also took the original Grounded Theory conception of theories emerging from the data, and altered it into a more densely codified, structured methodology. Strauss and Corbin (1998) defined grounded theory as follows: “Theory that was derived from data, systematically gathered and analysed through the research process. In this method, data collection, analysis, and eventual theory stand in close relationship to one another. A researcher does not begin a project with a preconceived theory in mind. Rather, the researcher begins with an area of study and allows the theory to emerge from the data” (p.12).

According to the grounded theory of Strauss and Corbin (1998), the text would ideally be engaged naively, without a template. Strauss and Corbin (1994) also contend that: "Interpretations must include the perspectives and voices of the people whom we study....Interpretations are sought for understanding the actions of individual or collective actors being studied” (p. 274).

4.3.2 Modified Grounded Theory
The grounded theory approaches described above have been criticised by some researchers for their increasing focus on positivism (Bryant, 2002; Clarke, 2005; Charmaz, 2006). It has been argued that it is not truly possible for researchers to approach their work naively. It would appear unrealistic and idealistic that a researcher would be able to work without any preconceptions or influences from prior experiences.

As its name suggests, Charmaz’s book “Constructing Grounded Theory” (2006) highlights the elements of the grounded theory method which are socially constructed and which are unavoidably so. Charmaz (2006) contends that even though many of the basic systematic grounded theory guidelines may be objective or neutral, how these guidelines are used by researchers is not neutral. The assumptions with which researchers approach their research, and how these assumptions are played out during the research process, are also not neutral. This modified grounded theory approach is based on the following assumption:

“My approach explicitly assumes that any theoretical rendering offers an interpretive portrayal of the studied world, not an exact picture of it” (Charmaz, 2006, p.10).

Rather than prescribing particular methods as rules to follow, Charmaz (2006) presents these modified grounded theory methods as tools which may be utilised during the research process. This approach was applied to the present study. The modified grounded theory of Charmaz takes a constructionist approach which states that the collected data should be placed in its relevant social and situational contexts:

“Data do not provide a window on reality. Rather, the ‘discovered’ reality arises from the interactive process and its temporal, cultural, and structural contexts” (Charmaz, 2000, p.524).

4.3.3 Limitations of Charmaz’s Modified Grounded Theory

Charmaz’s approach acknowledges the important presence of researcher bias. However, the acknowledgement of bias, without a concomitant effort to systematically avoid bias, has been deemed insufficient by some researchers. Glaser (2002) not only acknowledges this bias but also attempts to take this bias into account as a variable. According to Glaser, the researcher should analyse their own perspectives as just another form of emerging data. Glaser’s approach may be
interpreted as either an important effort at variable analysis, or as a futile attempt at positivism based on the assumption that the observer is neutral and expert (Puddephatt, 2006).

Constructionist approaches have been criticised because they may lead to the researcher forcing or shoe-horning data to fit their own perspectives. Glaser (2002) claims that “Constructionism is used to legitimate forcing. It is like saying that if the researcher is going to be a part of constructing the data, then he or she might as well construct his own way” (paragraph 20).

Charmaz’s approach to constructing grounded theory does include an attempt to understand data whilst being aware of one’s own perspective. However, Charmaz argues that the researcher is not free to “construct his own way”. Instead, the researcher attempts to understand how interviewees themselves construct their experiences and situations (Puddephatt, 2006).

Charmaz’s approach to methods is not prescriptive. A prescribed set of rules for analysis is not set out because constructionist approaches to grounded theory object to the application of systematic technologies. Such technologies have been associated with objectivist or positivist approaches to grounded theory. Applying technologies or prescriptions to the data rather than letting theory emerge from the data has been criticised (Puddephatt 2006). However, the lack of guidelines associated with Charmaz’s approach may lead to difficulties for researchers who do not have prior experience of carrying out grounded theory analysis.

Depending on one’s epistemological standpoint, the constructionist grounded theory approach of Charmaz might be criticised for denying the existence of a single conceptual reality. For example, Glaser (2002) argues that even though multiple viewpoints exist, they are all part of a single over-arching social reality or pattern of relations:

“Grounded Theory is a theory about a conceptualized latent pattern…Conceptual reality does exist. For example, client control is real, cautionary control is real. These processes and a host of others discovered in grounded theory impinge on us every day” (paragraph 31).

The modified grounded theory approach of Charmaz (2006) suggests that the literature review should be carried out at the end of the research process, after the data has been collected and
analysed. Charmaz argues that this can help reduce bringing preconceived ideas into the research process. At the same time however, Charmaz does not believe that the researcher can pretend to bring an atheoretical approach to the research process. This PhD took a different approach to Charmaz, and conducted the literature review before the data collection began. This literature review was deemed necessary so that the researcher could have a starting-point from where general interview topics could be initially formulated. It was felt that a literature review would also provide a useful way for the researcher to familiarise himself with existing literature in the area of recovery from psychosis, as well as allowing for a greater awareness and understanding of different existing conceptualisations of recovery. Despite having knowledge of these existing conceptualisations of recovery before the data collection began, the researcher framed questions about recovery as neutrally as possible. For example, during interviews research participants were asked “What does recovery from psychosis mean to you?”

4.3.4 Application to the PhD: data analysis

The empirical methodology will now be described in terms of its application during the research process, with particular reference to the stages of data analysis. The stages of data analysis according to Charmaz (2006) may include familiarisation with the data, indentifying codes, manual coding, nVivo coding, formulation of a thematic framework, finding associations between codes, and the construction of a grounded theory in the form of a narrative report.

1. Familiarisation

The first step undertaken after the collection of data was the process of familiarisation with the data. The interviewer listened to each recorded interview within a week of having originally carried out that interview. The transcript of each interview was subsequently read and re-read by the interviewer. The transcripts were also read by HL and AR.

2. Line-by-line coding
According to the modified grounded theory approach adopted in this PhD, coding is defined as follows:

“Coding means categorizing segments of data with a short name that simultaneously summarizes and accounts for each piece of data. Your codes show how you select, separate, and sort data to begin an analytic accounting of them” (Charmaz, 2006, p.43).

In the modified grounded theory of Charmaz (2006), coding is seen as the link between data collection and the emergent theory which explains the data. Coding defines what is happening in the data. In this PhD, coding was initially undertaken manually according to a strategy of line-by-line analysis. The line-by-line analysis allowed for a close investigation of the data, and ensured that codes fitted with the empirical world that was observed. References to nouns, verbs, actions, descriptions, or abstract concepts were coded. Whole phrases were also often coded. Many individual words or phrases were coded into two or more categories (double coding). The conceptualisation of ideas began here as the names of codes themselves were generated from the data. Even though the codes emerged from the data, it must be noted that codes were still constructed by the researchers who chose the words that constituted the codes. The constant comparative method of analysis was used to compare data with data (Glaser & Strauss, 1967; Charmaz, 2006). Any word or phrase in new data being coded was compared to previously coded data in order to see if a previously used code could be used to accurately represent the new data also.

For the first five SU interview transcripts and the first five GP transcripts, codes were hand-written by SR onto the transcript, directly above the data it represented. These codes were then discussed and debated with HL and AR to ensure appropriateness and reliability. Once a consensus was gained and the initial codes were agreed upon, further coding was carried out.

3. Focused coding, axial coding, and sorting into categories

A further five SU interview transcripts and five GP transcripts were coded using line-by-line coding. Once 10 SU transcripts and 10 GP transcripts had been coded using line-by-line coding, a second phase of coding began. As an ever-increasing number of codes were being generated
during the analysis of each subsequent interview, it was necessary to sort and order codes into manageable categories. This second phase of coding involved both focused coding and axial coding, so that codes could be ordered into categories.

Focused coding has been defined as follows as:
“using the most significant and/or frequent earlier codes to sift through large amounts of data. Focused coding requires decisions about which initial codes make the most analytic sense to categorize your data completely”
(Charmaz, 2006, p.57).

Focused coding allowed for the separation, the sorting and the synthesising of large quantities of data. It also led to the construction of abstract conceptual categories such as “Conceptualisations of Psychosis” and “Role of GPs”.

An additional form of coding was also used in this phase alongside focused coding. Axial coding was used to relate categories to subcategories. Axial coding reassembled the data which had been disassembled during initial coding, and gave coherence to the analysis which was emerging (Charmaz, 2006).

During this phase of focused coding and axial coding, similar codes continued to be collapsed into a single code where it was appropriate to do so. A list of the categories and subcategories that emerged from the data following the focused coding and axial coding of the first 10 GP transcripts (see Appendix 7) and the first 10 SU transcripts (see Appendix 8) were noted. These categories and subcategories were discussed by SR, HL, and AR, and were subsequently adopted following consensus agreement. This list is included as an example in order to provide transparency.

4. Coding using nVivo

Coding of the remaining transcripts continued using focused coding and axial coding, and this process was supplemented with the use of the computer program nVivo. By this stage, codes had
already been sorted into a preliminary framework of categories. Coding with nVivo was undertaken using this preliminary framework. nVivo was useful because it allowed the researcher to easily access and compare all the data which was coded under one code or under one category. It also enabled the easier viewing of associations between codes. However, it should be noted that nVivo only helped the researcher to see data which had already been sorted by the researcher. The initial tentative framework of categories was constantly evolving during this process. The sorting of codes into categories was iterative, and the categories were constantly evolving during each individual interview analysis. As the analysis progressed, some smaller categories were merged into larger over-arching categories.

nVivo provided information on the number of participants who mentioned each particular code or category, as well as the number of references to all codes throughout the entire sample. Information regarding the number of participants who mentioned each particular code was useful, as it informed decisions about which categories were worthy of reporting in the results. Although this study was not quantitative in nature, it was felt that counting the number of participants who mentioned each code or category might indicate some important trends in the data. Counting of codes and categories was undertaken although rare codes were also deemed important. Rare codes did not inform the main headings used in the theoretical framework, as it was felt that rare codes could have been chosen to be reported by the researcher, even though these codes had not been mentioned by the vast majority of participants. This could lead to a distortion of the findings. However, “deviant cases” which did not fit the data patterns were actively sought throughout the analysis (Silverman, 1997). Deviant cases and disconfirming evidence were used to counterbalance codes and categories which occurred more frequently. Such counterbalancing codes and themes or instances of disconfirming evidence were reported in the findings alongside the frequently mentioned codes which they contrasted with. Rare codes and disconfirming evidence also led to the modification of emerging codes and themes.

5. Formulation of a thematic framework and a grounded theory

A thematic framework was built up partly by applying the notion of “sensitizing concepts” to its conception (Blumer, 1969). The initial research focus of the PhD was used to provide a loose
framework with which the researcher pursued the formulation of themes during the analysis. In particular, some of the interview topic guide question areas were used to formulate an initial thematic framework. For example, one of the topic guide questions asked participants about how they viewed the role of the GP in promoting recovery from psychosis. Thus, “GP roles” was used as a thematic heading, under which all codes related to the role of the GP were placed. All sub-headings and codes, which were placed within these initial over-arching themes, emerged and were formulated from the data itself.

The formulation of the initial thematic framework was not guided solely by “sensitizing concepts” or by the interview topic guides. In accordance with the grounded theory approach, unexpected themes were formulated which were grounded in the collected data. Themes formulated in the thematic framework which were not topics initially asked about in the first topic guides included “Roles of other professionals” and “Structure of primary care services”.

Thematic frameworks were changed on an ongoing basis to reflect the data emerging and being analysed. The thematic frameworks were also modified following a number of discussions with HL and AR who were involved during the whole analysis process. A process of consensus-finding amongst the three investigators took place during each stage of analysis. Consensus-finding discussions took place during coding and during the formulation of thematic frameworks as well as during the drafting of the final constructed grounded theory.

The construction of a grounded theory from the thematic framework was carried out with the aid of freewriting. Freewriting entails typing up thoughts as they come to mind, with the goal of composing fresh material (Charmaz, 2006,). This technique helps the author to write in a natural voice and to unlearn past immobilising habits. It also allows ideas to emerge before decisions are made regarding what to include and exclude from a final draft. In addition, freewriting does not presuppose traditional structures or categories, and so the initial write-up is not restricted by attempts to place the analysis within such categories (Charmaz, 2006,).

A narrative was constructed based on the thematic framework by searching for relationships and associations amongst the themes and categories of data. Statements explaining these links or
theories were written down, and quotations taken from the data were used to support these statements. The interview data was searched for segments of text which were used to illustrate the themes which were chosen to be reported. One of the guidelines used to structure the reporting of themes was that the report would form a coherent narrative, whilst at the same time not excluding any important themes that had been generated from the data. This step in the construction of a grounded theory has also been alternatively referred to as theoretical sorting and integrating (Charmaz, 2006). Theoretical sorting and integrating involves the following processes:
- Creating and refining theoretical links.
- Making comparisons between categories at an abstract level.
- Attending to how categories fit together, or do not fit together.
- Integrating theoretical categories, so they reflect what was found empirically.

6. Iteration, leading to further questions and focus group questions

The codes, categories and themes which emerged from the interview data were used to modify the topic guides as further interviews were conducted. Grounded theory is an emergent and intuitive form of analysis. Grounded theories (interpretive theories) were built up in an inductive and iterative process from the emerging data. The themes that emerged from the interview data also formed a central part of the topic guides for focus groups which were subsequently conducted.

The focus group data subsequently underwent a similar form of analysis to the method just described. Once the data from the two focus groups were collected, the researchers underwent a process of familiarisation with the data through listening to the recordings and reading the transcripts. As described above for the interview analysis, focus group data also underwent line-by-line coding, focused coding, axial coding and sorting into categories. Unlike the interview data, the focus group data was not coded with the aid of the nVivo computer program. Instead, all focus group coding was carried out manually. Manual coding was deemed more effective because the two focus group transcripts could be accessed easily without the aid of a computer program, and their codes and categories compared with one another manually. This was in
contrast to the much larger number of interview transcripts (44) coded with the aid of nVivo. The formulation of a thematic framework and grounded theory based on the findings of the focus groups were built up in the same manner as the interview findings.

Focus groups were chosen as an additional method of data collection for a number of reasons. They allowed the researcher to carry out member checking or respondent validation – data collected during the initial interviews was fed back to the participants in order to check the validity of the initial interview data. Focus groups facilitated the in-depth exploration of recovery, and involved the sharing of individual personal perceptions and experiences.

Focus groups were also chosen because they may foster shared understandings and new insights for participants. Focus groups allowed an investigation of participant commonalities. Participants discussed the input of other group members, thus expanding on points left underdeveloped during the individual interviews. Furthermore, focus groups also enabled the collection of data regarding the dynamic elements of the groups, rather than simply the collection of thematic data. Focus groups have been criticised for traditionally relying on “realist” assumptions, for example that focus group findings provide a way of seeing participants’ opinions and attitudes (Barbour & Kitzinger, 1999). Social constructionists argue that focus groups with content-only findings fail to take account of the social interactive dimensions of the research situation (Billig, 1996). Crossley (2002) accepted these criticisms of traditional focus groups, and used focus groups which were informed by social constructionist theory, for the purpose of health service research. That research involved an examination of the social interactions and dynamics amongst focus group participants, alongside an analysis of the thematic content of the conversations. In this PhD, examples of focus groups dynamics such as agreement/consensus, conflict, and attitude change are reported in the results of the focus groups (Chapter 7).

Kitzinger and Farquhar (1999) identified a number of forms of group dynamics to remain mindful of during focus group analysis - arguments, mutual reinforcement, jokes, story-telling, and sensitive moments involving explicit comments, hesitation, awkwardness, surprise, shock, individual defensiveness, or tentative collective exploration. The analysis of focus group data in
this PhD did differ from the analysis of interview data. Sensitive moments where group dynamics were identified as causing a shift in the discussion were coded, in addition to the thematic coding.

Summary

This chapter has described the methods used in this PhD for collecting and analysing data in accordance with a modified grounded theory approach. The theoretical background to the methodologies employed was discussed, including a justification for the use of a qualitative approach to data collection for this PhD and a discussion of the critical incident technique. The possible impact of the interviewer’s background on the research was examined, as well as issues of reliability and validity. The empirical methodology was described in detail, with reference to access to and recruitment of participants, methods of sampling, the creation of topic guides, collection of demographic information, and the carrying out of interviews. The stages of data analysis were also described.

Modified grounded theory was applied to the analysis of the empirical data. This data consisted of the transcripts of interviews with GPs, interviews with SUs, and mixed focus groups. The results of this analysis are reported over the following three chapters. Chapter 5 presents the views of GPs regarding recovery from psychosis in primary care, Chapter 6 presents the views of SUs regarding the same topic, and Chapter 7 reports the results of the mixed focus groups.
Chapter 5

General Practitioners’ views on Recovery in Primary Care
Introduction

This chapter presents the results of the semi-structured interviews carried out with GPs. Semi-structured interviews were carried out with GPs to explore what recovery from psychosis meant to them, with a particular focus on recovery from psychosis in primary care settings. The results will be presented in two sections. The first results section focuses on the results which highlight commonalities shared by both GPwSIs and GPS. The second results section identifies themes which showed a general contrast in viewpoints dependant on whether the participant was a GPwSI or a GPS.

Response rates

In total 24 interviews were carried out with GPs – 17 interviews with GPwSIs and seven with GPSs. The response rate to participation requests from GPwSIs was 77% (17/22), while the response rate from GPSs was 5% (7/148). This considerable difference in response rates is important to note, as it highlights the increased likelihood of GPs with a professed interest in mental health participating in the research. Similarly, it is possible that the 5% of GPSs who responded to participation requests may have exhibited self-selection bias, and may have had a greater personal interest in mental health in comparison to those GPSs who did not respond. This is a limitation of the study. However, the difference in response rates may also be partly attributable to the different recruitment methods used with the two groups. GPwSIs were invited in person by the interviewer to participate, whereas GPwSIs were invited by letter. In addition, GPwSIs were not required to fax or post a response sheet to the interviewer in order to confirm their interest in participation, whereas GPSs were. These factors may have been an added physical or psychological barrier to the perceived ease of participation involved for GPSs. GPwSIs also had more available time to participate as they were attending a university course, and due to this were not directly involved in clinical practice-based work on the days of participation. This may have been a further reason for the higher positive response rate amongst GPwSIs.

Demographics
GPs were asked to disclose their gender, ethnicity, number of years worked as a GP, and whether or not they held a special interest in mental health. 24 GPs were interviewed, 13 GPs were male (54%), and 11 were female (46%). 21 GPs were White British (87%), and three were Asian (13%). The mean number of years that GPs had been working as a GP was 20.3 years, with a range of 4 years to 32 years. 17 GPs had a special interest in mental health (71%), while seven did not have a special interest (29%). These demographic details are presented in Appendix 9.

**Topic Guides**

The interviews explored the range of meanings that psychosis and recovery from psychosis had for individual GPs, as well as examining their experiences of observing or being involved in recovery in primary care settings. Some of the questions in the interview topic guide for GPs were based on the findings of the Critical Interpretative Synthesis. For example, GPs were asked to specify how they conceptualised recovery from psychosis. GPs’ opinions regarding the typical prognosis and trajectory of someone with a diagnosis of psychosis were obtained. Opinions were also collected regarding what factors influenced recovery from psychosis, particularly in the context of primary care. GPs were asked to describe their experiences of working with SUs who had psychosis. This element of the topic guide utilised the critical incident technique which was intended to elicit specific memories from interviewees. As part of the critical incident technique, GPs were asked to recall one case of a SU who had recovered particularly well, what indicated that the SU had recovered, and how the SU dealt with the episode. GPs were also asked to recall one case of a SU where it was felt that the SU did not recover particularly well. Data was analysed using modified grounded theory as discussed in the previous chapter.

**Results common to both GPwSIs and GPSs**

The following themes emerged from the semi-structured interviews with GPwSIs and GPSs which were common to both groups of interviewees – importance of continuity of care; central role of support networks; supporting families; and GPs’ experiences of communication difficulties with secondary care. These themes are now outlined along with supporting quotes.
taken from transcripts as evidence. Sub-themes are also outlined. A summary of the data is provided at the end of each of the four themes.

5.1 Importance of continuity of care

Continuity of care was mentioned by almost half of the GPs interviewed as being a key role of GPs in terms of helping SUs who experience psychosis.

Social and familial aspects of continuity of care

Many GPs, both GPwSIs and GPSs, reported that they felt one of their most important roles in terms of promoting recovery from psychosis, was the provision of continuity of care for SUs. The social aspects of care and the human interaction involved were emphasised by many GPs. One GP mentioned both of these in the description given below of his relationship with a particular SU whom he gave the pseudonym “Donald”. This GP’s description highlighted the important role which the GP played in terms of knowing all family members through consultations with them at his medical practice. The GP had “a great warm relationship” with the brother of the SU involved, and the GP and the brother of the SU discussed “his brother and his concerns”.

“Let's call him Donald; I remember him very well and remember his family really well, and he had his problems before I ever joined the practice, so he became my patient...for twenty odd years...I was involved with his brother who lived thirty miles away, but would often come over and have a chat with me about his brother and his concerns, and the fact his Mum and Dad were getting older, and we got on very well; it was a very, a great warm relationship; I knew all the family well, and I dealt medically with Mum and Dad as well” (GPwSI 3, male).

The continuity of care provided by GPs led to greater awareness amongst GPs of SUs’ longer term personal interests and social circumstances. In the example given below, stress levels and the triggers of stress were investigated and discussed by the GP and the SU. This care went beyond dealing with an acute crisis. This type of discussion was facilitated by the GP knowing the SU well due to continuity of care.

“Looking at the stress levels, and the social situation that they’re in, and the triggers, and looking at their personal interests, and what they feel they need as a human being to be nurtured
and to get better. Those are the kind of longer term GP type things that we would look at beyond the acute crisis” (GPwSI 1, female).

Unique to primary care
Primary care was contrasted with secondary care which was seen by many GPs as having relatively less capacity for offering continuity.

“If someone is under psychiatric services, contacts are probably very limited. I think we do have a role in knowing the person in a longitudinal sense” (GPwSI 12, female).

“They might find that their experience of secondary care services is quite discontinuous” (GPwSI 17, male).

Secondary care was seen as too removed from SUs’ daily lives, and meetings with professionals in secondary care were seen as too brief or infrequent, particularly for SUs who were already recovered somewhat.

“I think when you reach a certain point of recovery, secondary care cannot, it cannot meet the needs, because in a hospital at a distance, you go in and see the nurse or consultant for ten minutes or whatever. And where has the rest of your life fitted into that normally?” (GPwSI 16, female).

GPs were part of a wider team providing continuity
For some GPs, the role of continuity of support provided by GPs was seen as part of a wider group of professionals who were all involved in the provision of continuity of care within a wider primary care or community mental health service. This “team” included practice nurses based at the GP surgery, as well as community-based psychiatric nurses who visited GP surgeries and were able to provide additional resources. This group of professionals was seen as being equipped to provide immediacy and continuity of support, which aided recovery from psychosis in primary care settings.

“I think there are things that the GP could do, but yeah, I think it is actually probably a team of people, but it is about immediacy of support, about a continuity of support, and a communicating of support” (GPwSI 16, female).
Lack of continuity in other services increased the burden on GPs

The GP’s role in providing continuity of care was noted by another GP, who felt that fostering a stable and genuine relationship between the professional and the SU was a key factor in promoting recovery. However, it was noted that this role of continuity provider sometimes brought its own difficulties for GPs. When SUs disengaged with mental health services, and failed to create a stable relationship with professionals working in those services, SUs then by default returned to their GP. This was seen as frustrating and irritating for this GP who felt “dumped” upon by other services. The GP felt she needed help to carry out this role, but that this help was not forthcoming. It was difficult for this GP to accept this “fallback” role.

“It’s about stable and real relationships, and half the problem for any of the services involved with people is that the turnover is so great. So people stop going and then they just gravitate back to us. We feel frustrated and irritated because we want help and, also it’s difficult as a GP often to accept that role” (GPwSI 12, female).

Summary

GPwSIs and GPSs reported that continuity of care was an important factor in promoting recovery from psychosis. GPs generally felt that one of their most important roles in terms of provision of psychosis care was the continuous nature of their care for SUs. It was felt that support for SUs should be continuous and immediate if required. Many GPs felt that primary care was unique in its ability to provide such continuity and to successfully communicate this continuous availability of support to SUs. Such continuity enabled GPs, practice nurses and other members of primary care teams to foster stable and genuine relationships with SUs which promoted recovery. The social aspects of care and the human interaction involved were emphasised as important advantages of continuity of care. Continuity of care was believed to lead to an increased understanding by the GP of SUs’ social and family situations. Many GPs contrasted primary care with secondary care which was seen as less able to offer such continuity. Secondary care was seen as too removed from SUs’ daily lives, and meetings with professionals in secondary care were seen as too brief or infrequent, particularly for SUs who were perceived as beginning to recover. For some GPs, the role of continuity of support provided by GPs was positioned within a framework which included all professionals involved in the provision of continuity of care within a mental health service. However, when this continuity of care broke down in other areas of the
service, GPs felt frustrated, unduly burdened, and found it difficult to access additional help. It was felt that the lack of continuity of secondary care which some SUs experienced prevented the fostering of genuine relationships, and often led to disengagement from secondary care services.

5.2 Central role of support networks

The role of social support
When asked about their opinion on what were important factors in the promotion of recovery from psychosis, the majority of GPwSIs and GPSs said the availability of support from the SU’s social networks was important. This widely-held belief in the efficacy of social support networks amongst GPs was exemplified by the quote below.

“But, apart from just the medicine, the medical therapy, there needs to be a lot of support from the family, from the community. That is what is going to pull this person out of the psychotic episode, not just the medication” (GPwSI 12, female).

Conversely, if there was a lack of supportive social networks, GPs generally believed that this hindered the recovery of SUs.

“This is a young boy I knew, who's actually also known to the drug abuse services for cannabis and heroin, and really had very little social support. I did refer him to the psychiatric services and I think they have really tried, but he doesn't seem to have a consistently, well, support in the community he can tap into. He leads a very chaotic existence with his mother and step-father and, yes it careers from one crisis to the next really, it's very sad” (GPwSI 5, female).

Lack of social support networks was also identified as being a risk factor for relapse. One GP provided the example of a boy who was viewed as being a risk to himself and to others. The problem was partially attributed to the lack of social support networks available to the SU.

“He’s quite a risk. He lives on his own…he hasn't got a lot of social support” (GPwSI 8, male).

This belief amongst GPwSIs was echoed by GPSs, who also tended to believe that a lack of social support networks hindered recovery.

“Things that work against them…having a poorly supportive social network” (GPS 3, male).
Social support was seen by GPs as being provided most frequently by family members of SUs. According to a majority GPs, families played a very important role. One GP expected one of her SUs to recover with the help of his mother.

“He's living at home with his mum so he's got the support. He's got financial problems, which is unfortunate, but I think he will (recover), with the help of his mum and he's got some good friends as well” (GPwSI 11, female).

GPs reported that the friends of SUs provided another source of invaluable social support, which aided recovery. One GP mentioned how one of her SUs had friends who helped him to manage his situation better.

“He's got a few friends; he's starting to play in a band again. He's managing” (GPwSI 6, female).

Social support was also provided on occasion by the SU’s employer in the form of an understanding attitude. A GP spoke of one SU who worked as a joiner and was supported by his employer.

“Self employed joinery type person, travels all over the country...He's got his boss who is supporting him and he's got things in place that hopefully will lead to a good life for him” (GPwSI 11, female).

**GP interventions to enhance social support**

Social support networks were often embedded in a particular hobby or interest which the SU participated in. One GP highlighted the role that GPs can play in enhancing social support networks. She pointed out that GPs can encourage SUs to participate in new pastimes, or increase their participation in already existing interests. Thus, GPs may help to open up additional possibilities for the SU to create social support networks.

“I can think of one lady who was very socially isolated, had problems getting out of the house, would rarely be able to even to make it up to the surgery, but was an amazing artist and really loved gardening. When I tapped into these interests she sort of, said that you know, people hadn’t really asked her about those things before. There was a local project called the Green Gym
which is an outdoor working landscaping project to help people exercise and make social relationships in the context of doing gardening or landscaping…those kinds of connections which actually make people feel fulfilled” (GPwSI 1, female).

Services provided by local voluntary organisations were also seen as a source of help for GPs who wished to enhance the social support networks of SUs. One GP was aware of a befriending service provided by the charity MIND, and referred a SU to this service.

“So his social life has got much better, he's joined a befriending scheme um, and I'm waiting to see how that goes in MIND. Our local MIND run this befriending scheme, which I think will be really good for him, to give him a bit of confidence. You know, he's just getting out and about, he's got a life you know, which he didn't have. You know, he sat inside being an ill person um, and that was his life and everybody got very anxious about him, and now he's really yeah, much improved” (GPwSI 6, female).

GPs also described being able to help SUs to enhance their social support networks by taking on the role of an advocate for the SU, and representing SUs by canvassing local organisations. A GPwSI recalled a case where the sister of a SU wished to move closer to her brother in order to help support him. She lived in local authority housing, and was petitioning the authorities to move her into housing which was closer to where her brother lived. The GP in question lent his support to her campaign by writing a letter to the authorities.

“He's now living on his own, and his sister lives a mile and a half at least, but she's campaigning to move closer to him because she says she has to pop in all the time…And he's dependant on her….Do you write a letter of support for the sister to move closer to him…that's what I've done” (GPwSI 15, male).

Another GPwSI suggested that in order for some families, employers, and communities to provide adequate support for SUs, they may require additional support and education themselves.

“If you were aiming at perfection you would have an employment situation, a community and a family who were supported alongside the patient. They would have total understanding and no fears of the condition or the nature of it. They would understand that all of us are prone to places along the continuum of what's going on” (GPwSI 7, female).
Interestingly, although most GPSs recognised the importance of social support for promoting recovery, no GPS suggested an intervention which GPs could provide to improve a SU’s social support. It should also be noted however, that no interview participants were directly asked about possible GP interventions for improving social support. Those GPSs (all GPwSIs) who did propose possible interventions, had not been prompted by a particular line of questioning during the interview. One GPS did recognise the lack of interventions in the area of social support and social functioning, but this was in the context of mental health services generally, rather than in primary care specifically.

“I think that the services for helping people return to normal social functioning are very underdeveloped. So once somebody is no longer hearing voices many psychiatrists will just say, ‘okay, that is fine, we will discharge them.’ But actually their functioning is well, well below what it was before, and there is much more possibility if they had enough support. And the services - I am sure many could actually integrate much more” (GPS 6, male).

Summary
The availability of adequate social support networks for SUs was viewed by most GPwSIs and GPSs as being one of the most important factors in promoting recovery from psychosis. It was generally felt that social support was most frequently provided by families, although friends, community, and employers were also viewed as important sources of support. A lack of social support was considered a barrier to recovery and a potential risk factor for relapse. Some GPwSIs felt that they could help SUs to expand their social support networks. GPwSIs focused on referring SUs to organised institutions within the community when they contemplated implementing interventions intended to enhance the social support networks of SUs. For example, SUs were made aware of community gardening projects and befriending schemes. It was felt by some GPs that the building of friendships in the context of hobbies and shared interests led to more fulfilling connections and lives for SUs, and promoted recovery. In the case of local authority housing allocations, one GP took on the role of advocate, used his professional status to intervene on behalf of a SU and his sister, and canvassed for them to be housed closer to each other. GPs often noted the importance of the informal social support provided by families, outside of organisations or service providers. However, it was also felt by some GPs that
families, friends, employers, and the local community, all sometimes required support themselves in order to support SUs. This support could take the form of educational interventions to promote a greater understanding of psychosis, and enable members of SUs’ social support networks to overcome their own fears regarding psychosis. Although many GPSs recognised the importance of social support networks, none of the GPSs interviewed proposed potential interventions which GPs could implement to enhance a SU’s social support, whereas some of the GPwSIs did propose interventions to enhance support networks. It could be argued that the provision of continuity of care by GPs, in itself constitutes social support. This social support takes the form of organisational social support as opposed to the informal social support provided by families and friends. In this way, GPs may promote the social support networks of SUs and their recovery from psychosis, through interventions to enhance social support networks, but also through the provision of continuity of care which represents social support in and of itself.

5.3 Supporting families

Most GPs reported a belief that another aspect of their role in the promotion of recovery was located in their provision of support to families and carers, especially if the SU was not engaging directly with the GP. Having received support from their GP, it was felt families would then be more likely to be equipped with the necessary resources to, in turn, provide support to the SU. The resources that GPs were seen to pass on to families included increased knowledge and an understanding of psychosis.

Information provision

A majority of GPs felt that their own role included helping the families and carers of those affected by psychosis. For example, one GP felt that although GPs were not experts in terms of treating psychosis, they still welcomed talking to the families of people experiencing psychosis, and felt able to support families in terms of providing advice about the illness and the treatment options.

“If the family want to come and talk to us, most GPs won't be experts in it, wouldn't claim to be an expert, but probably know more than most” (GPwSI 4, female).
One GPS felt that this role was particularly important as SUs and families often trusted their GP as an independent voice who was not directly involved in sectioning or in treatment decisions. “You are not directly involved in making decisions about usually whether they are sectioned or whether they are taking treatment or not. You are seen as being slightly more independent and therefore in some ways it may be easier for them to accept the view or the ideas of a GP or the support of a GP” (GPS 6, male).

Another reported aspect of how GPs supported families was the provision of information by GPs about alternative sources of support which were available for families. However, it was felt that many GPs were not aware that such support for families was available.

“I don't really think it's really got through that there is a whole host of family support information for families. Those sorts of things are actually quite relevant to primary care” (GPwSI 13, male).

Value of a strong relationship with families and carers

It was felt that because GPs often knew family members and carers well, this helped GPs to provide support for families.

“I knew his family very well and I think that was fine; I think we know, you know, we were able to, I was able to support him and his family to do the sort of things that were important” (GPwSI 15, male).

A GPS agreed that GPs have an important advantage due to their detailed knowledge of families and their histories.

“We will know the family. Usually there is a family involved and it doesn't matter what it is, whether it is psychosis or something else. If there is an illness in one person in the family, the whole family are your patients. Then in some way they are going to be involved, whether it is a contagious thing or a family history thing, or whether it is just they are my nearest and dearest thing, somewhere they are going to be involved” (GPS 4, male).

It was argued that the concerns of family members and carers could be listened to carefully by GPs, and that the family could be supported more effectively in this way.
“It’s very important to take family concerns seriously, and not to close doors, not to reassure when you are not sure yourself what’s going on...so there is something about keeping the door open, listening very, very carefully to families who are distressed and concerned” (GPwSI 13, male).

Similarly, it was noted that the role of supporting families and carers could include facilitating their involvement in the decision-making process relating to a SU’s treatment.

“We had big dilemmas about, with him and his family, about is this a thing that is going to be okay? Um, what's the impact of this in terms of your mental health 'cos occasionally his mental illness would flare up, and how would that impact. Difficult decision, but in the end we decided no, this was not a good solution for him” (GPwSI 13, male).

This role of supporting families and carers of SUs experiencing psychosis was perceived by some GPs to be unique to primary care.

“You know families really well over the years, so your ability to support families is...part of what you can offer that other people can't do” (GPwSI 15, male).

The role of GPs in supporting families was highlighted by the example reported below, where a GP reacted to a call from a distressed family, and helped the family to deal with an emergency situation by going to help the SU and his family at the family’s home. The fact that the GP was able to de-escalate the situation was predicated on his long-term relationship with the family. It was felt that an “outsider” such as a locum GP or a secondary care professional might have invoked the Mental Health Act as an alternative strategy.

“The phone call came in: ‘Donald's got an axe in his hand and he is being silly at the moment, could you come out and help; we are quite worried about him’. So I walked into this house, terrace house, and I am not a brave doctor at all. I am hopefully a very careful doctor, and Donald was really agitated and he had got this axe in his hand, and Mum and Dad didn't know what to do with it and it was all, so I just walked up to Donald held my hand out and said, 'Hi Donald,' and he shook. He put the axe down to shake hands with me. So I said, 'you won't be needing this. Now what on earth’s been going on?'... It just needed me to come in from outside, someone who knows him, that wasn't hostile” (GPwSI 13, male).
Promoting patience and optimism for recovery amongst families

Supporting families and promoting optimism for recovery amongst family members were seen as key GP roles by GPwSIs, and were considered to be important factors involved in recovery from psychosis. An example was given of a woman who was experiencing psychosis and believed there were parasites in her house. The woman’s husband was supported by their GP who reassured the husband about his wife’s delusions, and encouraged him to be more patient with this wife and more optimistic about her recovery.

“We also had to recruit the husband and reassure him that there weren’t any parasites in the house, and that he should really adopt our hope and optimism and have a bit of patience as well” (GPwSI 8, male).

Families were GPs’ alternative contact point when SUs disengaged

One GPS stated that some SUs did not wish to see the GP, so the GP instead focused on supporting the families of those SUs.

“One has become very paranoid. They’re almost impossible to deal with, and one or two of them won’t come near us, you know. And we have to try and help the families” (GPS 3, male).

It was also reported that families sometimes helped the GP in trying to persuade SUs to engage with GP services and with other mental health services.

“Very important, yes, for the family. They try and bring these people to my attention, because their behaviour becomes difficult to manage and if we can persuade them to come for treatment then it’s helpful” (GPS 3, male).

Families support GPs

In a role reversal, families were also reported as providing support for GPs. An example of this was given by a GP who reported obtaining information about the health status of SUs from their families. The family supported the GP by providing information that was otherwise inaccessible to the GP. The GP also supported the family by providing advice in return, thus creating a symbiotic relationship. However, confidentiality issues in this situation were also recognised by the GP.
"I also think within primary care we have liaison with other members of the family as well, so if something is going a bit awry, you can get information from other people too, obviously within the confines of confidentiality. You have to be very careful with that and you cannot intrude without the consent of the patient, but often if family members have lived with somebody who has had episodes of psychosis throughout their life, they will start to recognise the signs much earlier than you or I would” (GPS 1, male).

Summary
Supporting the families and carers of SUs experiencing psychosis was one of the roles of GPs most frequently mentioned by GPwSIs and GPSs. This role was seen as being unique to primary care in the sense that the issue of GPs providing support for the families and carers was also clearly related to continuity of care. GPs had more of an opportunity to build links and create trust because of the longitudinal nature of their relationship with the SU and their family. GPs felt able to support families as a way of promoting recovery from psychosis for SUs. The provision of support for families and carers was seen as including a number of possible interventions: the provision of knowledge and information about psychosis and about treatment options with families, promoting an understanding and patient approach towards psychosis, encouraging an optimistic and hopeful attitude towards the possibility of recovery, the discussion of pressing issues, knowing the families well, listening to the concerns of families, and facilitating families involvement in decision-making regarding a SU’s treatment. GPs were often perceived as relatively independent of the sectioning process, and tended to be trusted more by SUs and their families as a result. The issue of GPs providing support to families was also related to the issue of GPs enhancing the social support networks available to SUs. Some GPs mentioned that they could inform families about alternative sources of social support. Sources included not only those which were suitable for the families, but also sources of social support which SUs could be directed towards themselves by their families once the GP had informed the families about them. Where a SU had disengaged with primary care services, families also provided an alternative contact route for GPs who wished to remain in communication with the SU. Families provided GPs with information about SUs’ situations that was otherwise inaccessible to GPs. This was especially the case where the family was well-placed to recognise the early warning signs associated with relapse.
5.4 **Informational discontinuity across the interface**

Many GPwSIs and GPSs reported that there was informational discontinuity across the interface between primary and secondary care. There was often felt to be a lack of adequate communication between some psychiatrists and GPs. For example, one GPwSI found that when he sought advice from a psychiatrist, his question was not answered adequately.

“*Sometimes I guess the response from secondary care psychiatry is not what you anticipate, and perhaps if you have a concern about someone - whether or not they're developing an early psychosis. Then you get an answer back which says ‘No they're not psychotic’. You know that they're not really answering the question that I asked of them*” (GPwSI 14, male).

Another GPwSI had a similar experience. She reported her experience of working with psychiatrists where she felt that some psychiatrists did not engage and communicate effectively with her. These psychiatrists were described as “remote”.

“*Having experienced a number of different sort of psychiatrists over the years, some are much more willing to engage with GPs and others aren't. People can be very remote if they want to be, and that can be really difficult sometimes for us*” (GPwSI 12, female).

Some GPSs also reported that they had little direct access to psychiatrists working on their local mental health teams, and found it particularly difficult to speak to psychiatrists.

“*Speaking directly to a psychiatrist can be very difficult, and does not happen*” (GPS 2, female).

GPs viewed their relationships with some psychiatrists and other secondary care professionals as being deficient in terms of GPs’ ability to liaise with such professionals, both in terms of their ability to obtain support and advice from them, and in terms of fostering a feeling of working closely together. One GP believed that both GPs and other mental health professionals may sometimes not allow themselves to be accessible to each other.

“*Some GPs surgeries are well supported and others are not. But where the support works and the liaison works it can be so beneficial, not just us, but for the patients, the carers and just a feeling that we are all working together to try and contain the situation. So yes, much more close*
working relationships. Of course we have a responsibility to be open to that as well, and I think GPs are not always accessible either, so I suppose it is about a two way process” (GPwSI 12, female).

GPs generally wished for enhanced communication between secondary care mental health professionals and themselves. In particular, GPs would like to have greater scope to obtain rapid advice and support from secondary care professionals. This was particularly important to GPs who felt they did not have the required skills, knowledge or experience to help SUs with psychosis. Many GPwSIs and GPSs both shared these sentiments, and wished to see more prompt and helpful communication from psychiatrists. This included receiving care plans and prompt clinic letters from secondary care, so that GPs could provide prescriptions and other information for SUs.

“It is helpful to have a helpful psychiatrist who you can approach and ask for advice, which is always a great help. Anti-depressants and things we are more familiar with, but as for anti-psychotics that is generally a bit more specialised really, so it is helpful to have advice regarding that. Just good communication with secondary care. Having a care plan from them, and knowing what is going on, and prompt letters from their clinics does help really when we are being asked for prescriptions and trying to manage the patient” (GPS 4, male).

GPs also reported having problems referring SUs on to secondary care services due to their inability to access those services. For example, some psychiatrists were reported by GPs as resisting referrals and denying access to secondary care services because SUs were considered by the psychiatrist to be “not ill enough”. GPs felt they had little alternative support in such cases where they could not refer a SU to secondary care.

“If we're trying to hold situations which are quite stressful, when perhaps a person is not quite ill enough to use the Mental Health Act, those are the situations that are difficult. Where it's sometimes I think too easy for psychiatry services to say, 'Well you know, they are not ill enough for us to arrange compulsory admission.' There is a sense of, so that's all we can do. And we are left holding the situation. That can be really, really hard for the families as well” (GPwSI 12, female).
Summary

GPs generally felt that there was inadequate communication and engagement with psychiatrists when GPs attempted to contact them. It was felt that both GPs and psychiatrists could be more approachable and open in terms of facilitating communication with one another. GPs encountered difficulties in the referral process, where SUs were refused access to secondary care due to not being "unwell enough", and not meeting the criteria for secondary care services. GPs desired consistent and prompt support from, and access to psychiatrists. This was especially the case for GPs who felt they did not feel they had the required skills, knowledge, or experience to help SUs recover from psychosis.

Results which were contrasting for GPwSIs and GPSs

There were some issues which emerged where the views of participants generally differed depending on whether interviewees were GPwSIs or GPSs. These themes tended to be largely dichotomous, with a majority of GPwSIs sharing one particular viewpoint, while a majority of GPS held a different and conflicting viewpoint. This section focuses on the four major issues where views differed: recovery conceptualised as either social functioning or biomedical recovery; medication as a recovery tool; GPs’ self-perception of personal expertise; and perceived importance of comorbid drug abuse.

5.5 Recovery conceptualised as social functioning or biomedical recovery

GPSs tended to frame psychosis primarily as a biomedical problem which could be potentially treated through the use of anti-psychotic medication. However, this was not a view shared by most GPwSIs, who tended to view recovery from psychosis in terms of achieving adequate social functioning.

Emphasis on biomedical recovery amongst GPSs

GPSs were much more likely to emphasise the importance of biomedical aspects of recovery such as symptom control, whereas GPwSIs more frequently referred to functional or social elements of recovery. For example, one GPS explained recovery in the following way.
"It is fairly easy to suppress the symptoms of psychosis and get somebody much more, kind of, mentally stable" (GPS 6, male).

This greater degree of emphasis on biomedical aspects of recovery amongst GPSs appeared to be related to their underlying belief in the efficacy of modern anti-psychotic medications to produce symptomatic recovery.

"They use today a typical antipsychotic drug. Olanzapine is particularly useful in that condition" (GPS 3, male).

**Emphasis on social functioning amongst GPwSIs**

GPwSIs generally reported that recovery from psychosis was signified by the SU’s return to a level of social functioning deemed to be adequate or normal by GPs. In other words, a SU was recovered or experiencing recovery if they could participate in, and engage with, society. This is seen as different from the concept of symptomatic recovery or discontinuation of a SU’s unusual perceptions.

"I would see recovery in functional terms, more than in necessarily getting rid of all the unusual perceptions, because I think there are people who can function well despite having persistent symptoms. So I would see it if someone was in a state where they could participate as fully as they were able in the outside world” (GPwSI 12, female).

Another GPwSI also reported her conceptualisation of recovery as being a return to normal functioning. However, the onus for promoting recovery in her view should have been on GPs. She felt that GPs generally did not invest enough effort into helping people with psychosis recover, especially when contrasted with the effort GPs invested into helping SUs with physical ailments. She described recovery as a return to a normal healthy life, similarly to recovery from other long-term conditions such as diabetes.

"I think enabling people to live a normal healthy life, as for any condition, you know, be it mental, be it physical. I think if you compare it to diabetes, we, doctors expend enormous amounts of time and energy for these patients trying to get them back to normal healthy living. I don’t think patients with psychosis necessarily get as good a deal. I think that they, well, there certainly can be an inequality in the care they get” (GPwSI 11, female).
This view of recovery as being a return to normal social functioning was echoed by many other GPwSIs. The representation of recovery as normal social functioning was sometimes coupled with the representation of recovery as a complete return to the level of health they had enjoyed prior to their first episode of psychosis.

“Recovery is enabling an individual to fulfill all the aspects of his life or her life that they were doing before they became unwell. But making them a fully functional part of the normal society, with normal relationships and work etcetera” (GPwSI 14, male).

Being in paid or voluntary employment, as well as being engaged in education, were mentioned by many GPwSIs as being an element of recovery, as was the ability to manage or cope with any remaining symptoms, without necessarily eradicating all symptoms.

“He's been discharged from secondary care psychiatry and he comes to see me now every three months basically. But he's started working on a voluntary basis and started addressing some physical health problems such as his weight and basically he's behaving as a normal patient would do, coming to see me basically, without any symptoms that he can't control or cope with” (GPwSI 14, male).

Recovery was also often felt to be linked to income from employment, which in turn was seen as providing the SU with control and independence.

“This person recovered from the psychosis, they went back to their education, got good A levels, went to university, did a degree and they are working, with reasonably good income resources and everything. They got a job. They have been able to get on with their life. They have kept their independence, their control of their own life” (GPwSI 1, female).

This return to normal social functioning and community integration could also be facilitated by the support of the SU’s family. In addition to normal social functioning, some GPwSIs also reported that recovery partly consisted of reducing medication to a minimum.

“It's been about how these people receive support from family, integrated back into their community, whether that's one lad with his school, for example, integrating them back into jobs,
together with not forgetting about medication. I think this is one group of people that there is a danger of them staying on medication for long, long periods of time, nobody dares stop it. So I think recovery is in terms of medical management, but more in terms of supporting them in their social environments and getting them back into whatever” (GPwSI 2, female).

However, there was also awareness that although returning to work and social functioning may be what recovery means to one person, recovery may mean something different to another person. Thus recovery should be based on the needs, desires and expectations of the individual SU.

“I think recovery…is something you have to define on an individual basis. What might be recovery to one person, might be functioning normally, back to work, absence of delusions. For somebody else it might be being able to return to their family, but they've still got psychosis, they've still got the illness. I think, for some, in my experience this is, some people do actually have delusions, but could actually say, 'I'm having delusions, I'm having hallucinations but they're not troubling me'. So, maybe that's also a recovery. I think, if it was me, I think it would be return to work” (GPwSI 8, male).

Psychosis was conceptualised by one GPwSI as an impairment rather than a disability. According to this viewpoint, psychosis became a disability only as a reflection of how society itself was structured, rather than it being inherently a disability. From this GPwSI’s viewpoint, recovery consisted of the SU acknowledging and coping with practical impairments so as to optimise their state, as well as finding positive strategies for dealing with other people’s attitudes and beliefs towards them. The idea of recovery being a process of focusing on one’s positive personal attributes was also discussed here.

“People can have disorders, impairments, which like psychosis, would give you certain impairments and it is how you deal with it and how society deals with you, and how your families work through it. So you can have impairments, but it's the interaction of impairments with community, family, and society that create your disabilities. So part of what you have, what you need to do as an individual with a psychosis, is to find positive strategies for dealing with often people's attitudes and beliefs towards you as much as some of the practical impairments that you have to deal with. So I think optimising your state, acknowledging that you have some
impairments maybe, and then getting on with it, dealing with those and also working on the positive things inside you” (GPwSI 13, male).

The view that recovery is partly about the SU optimising their state, or making the best of their situation, was echoed by other GPwSIs. In addition, one GPwSI believed that full recovery was the gold standard which should be aimed for.

“You sort of get to the point where you perform the best with what you have available. But, my experience, I mean, my experience is you know, people do fully recover and…I think we should be going for full recovery with everybody. That should be our goal, complete back to normal” (GPwSI 15, male).

For most GPwSIs, recovery from psychosis also meant the ability to live independently in good quality accommodation and to develop positive social relationships if that was what one wished.

“To my mind a big part of recovery is making sure that they have a life where they have the possibilities to be socially included, that they can get, if they want to, they can get married, have kids, have jobs, live in a decent house and have money. If those are the choices they want, that those routes, because they have psychosis, are not closed to them” (GPwSI 11, female).

An indication of recovery was when SUs were able to live independently without day-to-day help from carers or from health professionals.

“He's living in his own place and has managed that” (GPwSI 6, female).

**Summary**

There was evidence that GPSs were much more likely to emphasise the importance of biomedical aspects of recovery, and tended to focus on symptomatic recovery. This biomedical conceptualisation of recovery required the suppression of psychotic symptoms and a return to mental stability. It appeared to be related to a belief held by most of the interviewed GPSs regarding the efficacy of anti-psychotic medications as a way of producing this recovery outcome. GPwSIs more frequently referred to functional or social elements of recovery. GPwSIs generally reported that recovery from psychosis was signified by the SU’s return to a level of social functioning deemed by GPs to be adequate or normal. It is important to note that the
definition of adequate or normal functioning was often, though not always, based on the perceptions and interpretations of the GP rather than those of the SU. The conceptualisation of recovery as social or functional recovery tended to include ideas around social inclusion such as being involved in the community, being employed gainfully or voluntarily, being engaged in education, living independently in good quality accommodation, developing positive social relationships, as well as optimising one’s state of wellbeing within the limits of what is possible due to the experience of psychosis. For some GPwSIs, functional recovery meant a complete return to premorbid levels of health, but for most GPwSIs functional recovery meant the ability to manage or cope with any remaining symptoms, without necessarily removing symptoms. This importance of social inclusion and social recovery for GPwSIs was related to the previously reported importance of social support in promoting recovery. The role of the family in supporting the SU’s social recovery, as well as the potential for GPs to be more involved in promoting social or functional recovery, were both reported by GPwSIs. The conceptualisation of functional recovery by some GPwSIs also included a reduction in the intake of anti-psychotic medication in the longer-term – this is a thread which will also be picked up in the following section.

5.6 Medication as a recovery tool

Medication as one potentially useful intervention
The vast majority of GPwSIs felt that anti-psychotic medication could be useful in helping to promote recovery from psychosis, although there was also an awareness of the negative side-effects of medication as well as a general consensus that medication was not the only useful means of promoting recovery.
“I am not always an advocate that medication is the only way” (GPwSI 12, female).

Many GPwSIs did report cases where they felt that medication made a positive contribution to the mental health of SUs. One GPwSI described a SU with bipolar disorder who was not improving, so carbamazepine was added to her treatment regime. After its introduction there was a positive outcome.
“She has been completely well since…I think it was because of medication, I really do think it just stopped the switch from flicking” (GPwSI 12, female).
Another GPwSI gave a similar example of a positive outcome derived from the use of anti-psychotic medication.

“A lady who had very florid paranoid psychosis, who did very well on medication...She has no symptoms; she is symptom free and has been virtually for quite a long time” (GPwSI 2, female).

Some GPwSIs went further, stating that compliance with a treatment regime of anti-psychotic medication was a necessary requirement in order for recovery to be maintained. The GPwSI quoted below, was an example of a GPwSI who held this viewpoint. He justified this stance by referring to testimonies from SUs who agreed with his viewpoint.

“As long as they take their medication they’re fine. When they don’t take their medication, and even they themselves will tell you: ‘I’m beginning to, you know, I can recognise I’m going off’. That’s when they come and say, ‘I need my olanzapine again’ or whatever”

(GPwSI 8, male).

Other GPwSIs pinpointed the usefulness of anti-psychotic medication specifically to acute psychotic episodes.

“In that acute psychotic episode, I think we should get a secondary, help from secondary resources. Because that’s when there is more place for antipsychotic agents”

(GPwSI 12, female).

Some GPwSIs felt that medication was needed to maintain the SUs’ mental health and avoid relapse. However, GPwSIs also tended to believe that in ideal scenarios, medication would be reduced to the lowest minimum levels required for stability to continue. A reduced level of anti-psychotic medication intake was seen as an indicator of full or partial recovery.

“Now a few years on he is still on medication but much lower doses...He's definitely moved on hugely” (GPwSI 6, female).

The majority of GPwSIs believed that apart from anti-psychotic medication, other factors and interventions were also important in promoting recovery from psychosis.
“Now I realise that there is a whole range of different interventions that make a big difference, particularly early on” (GPwSI 13, male).

Alternative interventions mentioned by one GPwSI included psychosocial interventions and CBT. This GPwSI believed that any intervention with an evidence base could be utilized. “I think certainly the social recovery step is vital. I know it sounds a bit odd, but I would probably place that higher than the medication, but I do recognise that medication has a part to play...It's like a whole package isn't it? You've got your traditional, your medical stuff, but then you've got the psychosocial stuff. The evidence does say that CBT is effective in psychosis, so that has a place as well” (GPwSI 11, female).

Medication was often prescribed in addition to simultaneously implementing other treatments. One GPwSI explained that he recommended a two-pronged approach to promoting recovery. On the one hand he prescribed anti-psychotic medication, while on the other hand he simultaneously instilled a sense of therapeutic optimism in the SU by repeatedly assuring her of his expectation that she would recover. “We prescribed medication to her, which she took, and we persisted on a firm explanation and instilled um, kept repeating the statement that she will recover from this and that this is not a permanent situation. With that persistence and the medication, she improved” (GPwSI 9, male).

Other important non-medical factors which influenced recovery, but which were not necessarily related to medical intervention, included family and community support. “Apart from just the medicine, the medical therapy, there's, there needs to be a lot of support of the family, of the community. That is what is going to pull this person out of the psychotic episode, not just the medication” (GPwSI 12, female).

For some GPs whose preferred treatment route was to refer SUs to a psychiatrist, medication was seen as a back-up intervention in cases where they could not access a psychiatrist quickly enough.
“I think if somebody is psychotic, I would refer them immediately to secondary care. Or, though, if I couldn't see somebody immediately, I would give them antipsychotic medication...if they couldn't access a psychiatrist immediately” (GPwSI 14, male).

**Reservations about medication**

Many GPwSIs reported reservations about the usefulness of anti-psychotic medication as a tool in the promotion of recovery from psychosis. An associated problem reported by some GPwSIs was the lack of knowledge regarding appropriate dosage and length of treatment.

“Well recovery, we can talk about obviously controlling the positive symptoms...and to be fair, medication can be very effective in doing that. There is research showing that if you use drugs appropriately, although I think that is the hard bit...What dose do you use? How long do you keep them on? How long is your maintenance phase? I don't think anybody’s really worked that out” (GPwSI 11, female).

It was widely understood by GPwSIs that anti-psychotic medications had negative side-effects. One GP spoke of these side-effects as an “illness” in itself, thus pointing to the iatrogenic consequences frequently associated with anti-psychotic medications.

“You've got to be so careful with it because of the side effects and problems with it, the illness it can cause through giving it” (GPwSI 11, female).

One of the side-effects observed by a GPwSI was hypersalivation or “drooling” which seriously impacted upon the SU’s quality of life.

“He was having problems with drooling” (GPwSI 13, male).

On the other hand, most GPSs did not mention the side-effects of anti-psychotic medication as being a potential barrier to recovery. However, there were exceptions to the rule. Side-effects mentioned by one GPS included weight gain, high cholesterol, and increased risk of cardiovascular disease.

“She is overweight, she does have high cholesterol, so I think that is partly related to the olanzapine, so we kind of give her the minimum dose possible” (GPS 3, male).
Another GPS spoke of a SU who had experienced other serious side-effects such as leukopenia (reduced white blood cell count) and blue skin. This was indicative of an awareness of anti-psychotics’ side-effects.

“She was on clozapine at one point and developed a leukopenia, which is a side effect from it, so that had to be stopped, well that was being effective. She was on high dose chlorpromazine at one point and developed this blue skin, which again is a noted side effect from it, but honestly she looked like a Smurf” (GPS 4, male).

Medication Compliance
All GPSs who were interviewed expressed the view that a major factor determining a SU’s recovery from psychosis was whether or not they complied with the prescribed anti-psychotic medication. This emphasis on medication compliance was not as evident amongst most GPwSIs, although some GPwSIs did also mention it. When SUs stopped taking anti-psychotic medication, one GPS believed that this generally led to a reoccurrence of psychotic symptoms.

“She is still getting the reoccurrence of the incidents that are there. If she doesn’t do her medication, then she slips back and does it again” (GPS 1, male).

For most GPSs, medication compliance was the single most important contributor to recovery from psychosis. GPSs believed that compliance with medication tended to lead to mental health stability, whereas non-compliance tended to lead to instability:

“With the modern drugs, you seem to be able to get them to a kind of, stable point. And those who are very unstable, it tends to be because they are non-compliant with treatment” (GPS 6, male).

Compliance and maintenance of medication intake was seen as leading not only to symptomatic recovery, but for the minority of GPSs who thought in terms of social recovery, it was also seen as leading to functional independence.

“Q: What would recovery from psychosis mean to you?
A: Patient returning to the community in good health and able to function independently, most of which do that provided they maintain their medication” (GPS 3, male).
Most GPSs tended to believe that the widespread lack of compliance with anti-psychotic prescriptions was due to a lack of insight or acceptance of the diagnosis on the part of the SU. In contrast with GPwSIs, there appeared to be less awareness amongst some GPSs of the possibility that side-effects from medication might be an alternative reason for non-compliance.

“I think most people will recover from an acute psychotic illness with the right medication. A percentage doesn’t come sufficiently to terms with it and therefore they stop the medication and they relapse” (GPS 7, male).

One GPS believed that if medication compliance was not forthcoming from the SU, enforced hospital admission might be a means of facilitating medication intake and treatment adherence.

“It came to a stage where to actually get the person to comply with medication we needed an admission to be facilitated. And then once in hospital, compliance was much better, and I think eventually actually had ECT treatment as well” (GPS 5, female).

Unlike GPSs, most GPwSIs did not mention medication compliance as an important barrier to recovery. However, there were exceptions. One GPwSI mentioned the difficulties she encountered in persuading SUs to comply with lengthy medication-based treatments.

“If you start the younger person on the antipsychotic early at a low dose and you try and persuade them to stay on it two or three years, it has been shown to be beneficial. But trying to persuade somebody to take these sort of drugs for that length of time is very difficult” (GPwSI 11, female).

**Summary**

All GPSs saw anti-psychotic medication as a useful intervention which often had positive outcomes in terms of promoting recovery from psychosis. Some GPwSIs also believed that the continued use of medication was necessary to keep people well. However, most GPwSIs also expressed reservations about anti-psychotic medications, and medication was not seen as the only means of promoting recovery. Other social factors such as family and social support were also seen by many GPwSIs as being important in the promotion of recovery from psychosis, as well as psychological interventions such as CBT. In contrast to this, GPSs placed a great degree of emphasis on ensuring the compliance of SUs with medication treatments, and the importance of
compliance. Although some GPwSIs did mention non-compliance as a drawback of using anti-psychotic medication, non-compliance tended to be discussed in the context of the medication’s serious side-effects which may have led to an understandable desire to avoid taking such medication.

5.7 Self-perception of personal expertise

Most GPSs felt that they lacked the requisite knowledge about psychosis to carry out certain tasks. GPSs reported a lack of confidence in their own ability to diagnose psychotic disorders, their knowledge of how to treat psychosis, and their knowledge of anti-psychotic medications. “I found it very difficult to do the assessments within primary care, and again felt that maybe if I had been able to speak directly to a psychiatrist it might have helped considerably” (GPS 5, female).

One GPS not only felt she lacked knowledge and skills, she also found dealing with a particular case of psychosis to be “intimidating” and “frightening”. She had been asked to carry out an assessment for a sectioning, and found this outside her “comfort zone”. This may indicate some GPSs’ uneasiness with psychosis and psychiatric wards as fearful and dangerous, alongside GPSs’ self-perception of a lack of personal expertise in the area.

“I was then involved in sections where I had to go to assess twice at the hospital, and again it is always out of your comfort zone going to do a section anyway, particularly on the psychiatric ward, and on this particular occasion it was a locked psychiatric ward as well, so not something I have experienced since I was an SHO, and quite intimidating and quite frightening” (GPS 5, female).

This self-perceived lack of personal expertise about psychosis amongst GPSs was seen as an inherent element of the role of the GP as a non-specialist practitioner in a primary care setting. GPSs differentiated themselves from GPwSIs and psychiatrists who were seen as having specialised expertise in the area of psychosis.

“Well in primary care it cannot offer what secondary care can. It is a specialist job, I don’t think it is a job that everybody or anybody can do. Those GPs who have a special interest can do
something for the patient, but most GPs unless they work in psychiatry, they don’t have the expertise” (GPS 1, male).

SUs presenting with psychosis were usually referred to psychiatrists in secondary care. It is evidence-based good practice to refer at presentation, as supported by NICE guidance. One GPS mentioned that he would not be comfortable offering continuity of care for long-term “chronic” management of the condition without supervision from a psychiatrist.

“Primary care can offer continuity of care, so long as a psychiatrist and the mental health team supervise it” (GPS 1, male).

Another explanation given by GPSs as to why they did not feel that they were adequately equipped to deal with cases of psychosis within primary care was that they were not frequently exposed to people experiencing psychosis.

“We do not see it very often in general practice, but when we do the alarm bells start to ring” (GPS 5, female).

Although SUs experiencing a first episode of psychosis may present initially to the GPS, it was reported that such SUs may be directed to remain in contact with secondary care services for up to three years, rather than returning to primary care. Again, for GPSs this led to reduced exposure to, and experience of psychosis. This may in turn have contributed to GPSs’ lack of confidence in treating psychosis.

“A lot of those people are kept under the care of the mental health teams quite closely and we do not get too involved in that. It is the initial diagnosis and then the chronic management that we get involved in really” (GPS 5, female).

GPwSIs generally reported a greater degree of perceived personal expertise and comfort in the area of psychosis. GPwSIs reported having more confidence in their own abilities to deal effectively with people experiencing psychosis. For example, one GPwSI reported being solely responsible for a person with psychosis. In that instance, the SUs’ mother appeared to have confidence in the GPwSI’s personal expertise and his ability to deal effectively with the situation.
“Now he's not involved with the psychiatric services. He does seem to have recovered. He's on medication. I think his Mum, who he lives with, is quite good at picking up when he's beginning to go off, and either encourages him to come and see me, or drags me out to see him” (GPwSI 8, male).

There are two important caveats relating to the findings reported above. Firstly, only seven GPSs were interviewed. It would not be appropriate to generalise beyond those GPSs who participated in the interviews, or to make inferences about the general self-perception of specialist knowledge regarding psychosis amongst GPSs. Secondly, GPwSIs are by definition more specialised in the area of mental health. It would be expected that GPwSIs would feel more confident working with psychosis. In addition, the GPwSIs interviewed were attending a Masters course in primary care mental health, and would be expected to have additional psychosis-related knowledge as a result.

**Summary**

GPSs perceived themselves as inadequately skilled and inadequately knowledgeable about the nature of psychosis to allow them to treat SUs effectively. GPSs reported not being confident about many aspects of treating psychosis, such as lacking the knowledge required to carry out assessments, to prescribe medication, to carry out a “section”, or to manage “chronic” psychosis on a long-term basis without supervision from psychiatrists. The reasons given for this lack of personal expertise included encountering relatively few people with psychosis, and not being specially trained in psychosis. There was a prevalent feeling amongst GPSs that psychosis was an area of care which required professional specialisation for effective treatment. This lack of perceived self-efficacy was linked to the desire amongst GPSs to have enhanced communication with psychiatrists. In contrast, many GPwSIs reported having more confidence in their own knowledge of psychosis and in their ability to effectively treat psychosis. In particular, GPwSIs felt confident in working with SUs who were somewhat recovered, and were no longer in contact with secondary care services.

**5.8 Perceived importance of comorbid drug misuse**
Most GPSs tended to place a greater degree of emphasis on drug use as one of the most common causes of psychosis. According to a majority of the GPSs interviewed, psychosis was frequently induced by the use of illegal street drugs such as cannabis, amphetamines, or cocaine.

“Most of the patients here are drug-induced psychoses; they’re under the influence of either amphetamine or cannabis” (GPS 3, male).

GPSs felt that the continued abuse of drugs by SUs was a key barrier to their recovery from psychosis. Relapses and reoccurring episodes of acute psychosis were attributed to drug abuse.

“I’ve got these two young men who I remember sectioning in 2001/02 with definitely amphetamine driven psychoses, who were in hospital for quite a long period and came out in the community and their families are still having to help them and having these relapses, possibly because they are still abusing you know. I think that might be part of the problem. I think the worst ones are the cannabis users” (GPS 3, male).

Most GPSs felt that the prognosis for recovery was more optimistic for those SUs whose psychosis was initially triggered by drug abuse compared to those whose psychosis was not triggered by drug misuse. This optimism regarding recovery from drug-induced psychosis was conditional upon the SU’s discontinuation of drug use.

“For quite a lot there is something fairly specific which has triggered the problem. Now for some people that is drugs and in some ways those are the easiest people to treat. Once they stop taking the drugs they may quite quickly settle down. In fact it may not be as much of a long-term problem” (GPS 6, male).

One GPS felt that SUs might recover better from drug-induced psychosis due to the more easily understandable explanation for their experiences which this form of psychosis provided. This GPS felt that SUs might more readily accept their psychotic experiences if they believed that their drug use had caused those experiences.

“Drug induced things, which might be easier for a person to come to terms with because they can see a clear cause and effect” (GPS 7, male).

The origin of psychosis for such people was postulated by some GPSs to be based on drug misuse, and so was “external”. This was contrasted with other forms of psychosis which were
described as “primary psychotic illness” and may have had “internal” precursors such as neuro-pathological or psychological factors. This viewpoint was congruent with a biomedical system of thought regarding recovery from psychosis.

“These patients are drug driven. They don’t have a primary psychotic illness as such you know, although it becomes mixed and difficult to know what’s what. But as I say, as a primary psychosis, I have one, I think one man who became schizophrenic not due to drugs. And I’ve had about seven that have. So I mean, that’s the way it has been the last ten years” (GPS 3, male).

Most GPSs felt more comfortable dealing with cases of drug-induced psychosis, even though the symptoms presented by people experiencing both forms of psychosis were the same. Again, this is consistent with the feeling professed by GPSs that their domain of expertise did not include psychological problems. GPSs were more comfortable dealing with psychosis which had “physical” origins such as drug use, rather than dealing with psychosis as the “primary illness”.

“The drug induced ones I tend to see...are the ones that we probably better deal with here; whereas they (CPNs) are better dealing with patients who need to see the psychiatrists regularly” (GPS 3, male).

The presence of comorbid alcohol misuse amongst those experiencing psychosis was also emphasised more frequently by GPSs than GPwSIs.

“He has actually carried on taking the treatment, but I think he continues to drink moderately heavily and he will have no contact with any medical services at all” (GPS 6, male).

As with illegal drug use, GPSs saw the misuse of alcohol as a very important barrier to recovery from psychosis. In contrast, GPwSIs did not mention either alcohol or drug use as an important barrier to promoting recovery in primary care.

“He often did not turn up to appointments, does drink alcohol, smokes cannabis, despite a lot of input from the Mosaic, the drug and alcohol team, and from the psychiatrists as well. So he is not working. He is in and out of hospital” (GPS 4, male).

Summary
Many GPSs reported the use of illicit drugs as being a common cause of psychosis, as well as an important barrier to recovery. Psychosis onset may have been seen to stem partly from the behaviours of SUs. The focus on illicit drug use may also have been linked to GPSs’ biomedical conceptualisations of recovery, and bio-chemical theories of psychosis onset. In contrast to GPSs, GPwSIs did not emphasise comorbid drug and alcohol use as an important causal factor in psychosis, and did not emphasise drug and alcohol abuse as being one of the major barriers to recovery from psychosis. Instead, as mentioned previously, GPwSIs focused on how social functioning and recovery could best be promoted, without focusing on drug and alcohol abuse as being major barriers to achieving recovery.

Conclusion

Overall, a number of themes were identified during the interviews with GPs. Some of these identified themes were common to both GPSs and GPwSIs. For example, GPs believed that they provided continuity of care, and this continuity tended to be less evident in secondary care services. Continuity of care was seen as an important element of the care GPs provided, and was seen as an important factor in promoting recovery from psychosis in primary care. GPs agreed that existence of social support networks was another important factor in promoting recovery from psychosis, with GPwSIs in particular believing that GPs had a role to play in promoting the social support networks of SUs through primary care interventions. GPs also agreed that they had a role to play in terms of supporting families, and family support was seen as another important factor in promoting recovery from psychosis. There was also a commonality between GPSs and GPwSIs in terms of their desire for better communication with psychiatrists and access to secondary care psychiatric services.

However, other themes identified during interviews highlighted the marked differences evident between the responses of GPwSIs and GPSs. For example, a functional or social conceptualisation of recovery was much more evident amongst GPwSIs, while a biomedical or symptomatic conceptualisation of recovery was more common amongst GPSs. Similarly, the side-effects of medications were more prominently reported by GPwSIs, whereas medication compliance appeared to be a more pressing factor for GPSs in terms of promoting recovery.
GPwSIs reported a greater sense of self-efficacy and expertise in promoting recovery from psychosis in primary care, whereas GPSs tended to report feeling less confident and more reliant on secondary care services for help. Finally, GPSs were much more likely to report that comorbid drug and alcohol use amongst SUs was a key barrier to recovery from psychosis.

This chapter has presented the findings of the first part of the empirical research for this PhD – the views of GPs on recovery from psychosis in primary care. The following chapter will present further empirical research. It will focus on SUs’ views regarding recovery in primary care, including SUs’ conceptualisations of recovery from psychosis, and the factors deemed important for the promotion of recovery in primary care settings.
Chapter 6

Service Users’ views on
Recovery in Primary Care
Introduction
This chapter will present the results of semi-structured interviews with SUs. The interviews focused on SUs’ views regarding recovery from psychosis in primary care. As with the previous chapter, the results are presented thematically. Exclusion criteria, participants’ demographic information, and the interview topic guides will be outlined before the results are presented.

Exclusion Criteria
All SUs who reported having been given a psychosis-related diagnosis or a schizophrenia-spectrum diagnosis were included in the study. 15 SUs described the mental health diagnosis which they had received from a medical professional as one of the following: psychosis, schizophrenia, paranoid schizophrenia, or schizoaffective disorder. An additional three SUs who did not report having received such a diagnosis, described their respective individual mental health problems as “psychosis”, “bipolar disorder”, and “hearing voices that others don’t”. Two further SUs did not disclose information about their personal mental health diagnoses, but were living in supervised accommodation. This accommodation was aimed specifically at housing people who had experienced psychosis, so it was assumed that these two participants had experienced psychosis. This brought the total number of SUs included in the study to 20. There were three further interviews undertaken which were not included in the final results because the participants had experienced problems that were not psychosis-related: obsessive compulsive disorder, social anxiety, and moderate learning difficulties.

Demographics
Demographic information was collected for all participants. SUs were asked to give their gender, age, ethnicity, housing status, self-reported mental health diagnosis, and the diagnosis given to them by mental health professionals. Of the 20 participants, 14 were male and six were female. In terms of ethnicity, 13 participants were White British (65%), four were Black (20%), and three were Asian (15%). Of the 18 SUs who disclosed their age, three were in their 20’s (15%), six were in their 30’s (30%), six were in their 40’s (30%), one was in their 50’s (5%), one was in their 60’s (5%), and one was in their 70’s (5%). The mean age of participants was 40.5 years,
with a range of 24 years to 74 years. Of the 15 participants who pinpointed the specific age of onset of their first episode of psychosis, one reported their onset as having occurred during childhood (7%), four as teenagers (27%), nine in their 20’s (60%), and one in their 30’s (7%). The mean age of onset of first-episode psychosis was 21.4 years, with a range of 4 years to 31 years. 13 SUs were living independently and seven SUs were living in supervised accommodation. Of the 19 SUs who disclosed whether or not they were currently accessing secondary care mental health services, 16 said they were currently accessing services and three said they were not. These demographic details are presented in Appendix 10.

**Topic Guides**

The interviews explored the range of meanings that psychosis and recovery from psychosis had for individual SUs, as well as examining their lived experiences of recovery in primary care settings. Some of the questions in the topic guide were based on the findings of the CIS and asked SUs to talk about how they conceptualised recovery from psychosis. Opinions were also collected regarding what factors influenced recovery from psychosis, particularly in the context of primary care. SUs were asked to describe their experiences of their GPs’ service provision in relation to psychosis. In particular, SUs were asked to recall one episode from which they recovered particularly well, what indicated that they had recovered, and how they dealt with the episode. SUs were also similarly asked to recall one episode where they felt that they did not recover particularly well, and what factors were involved. SUs were asked what GPs could do differently to better promote recovery from psychosis in primary care, as well as how such changes to service provision might best be introduced.

**Results**

Four main themes emerged during the interviews with SUs. These were as follows: a psychosocial or “whole person” approach to recovery; greater autonomy and input for SUs; a shift in responsibility for psychosis from secondary to primary care; and the wider societal context, including stigma and social exclusion. These four themes will now be discussed on greater detail.
6.1 Psychosocial or “whole person” approach to recovery

Opposition to biomedical approach to recovery

Many SUs who experienced psychosis reported that they would like to see a greater focus amongst GPs on interventions in primary care which dealt with the person as a whole, both physical and psychological: an all-encompassing “whole-person” approach to recovery from psychosis. This approach was reported as including a reduced emphasis on medication as a method of dealing with psychosis, as well as an increased emphasis on the importance of nutrition and psychosocial interventions.

“I think it should be holistic. They can't give you something that basically cripples people, or gives them Parkinson’s or something like that when they've already got a lot of stigma as it is with their mental health, and then say, well at least their brain’s fine or whatever. How is it going to be fine if they've got that to live with, on top of everything else?...I just think I'd like them to try and treat the whole person, and not just treat them like they've got a brain that has a major disorder, so don't worry about anything else” (SU 13, female).

A whole-person or a psychosocial approach to recovery from psychosis was identified as being in opposition to the perceived approach of most GPs which consisted of the biomedical approach, with its focus on diagnoses, symptoms and chemical interventions such as anti-psychotic medications.

“The doctors just see it as a chemical imbalance, and they say, 'We'll give you more medication. It's important you stay on your medication.' They lower the medication and they up the medication...I don't think they understand the whole person, they just understand the symptoms” (SU 15, female).

Anti-psychotic medications lack efficacy

The opposition to GPs’ perceived biomedical approach to recovery from psychosis was partly based on this approach’s perceived lack of efficacy. In particular, most SUs conveyed their
frustrations with anti-psychotic medications which tended to not be satisfactory or efficacious in their attempts to promote recovery.

“Medication does numb it a bit, it does help a bit, but it should help a lot more, there should be a lot better medications out there” (SU 5, male).

Most SUs felt either that the positive effects of anti-psychotic medication were not enough to alleviate most of the problems associated with psychosis or that anti-psychotic medication simply did not have any positive effects.

“I fall ill if I’m on the medication, I fall ill if I’m not on the medication” (SU 13, female).

Apart from SUs’ criticisms of the efficacy of anti-psychotic medications, most SUs also reported that they had experienced negative side-effects from taking such medication such as hyper-salivation, which affected their daily lives.

“It has been going on for a long, long time this hyper-salivation. They keep changing their mind, and nothing works, and you get so frustrated, you really do” (SU 12, male).

**The GP’s role in psychosocial recovery**

A number of SUs reported that when they first began taking anti-psychotic medication, they had not realised the serious negative impact those medications would later have on their quality of life. It was felt that GPs could do more to explain and discuss the consequences and side-effects of anti-psychotic medications before the SUs began taking them.

“It would be good if they told you more about the side effects of the drugs as well. What to expect” (SU 14, female).

As part of a whole-person approach to recovery from psychosis, some SUs felt that GPs could do more to help direct and advise SUs on how to improve their nutritional intake. However, it was felt that at present most GPs did not focus on nutritional intake as much as SUs desired. Most SUs felt that GPs tended to take a medication-orientated approach to intervention, which was not balanced by a focus on additional nutritional requirements.
“If they knew actually about food, and they were even trained in nutrition…it’s scary that they don’t know anything about food. They just know drugs, they’re all chemists. It’s totally not on balanced in any way” (SU 3, male).

Local peer-supported services and SU groups were frequently reported as being useful and beneficial through their promotion of recovery from psychosis. Peer-supported services provided a social support network of people with a shared experience of psychosis. It was also reported that such services and groups were important in normalising and de-medicalising the experience of psychosis for some SUs. As part of a more psychosocial approach to interventions and to recovery from psychosis which was desired by SUs, it was believed that GPs could play an important role by being more proactive in signposting local peer-supported services for SUs. It was felt that this signposting could be particularly beneficial to vulnerable SUs who were not motivated to search for such local services.

“They could say, even if they've not got the time, they could say, 'Well, we can't talk at the moment’, but maybe look into some information, at groups that they can go to, other alternatives. Fortunately, I did most of my own work, but somebody who feels a bit vulnerable or low or perhaps a lot of bad things have happened and they don’t seem motivated” (SU 15, female).

Some SUs included psychosocial interventions and psychological therapies as part of how a “whole person” approach to recovery from psychosis was defined. It was felt that GPs could do more to create awareness amongst SUs that psychological therapy was an intervention option, to refer more SUs for psychological therapy instead of prescribing anti-psychotic medication, and to have a more positive attitude towards psychological interventions in general. There was a feeling amongst some SUs that GPs preferred to prescribe instead of listening to the SU because it was the easier option for the GP, requiring the allocation of less time and energy resources from their busy schedule.
“They don't have any training in psychology or psychological intervention. It is all too easy to prescribe a pill, sign a piece of paper, ‘There you go, take two in the morning and call me in a week’” (SU 16, male).

However, although many SUs desired psychological interventions, it was difficult for many SUs to gain access to psychological interventions for psychosis through their GP, and medication was the most common intervention reported.

“I've never been able to have family therapy or address underlying roots to things”
(SU 13, female).

It was felt by many SUs that instead of focusing on medication levels, GPs could better promote recovery by talking to the SUs about their life stressors and other everyday experiences which may have contributed to their experience of psychosis or to relapses.

“I just feel that taking more medication isn't the answer. If they spent time and spoke to me and said, 'Okay we've got twenty minutes.' Ask me what is happening in that time in my life and why I've had a relapse, rather than saying, 'Okay instead of taking 10mg of Risperidol, take 12mg.'” (SU 8, female).

**Summary**

There was a general desire amongst SUs for a psychosocial approach to defining and promoting recovery in primary care. It was felt that the social and psychological aspects of people should be attended to, as part of a “whole person” approach to promoting recovery. However, GPs were reported to focus primarily on biomedical recovery, with its emphasis on diagnoses, symptoms, disorders of the brain, and chemical interventions. Medications were generally criticised by SUs due to their side-effects and apparent lack of efficacy in promoting recovery or in preventing relapse. There was a feeling amongst many SUs that treatment for psychosis should not simply be focused on the biochemistry of the brain. Many SUs expressed the belief that when discussing treatment options, GPs could warn SUs of the side-effects of medications, as well as offering
information on alternative interventions such as local peer-supported services, SU groups, psychological therapies, and nutritional advice.

6.2 Greater autonomy and input for SUs

**Consultations and the decision-making process**

GPs were often reported as wielding great power in the doctor-client relationship. The GP was seen as being in control by many SUs, and the power dynamics of the relationship were seen as unequal. GPs controlled the intervention decisions and SUs felt that they did not have much input into the structure of their own treatment plans.

“That is sort of trained into them through medical training. It’s sort of a client-master relationship, where they are the master above the client. They are the ones in control, and they can tell you what to do, and they push you around. I do not work like that. I am peer to peer” (SU 16, male).

Many SUs reported that their GPs did not listen to their desires and wishes regarding the interventions they would like. There was a general belief amongst SUs that greater listening skills on the part of GPs were required, and that if this change was implemented it would be beneficial for the SU. It was felt that if SUs were listened to by their GP, the views of SUs could be given greater weight in the decision-making process regarding their own treatment plans.

“That first GP who didn’t really help me - he didn’t listen to me. He just kept giving me tranquilisers all the time, different one nearly every month” (SU 1, male).

Some SUs identified the problem of GPs not listening adequately to SUs’ concerns as being related to the time constraints which GPs were operating under. It was felt that longer consultations might help alleviate this problem by reducing the rushed nature of consultations.

“They are normally in a rush and you feel like you are taking up their time, so you miss things out when you go in... It’s all about time - they haven’t got enough time. They might want to help but they just haven’t got the resources” (SU 14, female).
SU input into their treatment plans during primary care consultations was seen as a factor which promoted recovery. Many SUs felt that it was important to make choices about their own treatment, and shared decision-making with the GP was seen as a way of facilitating this. It also provided SUs with a sense of control and ownership over their own recovery, which was empowering in itself.

“It’s choice. A lot of people feel that if they have been prescribed the tablets they have got to take them, they cannot reduce them, they have no choice” (SU 16, male).

When GPs did listen to SUs’ concerns and allowed SUs to have input into their own care or treatment plans, it was received positively by SUs.

“He is helping me reduce my meds and he is doing it very, very well. I go in and it is not a matter of debating or anything like that. He will just automatically do it for me. We have got a good relationship” (SU 10, female).

Another SU was also satisfied with a GP consultation where her GP expressed an interest in exploring the details of her experience of hearing voices, and engaged in a discussion with her about the subject.

“There was one good doctor. There was one occasion, when the doctor actually sat down with me and she said, ‘What are they saying? How many are there?’” (SU 15, female).

“Fobbing off” and “Hand-washing”

Some SUs reported feeling that GPs had wanted to “fob them off” and avoid the responsibility of having to deal directly with the problems of the SU. It was felt that this reported attitude of some GPs was manifested in their perceived lack of interest in the SU. Some SUs were also of the opinion that they may have been referred to a psychiatrist because their GPs were not interested in initiating interventions or even engaging with the SUs themselves.
“I will go to the doctor, but when he fobbed me off, he just said, ‘I think you are not coping very well. I think you had better go and see your psychiatrist.’ It was like he was washing his hands” (SU 8, female).

One SU felt that it was a lack of understanding of psychosis on the part of GPs which resulted in their reticence to communicate with SUs, and their preference for referrals to psychiatrists. This approach was described by the SU as being a “conveyor belt” approach to dealing with psychosis as it was lacking in sympathetic human communication.

“I don’t think he understood it because if I went to him and I said, ‘You know, doctor this...’, he would say, ‘Just contact your psychiatrist, the psychiatrist will help you.’ He never seemed to want to; it was like it was a conveyor belt, ‘Just tell me what you want and then go.’” (SU 8, female).

Another SU felt that the desire for GPs to “fob off” SUs was due to a perception amongst GPs that SUs experiencing psychosis were “problematical”.

“They won’t listen and they just see me as just problematical. You know, I am looking for support, I am looking for help, I am looking for a way to deal with this, and recover some semblance of normal life. They cannot give it to me because they just cannot see beyond their sort of, ‘You are a little person, I am a big person, you do as I say’” (SU 16, male).

Summary

SUs reported many experiences of being unable to influence decisions regarding their treatment plans during consultations with GPs. Many SUs felt that there was a sense of inequality in their relationship with GPs, with SUs often not feeling empowered to exercise choice over, or provide input into their own treatment plans. It was felt that such empowerment and autonomy were not only important ways of enabling a SU to have a say in their own treatment, but were also seen as key elements themselves in the promotion of a SU’s recovery. However, many SUs reported that GPs did not listen to them, and that some GPs did not communicate empathically during consultations. It was felt by a number of SUs that better listening and communication skills were
required by GPs. One reason proffered by SUs for this lack of listening skills was the rushed nature of consultations. Some SUs felt that GPs wanted to end consultations quickly, which may have resulted in SUs being seen as “problematical”, and SUs ultimately being “fobbed off” with referrals to psychiatrists or with altered prescriptions for medications.

6.3 Shift responsibility for psychosis from secondary to primary care

Greater GP involvement

Although the relationship between SUs and GPs was generally not reported to be ideal, many SUs still stated a preference for being seen for psychosis by a GP in primary care rather than by a psychiatrist in secondary care. There was a tension evident in the data between SUs’ criticisms of current primary care provision, and the preference of those same SUs to be seen for psychosis in primary care rather than secondary care. Many SUs desired to see a GPwSI who was trained in mental health. GPwSIs were felt to be in a better position than psychiatrists to provide continuity of care, while still having a certain level of mental health knowledge and skills.

“What I actually want is a doctor in a surgery that specialises in mental health. In my last practice, I actually asked to see the doctor who specialised in mental health on the sheet, but she only was qualified in Alzheimer’s and stuff like that. So what I actually want is more specialism within a GP surgery, so you didn’t have to keep being referred to a psychiatrist” (SU 4, female).

SUs reported a desire for more psychosis-related consultations with GPwSIs, which would take place in the local GP practice. This would mean that SUs would not have to travel as frequently to a hospital or an outpatient clinic to see a psychiatrist, thus reducing travel times and reducing the stress and stigma that some SUs feel is associated with psychiatric hospitals. SUs associated primary care with reduced stigmatisation, as well as a perceived reduction in the likelihood of their being sectioned.

“It's not got the stigma of the hospital. Psychiatrists have always got that stigma of hospital, and they've also got the power to section” (SU 17, male)
Although some SUs stated a preference for wanting a GPwSI to be the professional who primarily dealt with their mental health problems rather than a psychiatrist, other SUs went further and stated that their preference was for any GP (with a special interest or with none) to deal with their mental health problems rather than a psychiatrist. For these SUs, a shift in responsibility for psychosis care from secondary care to primary care was desired. The GP was seen as someone with whom many SUs could potentially actively engage in conversation and “talk”, whereas the psychiatrist was generally perceived as someone from whom the SU passively received medication.

“I'd rather talk to a GP…The psychiatrist - they're just there to give you your meds and make sure that you're stable, that's totally what they're there for” (SU 17, male).

In this desired scenario where responsibility for psychosis care was shifted from secondary care to primary care, many SUs envisaged a more prominent role for GPwSIs. This role would involve greater involvement in the coordination of care, in collaboration with SUs. Most SUs who expressed a desire to see GPwSIs having greater responsibility for mental health care, also expressed disillusionment with their experience of the care which they had previously received from psychiatrists.

“I would like him (GP) to be the main carer, sort of, coordinator or whatever he is really, next to myself. Give me any help that I really need. The psychiatrists have been totally useless, a total waste of time” (SU 5, male).

However, there was a feeling expressed by some SUs that GPs perhaps did not wish to become more involved in mental health care. Even so, many SUs still felt that increased GP involvement in service provision for psychosis would be beneficial.

“I do not have a problem with my GP. The only thing I would say is that it would be good if they looked after people a little bit more, got involved a little bit more instead of just writing things down and just prescribing the medication. If they were to get involved a little bit more I think things would be a 100% better” (SU 10, female).
As we have seen, many SUs were unhappy with the service they received from GPs in primary care. However, this was not a universal experience of all SUs. When SUs compared the care they received from GPs with that which they received from psychiatrists, they tended to evaluate GPs more favourably. SUs generally reported having a better relationship with their GP than with their psychiatrist. This positive relationship which some SUs had with their GP was often based on trust having been built up over a number of years of continued care. Easier and more frequent access to GPs also played a part in this positive attitude. SUs reported having more face-to-face time with their GPs, thus allowing for trusting relationships to be built. Some SUs also reported that GPs were good communicators, allowing SUs to make more informed treatment choices. This more positive attitude of SUs towards GPs may be particularly important in situations where a SU is feeling anxious or wary of other mental health professionals.

“\textit{I did not feel when I went into the office with the psychiatrist that there was a relationship there, that I could actually be coherent enough in order to make an informed choice. So I wanted to play for time. But also as I say, I had a good relationship with my GP. Whereas my first instincts might be to say no to things, when it comes to my GP, I don't have a second instinct. I don't necessarily think she has got my worst interests at heart, so I am more willing to listen and give her the benefit of the doubt, and at least try and take steps to change my opinions on certain matters}” (SU 16, male).

Another method of increasing GP involvement in psychosis care was the idea of a “shared role” which would mean GPs and psychiatrists sharing responsibility for psychosis care. This increase in collaboration between GPs and psychiatrists regarding mental health care decision-making was desired by some SUs. One SU mentioned that he would like to see GPs have more responsibilities in this area because in his experience his GP was more receptive to the SU’s own desires and input.

\textit{“I don't like psychiatrists. No, I think psychiatrists have got too much power. If it was a shared role kind of thing; sometimes you need your medication reduced, but you don't actually need to see a psychiatrist and go through the rigmarole of explaining why or anything. You just need your medication reduced because you know it's time”} (SU 17, male).
Increased collaboration between GPs and psychiatrists was viewed positively by SUss, not only because it would enhance the role of the GP in psychosis care, but also because it was hoped that it might reduce any potential conflict between GPs and psychiatrists. This collaborative spirit of shared responsibilities would also include SUss having increased input into the decision-making process along with health professionals.

“If you get a psychiatrist who’s good, and the actual GPs all need to work together, work with the psychiatrists not against them, that just causes conflict. And also include the patient and what he wants” (SU 15, female).

The lack of a collaborative approach to working together between GPs and psychiatrists was evident in other SU experiences. SUss reported frustration at problems that GPs and psychiatrists had in communicating effectively with each other.

“The communication is so bad, like you’ll tell your doctor I want my appointment in the evening or a Saturday and they’ll say yeah, and you’ll get a letter from the psychiatrist for a Monday at two o’clock. And then you have to tell them again, re-make the appointment” (SU 4, female).

There was another alternative possible method reported regarding how one might shift the responsibility for promoting recovery from psychosis from secondary care to primary care. One SU wished to see more psychiatrists working in GP practices as an “in-house psychiatrist”. This desire reflected the importance of where services were located as a potential factor in the promotion of recovery.

“The improvements that could be made in GPs about having more specialism in the surgery, or an in-house psychiatrist, that’s the main issue” (SU 4, female).

**Provision of training for GPs**

Although many SUss reported a desire to see a shift in responsibilities to primary care, there was also a feeling expressed by many SUss that additional mental health training for GPs would be beneficial whether or not there was to be an increased role for primary care. Many SUss felt that
GPs did not always appear to have a sufficient level of knowledge or ability to deal with serious mental health problems such as psychosis. Some SUs felt that the provision of training for GPs in mental health issues and in psychology would be beneficial. For some SUs, a hoped-for outcome of additional training was that GPs who accessed training might have an enhanced awareness of non-medication based interventions.

“I do think that there is a lot of training that the GPs need that they have not got...Teach them to be a little bit more of a psychologist, get inside the patient’s mind. Not just from the point of view of psychosis would that be helpful, but from the point of view of just general wellness” (SU 16, male).

Another option proffered by a SU was the proposal that greater numbers of GPs could be trained to be GPwSIs. The SU hoped that if there was a sufficient increase in the number of GPs trained with a special interest in mental health, this would lead to situation where most practices would have at least one GPwSI who had a special interest in mental health.

“I think there should be more psychiatry trained GPs. I mean, in our practice there is one. But in some practices there are none at all” (SU 2, male).

Summary
A shift in responsibility for psychosis care from secondary to primary care was desired by many SUs, with a particular interest expressed in the possibility of greater GPwSI involvement. Primary care was perceived as being better equipped to promote recovery because it provided greater continuity of care, facilitated more engagement from health care professionals, was located in a less stigmatising setting, and was more local and accessible. One SU felt that it would be helpful if psychiatrists provided their services from GP practices, highlighting the importance of consultation location for some SUs. SUs often reported having a more positive relationship with their GP than with their psychiatrist, with a perception that some GPs were more receptive to the input of SUs. SUs felt that GPs could be more involved in promoting recovery from psychosis either as the main medical co-ordinator of care, or working more collaboratively with psychiatrists. However, some SUs also believed that GPs would not wish to
become involved in the provision of additional care for psychosis. To facilitate a more prominent role for primary care in recovery from psychosis, it was felt that there could be an increase in the provision of training in mental health and psychology to all GPs. Alternatively, the number of GPwSIs could be increased so that it would be easier for SUs to access a GPwSI.

6.4 Wider societal context: Stigma & Social Exclusion

Stigma & Normalisation
It was felt that GPs could be more aware of other factors outside of the immediate primary care context, which may hinder or promote recovery from psychosis. One issue that was frequently reported by SUs was their experiences of stigma. They felt stigmatised by their medicalised identity, as a patient with a diagnosis of schizophrenia, and as a person experiencing psychosis. Some SUs reported that recovery could be aided by an increased understanding of issues surrounding psychosis amongst health professionals, including GPs and CPNs. It was felt that recovery from psychosis could be promoted by health professionals taking a less medicalised view of SUs’ everyday problems.

“All the CPNs were worried about was, ‘Oh, your house is untidy, you should be tidying it.’ If I did say that I had a problem, the first thing they would say is, ‘Are you taking your medication?’ I found that to be really annoying” (SU 8, female).

SUs also felt that they had other professionals such as police had treated them in stigmatising manner. One SU reported an incident where he was speaking with a police officer. The SU was in a vulnerable state at the time, and was undertaking the emotionally difficult process of disclosing his experience of having been sexually abused as a child. The police officer betrayed a lack of understanding of psychosis by equating schizophrenia with violence, unpredictability, murder and suicide. The police officer also showed a lack of compassion, empathy and humanity. It was felt that public sector workers dealing with vulnerable people could be better educated about issues such as the stigmatisation of mental health problems.
“I experienced child abuse when I was a child which I only plucked up the courage to report this year, and the police officer who was taking me to my interview had obviously read my file. He said, ‘I notice you’re schizophrenic.’ ‘Yeah.’ ‘You’re not going to kill me are you?’ ‘What?’ And he said it again. I said, ‘No, I’m not.’ ‘You’re not going to open the door and chuck yourself in front of the bus?’ ‘No, I am not.’ It was like, hang on you’re a copper mate, you can’t ask me questions like that” (SU 2, male).

The continuing prevalence of SUs experiencing stigma related to psychosis was partly attributed by one SU to distortions of the psychosis experience as portrayed in the mass media, including in newspapers and on television.

“I know this sounds bad, but I conjure up things like horror films, and what they say in the papers, because they actually use the words like ‘psychotic serial killer’ and things like that” (SU 15, female).

Some family members were also reported to have medicalised or stigmatised SUs’ experiences of psychosis and SUs’ experiences in general, with detrimental effects on SUs.

“It’s just that my family circumstances, they wouldn’t accept the path that I’d chosen, like dance and things like that. They didn’t accept those things were the right things for me, so they tried to medicalise a lot of things that were happening to me, that I was going through” (SU 13, female).

Despite the perceived lack of a noticeable reduction in experiences of stigma encountered by SUs in primary care health services and in society generally, one SU decided to normalise her experience for herself. She replaced the frequently used medical term of “mental health patient” with the less diagnostically-derived term “voice hearer”.

“I call myself a voice hearer; I’m trying to get away from ‘mental’. Instead of living my life as a mental health patient, I want to live my life as J. if you see what I mean?” (SU 15, female).

Socialising and seeing friends was seen as a very important activity for most SUs, an activity which was central in helping their recovery from psychosis. Although friendships and socialising
were perceived to be central to the recovery process, some SUs reported that meeting certain friends or acquaintances could be difficult because some friends and acquaintances held incorrect views about psychosis. These incorrect or prejudiced views regarding psychosis were felt to be based on the stigma sometimes associated with a diagnosis of schizophrenia. One SU reported how one of his friends referred to him as not being “alright in the head”, while another SU reported the confusion amongst some people regarding the nature of her illness.

“People, like friends and that, have different varying concepts of what my illness actually is” (SU 13, female).

Social Exclusion

Many SUs also felt that issues relating to social exclusion were important if recovery from psychosis was to be more effectively promoted in primary care. It was felt that GPs could have greater awareness of factors outside of the primary care context, which could help promote recovery from psychosis. Community groups focusing on hobbies such as art, sculpture, poetry, writing, drama, and dance were seen as very helpful to the recovery of SUs. GPs could become more aware of local groups and signpost SUs towards them, especially those services which were accessible to SUs in financial terms.

“Harpurhey Day Centre, I go three times a week. I want to do more. I’ve got in touch with this Sunshine Studio place that does a lot of music and acting and singing and stuff like that. I checked it out, it is a bit pricey. They only do it like a couple of hours a week, I thought it would be more every day, but it isn’t. I would like to get out myself if I can go out. There is some talent there that is not coming out” (SU 5, male).

Another area where SUs experienced social exclusion was in employment. Being employed in voluntary or paid work was an important milestone along the journey of recovery for many SUs. However, employers did not always understand SUs’ experiences of psychosis, or how those experiences might affect their work practices. In one example, a SU’s experience of hearing voices was framed by his employer as requiring a “disciplinary” meeting. When the SU was
unable to attend the meeting due to unavoidable health reasons (hospitalised), this was deemed by his employers to be an offence for which dismissal was appropriate.

“The supervisor cut my call off. They called me in, ‘What was that all about?’ So I told her, and I said I heard voices, and the voices were playing up, and then I left and got admitted into hospital. They sacked me whilst I was in hospital. They sent me for a disciplinary whilst I was in hospital, that I couldn't go to, and sacked me” (SU 2, male).

People who experienced psychosis also reported facing social exclusion in terms of their housing needs. Many SUs lived in supported housing, with the housing itself being of poor quality, and located in socially disadvantaged areas. Placing SUs in poor quality housing, in socially disadvantaged areas where “there’s lots of trouble” was felt to potentially exacerbate psychosis.

“If it is supported housing, they tend to put people with mental health issues in very bad accommodation, full of repairs and stuff, in bad areas where there's lots of trouble” (SU 15, female).

Supported housing was also another form of accommodation in which SUs reported being placed. Negative experiences were reported where SUs/residents of the supported house were experiencing an acute episode of psychosis which affected the mental health of neighbouring SUs.

“Supported housing, even though it's there to help, there's a lot of people who are very unwell in there, they get on each other's nerves and disturb each other. Some people use music as a helping strategy or they might scream and shout. I think that a bad environment can make it worse. Also if people who are not nice to you sometimes, that can make it worse, because it ends up turning into insulting voices and you can't tell what's what” (SU 15, female).

One SU felt that due to the location of where he was placed in local authority housing, he received racist abuse from his neighbours. It was felt that GPs could be more aware of social exclusion and other social issues which SUs face, as well as medical or psychological issues. It
was felt that more could be done to help alleviate the social exclusion of SUs, and that this might prove to be an important step on their road to recovery from psychosis in primary care.

“I get a bit of harassment from the neighbours. They swear and shout at me from outside. I live on the second floor and some of them go outside and swear and shout at me. There was one man living in his own flat and he used to shout racist things, but eventually I called the police and they had a word with him and he stopped” (SU 1, male).

Summary

Many SUs reported that they felt stigmatised by their mental health diagnoses and their medicalised identities. This was seen as a major barrier to recovery from psychosis. It was felt that GPs could be more aware of the social barriers to recovery such as SUs experiencing stigma and social exclusion, as well as the biomedical factors. SUs reported experiencing mental health related stigma, misunderstandings, and prejudice from a variety of sources including family, friends, acquaintances, police officers, and employers. Housing was seen as a potential barrier to recovery, especially if SUs were housed in poor quality accommodation, in socially disadvantaged areas, or were sharing accommodation with other people experiencing psychosis. Many SUs also wished to see GPs become more aware of local and accessible community groups, and signpost SUs in the direction of groups which might facilitate or foster the interests and hobbies of SUs. These community groups were reported to be beneficial in promoting recovery.

Conclusion

A “whole-person” approach to psychosis in primary care was desired by many SUs. This would include a greater focus on psychosocial interventions, helping SUs to improve their nutritional intake, and informing SUs about local peer-supported services, as well as an increased awareness on the part of GPs regarding the severity of anti-psychotics’ side-effects, and the perceived lack of efficacy associated with such medication.
A shift in responsibility for psychosis care from secondary care to primary care was also desired by many SUs. Primary care was perceived to be a low-stigma and easily accessed setting. Many SUs reported that they knew and trusted their GP more than secondary care professionals. An increase in collaboration between GPs and psychiatrists regarding mental health care decision-making was also desired.

Recovery from psychosis in primary care could be promoted by recognising the social concerns of the SU, and the wider societal context within which recovery was situated. SUs reported that stigma and social exclusion were key factors affecting their recovery from psychosis, and that GPs had a role to play in helping SUs to overcome problems related to these factors. Housing and employment problems were identified as barriers to recovery. SUs felt that local activity groups were potentially beneficial to their recovery, and that GPs could do more to signpost such groups. Recovery could also be aided by an increased understanding of issues surrounding psychosis amongst primary care health professionals, as well as in society more generally.

The desire expressed by many SUs to see a psychosocial approach to recovery in primary care was tied in with the desire to see GPs become more aware of the wider societal context surrounding psychosis. This context included the social barriers to recovery such as stigma and exclusion which SUs experienced. SUs’ opposition to anti-psychotic medication was often linked to a desire for alternative social remedies such as signposting peer-supported services or local activity groups. Involvement in local activity groups helped to de-medicalise and normalise the experience of SUs, while also helping to address social isolation and exclusion. Shifting the responsibility for psychosis care to primary care might also help to de-stigmatise and de-medicalise psychosis to some degree, particular if the shift was accompanied by a more psychosocial approach to recovery.

Greater SU autonomy and input into consultations and the decision-making process was desired by many SUs. SUs could be better listened to by their GP and their views could be given greater weight in the decision-making process regarding their own treatment plan. Greater listening skills
on the part of GPs, as well as shared decision-making between the GP and the SU, might increase
the SU’s feeling that the consultation was more helpful, and that the SU was not being “fobbed
off” due to time constraints or a lack of understanding. There was a feeling amongst some SUs
that if the concerns of SUs were more closely listened to by GPs, this would then lead to a
number of benefits. Firstly, it would allow SUs to have greater choice in treatment plans, and to
provide feedback to GPs regarding which options worked or didn’t work for them. Secondly,
being empathically listened to by GPs would be a therapeutic process in itself for SUs. Thirdly,
creating a sense of autonomy or ownership over the decision-making process would be
empowering and normalising for SUs, and would aid the recovery process. Fourthly, being
listened to by GPs would facilitate the desire of many SUs for psychosocial rather than
medication-based interventions. Such an approach might be encouraged by the provision of basic
training for all GPs on how to address serious mental health problems through the use of
psychosocial interventions, or by taking a “whole-person” approach to mental health problems.
Similarly, an increase in the number of GPs with a special interest in mental health was desired
by many SUs.

Some SUs reported a wish to see greater provision of mental health training for GPs. This
training could incorporate a number of other findings gathered from the interviews with SUs.
Firstly, GPs could be trained to discuss the potential side-effects of medications more thoroughly
before making prescription decisions. This would appear to be an appropriate role for GPs,
especially taking into account the findings of the interviews with GPs, where some GPs
considered themselves to be independent and trustworthy sources of information in the eyes of
SUs and their families. Secondly, GPs could be made more aware of local peer-supported
services and community activity groups, so that could signpost SUs in the direction of such
groups. This would also provide SUs with alternative intervention options other than medication.
Thirdly, GPs could be trained in listening skills, with all the concomitant benefits discussed
previously. Fourthly, GPs could be provided with social exclusion and stigma awareness training,
so that the wider societal context of SUs’ experiences might be made more apparent for GPs.
This chapter has reported the views of SUs regarding recovery from psychosis in a primary care setting. The following chapter reports the findings of mixed focus groups involving both GPs and SUs. The focus groups further explored key themes relating to recovery in primary care.
Chapter 7

Results of
Mixed Focus Groups
Introduction

This chapter presents the results of two mixed focus groups, each involving both GPs and SUs. The results are presented as five main themes: conceptualisations of recovery; barriers to promoting recovery in primary care; recovery-orientated services at the level of individual GPs; recovery-orientated services at the level of the primary care system; and introducing change to primary care.

A pilot focus group was arranged in Liverpool prior to the main study to test out the topic guide and enabled the researcher to practice his focus group moderating skills. The themes that emerged from the interview data formed a central part of the topic guides for the focus groups, although questions not previously focused on during interviews were also included. Having taken the interview results and the pilot focus group into consideration, a final topic guide was then agreed upon by SR and HL.

The first 45 minutes of each focus group were used primarily to validate previous findings from the interviews, as well as stimulating further discussion surrounding themes that arose in interviews regarding recovery conceptualisations, participants’ previous experiences of recovery, and the services that GPs already provide which promote recovery. The second 45 minutes of each focus group was then used to pose new questions that had emerged as a result of the interviews. In particular, there was a focus on the specifics of what any future recovery-orientated primary care service might look like, and the practicalities associated with implementing it. The focus groups were carried out so that recovery from psychosis could be examined beyond the level of individual experience, and that primary care service development could be prioritised in terms of research focus.

Results
Five main themes emerged from the focus groups: conceptualisations of recovery; barriers to promoting recovery in primary care; recovery-orientated services at the level of individual GPs; recovery-orientated services at the level of the primary care system; and introducing change to primary care. As previously described in the methods chapter, the grounded theory analysis of the focus group data was conducted in a similar way to the analysis of the interview data.

7.1 Recovery conceptualisations

Recovery as acceptance and coping
Participants in both focus groups were asked to recall an episode of psychosis they were involved in (either as a GP or a SU), and what promoted recovery on that occasion. Conceptualisations of recovery were offered by the participants as part of this recollection process. These recollections acted as a form of respondent validation. As all participants had also previously provided their conceptualisations of recovery during the individual interviews, the themes emerging from the focus groups and from the individual interviews were compared.

There was a consensus amongst the participants of both focus groups that recovery from psychosis involved an acceptance of the existence of psychosis, and an ability to cope with the day-to-day problems associated with psychosis.

“I think the biggest step to recovery is accepting. If you hear voices, accepting the voices you hear are real, they are real to you. Even though other people might not be able to hear them, accept it and learn to cope with it and learn coping mechanisms”
(SU 1, female).

Having accepted the presence of problems associated with psychosis, and having coped with those problems, one SU reported then being able to experience an increasingly fulfilling and functional life, especially in terms of involvement in social activities.

“Getting involved with some voluntary work, hobbies, interests, sort of trying meaningful and adaptive things that I can engage in regularly to sort of lead a normal life” (SU 4, male).
**Recovery as normalisation**

The conceptualisation of recovery as coping with psychosis and being involved in social activities was extended further by one SU. He described recovery as being involved with activities and having friends that were drawn from outside the sphere of mental health services and peer support groups. Peer support groups were, however, seen as the first step on the “road to recovery”.

“I earned enough confidence through going to self help groups to then take it on” (SU 4, male).

The normalisation process as part of the recovery process was furthered through the SU’s involvement with “pre-illness” activities and through developing friendships with people not associated with mental health services. His self-identity was therefore extended beyond that of simply being a SU.

“Joining a squash club, that was something I enjoyed when I was younger, pre illness. I’ve now got a common interest with people who play sport or squash rather than people who have mental health difficulties” (SU 4, male).

Another aspect of “normal” functioning and recovery as defined by this SU included the ability to hold down a job and have a partner, as well as not being noticed or defined by others as being mentally ill.

“I’m able to live a functioning life and not to be noted or looked at by other people and feel like I need support or help with the symptoms as much as I did in the past” (SU 4, male).

One of the GPs in this focus group came to a shared understanding of recovery with the SU.

“So it’s like sort of normalising things” (GPwSI 3, female).

**Recovery as avoiding hospital admissions and psychiatric medication**

One of the SUs in the first focus group described the distressing nature of his stay in a psychiatric ward – referring to the hospital as “really scary”. He also described the side-effects of anti-
psychotics as being negative to such a degree that they could actually “induce psychosis” themselves just by taking them. Based on this, he felt recovery was predicated on an avoidance of, or an escape from hospital and medication.

“You start your recovery when you leave hospital, not while you are in the hospital. I believe the only way that you can recover properly from a breakdown or a breakthrough, whatever you want to call it, is to get off your medication and to get away from going into hospital” (SU 3, male).

However, unlike the other conceptualisations of recovery reported, this particular definition did not meet with agreement from the other participants of the focus group. For example, another SU disagreed with the conceptualisation above, instead stating that short-term hospital stays could have a positive impact on recovery because hospital staff were aware of the effects of medication, they showed understanding, and they provided positive feedback to SUs.

“I think short-term, every hospital stay could be good...they are more understanding than your parents could be, they know the effects of medication. You are getting more like a positive feedback off the staff rather than your parents” (SU 2, male).

Similarly, in the second focus group, this solely negative evaluation of anti-psychotic medication was challenged by the two GP participants who claimed that although some SUs experience negative side-effects, for other SUs the experience of taking medication is positive and promotes recovery.

“There are people who can settle onto medication that’s got acceptable...they feel okay and there isn’t any major side effect. I think it is individual” (GPwSI 3, female).

**Recovery as a three stage process**

In the second focus group, a GP gave his conceptualisation of recovery from psychosis which was a three stage process. These three stages were an initial stabilisation after an episode of psychosis, followed by a return to social functioning, and finally coming off treatment.

“I sort of think of it in three phases in a way. The first phase is just learning to kind of function at all I suppose. And the next stage I’d see as getting back more and more to whatever was
normal for them before they became ill. And then there’s a third phase which happens for a few people, but not so many, which is that after some period they may be able to come off treatment” (GPS 2, male).

**Recovery as an individual journey based on optimism**

Recovery was described by another SU as an individual journey. He felt that SUs needed to explore possible pathways to recovery themselves in a trial-and-error fashion. He dismissed other approaches to recovery, such as prescriptive interventions. What was most important was an optimistic belief that recovery could occur.

“People seem to think, oh I’ve been here, I know the route and everybody just has to follow my route and they’ll all be all right. And I look at it from the point of view, there is an element of finding your own way and you’ve just got to believe it’s possible” (SU 5, male).

Again, there was a consensus on this point, with a GP concurring that optimism and hope were important for promoting recovery from psychosis in primary care.

“I think that’s the point to pass on, isn’t it, the hopeful bit, not I’ve got the answer” (GPwSI 3, female).

The other SU in that focus group also agreed that recovery was an individual route involving a trial-and-error approach to identifying what is or is not efficacious for that individual.

“I totally agree there. Some people can say, ”Well, what is it?” What’s good for one is not necessarily good for another. And that's the bit where I guess trying to identify what is good for you as a person and yourself and what route you'd like to take and try it and see. And if it works, then brilliant. If it doesn't, you're one stage closer to finding out the next thing that could be the thing that works. Because if you always do what you always did you'll always get what you always got” (SU 4, male).

**Recovery as removing socially constructed forms of disability**
Recovery was defined as the removal of disability by a SU in the second focus group. In this conceptualisation, psychosis was framed not as an illness, but as an impairment. This impairment only becomes a disability once it has been socially constructed in that way. Although the terminology differed slightly, the SU was echoing the social theory of disability, which states that people with impairments are disabled not by an illness but by how society treats and interprets impairments.

“I always have the feeling sort of it’s not an illness, it’s more a disability. In order to deal with it, the world has to adapt to me and not me to the world” (SU 5, male).

In the first focus group, one of the SUs identified that recovery involved learning to cope with psychosis-related impairments.

“Learn to live with it” (SU 1, female).

One of the GPs in that group agreed with this conceptualisation, while adding that recovery would mean the SU would no longer be disabled by their experience.

“I think that's the main point isn't it? What we are looking for is someone not to be disabled by their condition” (GPS 1, female).

The consensus on this point was confirmed by SU 1 when she interrupted GPS 1’s statement above. SU 1 interrupted in order to complete GPS 1’s sentence. SU 1’s completion of GPS 1’s definition underlined their shared conceptualisation of recovery as the removal of socially constructed forms of disability.

“...be able to carry out tasks” (SU 1, female).

Recovery as a devalued term and a formulaic model
During the second focus group, one of the GPs argued that the term recovery had become so commonly used in relation to psychosis care within the NHS that it had become devalued through unclear usage and overuse, and had lost its meaning.
“Like any word that's used, becomes in common usage in services, it becomes a bit of a word that people stop thinking about what it actually means” (GPwSI 3, female).

This GP identified an additional problem which was that the recovery model was being introduced to services in a formulaic way, which sometimes led to the inappropriate use of recovery pathways for SUs with complex and long-standing problems who were not yet ready for such pathways.

“This is the way people perhaps are being trained now and it's become a bit of a sort of, oh well, we move people towards recovery in a rather formulaic way” (GPwSI 3, female).

The GP gave an example of a case where she felt the recovery model was inappropriately introduced with one of her patients who had been experiencing psychosis for many years.

“Her care coordinator at the moment is someone, very sort of, quite young and keen, that is trying to sort of get her down a recovery pathway, when it's clear that the situation is more complex than that” (GPwSI 3, female).

**Recovery as an unrealistic promise**

This lack of clarity about what recovery meant was evident in how different participants defined recovery, and how their attitudes towards recovery differed. One SU in the second focus group believed that recovery was not possible in the sense of getting “over it and becoming normal again” This was his definition of recovery, and so, for him, recovery did not exist and was illusory. However, he did believe that one could come “to terms with things”, which was actually how other SUs defined recovery itself, highlighting the multiple meanings held by SUs.

“I don't think you're ever really truly recovered from mental illness. Sometimes I feel that by promising people recovery in the way that we do we're trying to make it into the realms of, it's just a cold, you can get over it and become normal again. I don't believe that to be true. Your mind functions differently to everybody else's, and it's a case of coming to terms with things” (SU 5, male).
A GP in that focus group agreed with the SU’s interpretation that recovery was an unrealistic promise. She felt that the over-expectation associated with the promise of recovery could lead to frustration and disappointment for those who did not feel that they were recovering.

“(Recovery) sounds like you’ve had an acute illness from which you go back to where you were. And of course that would be the ideal. I just worry about the people who don’t achieve that and what it feels like to be told all the time, ‘Oh, we’re going to help you towards recovery’” (GPwSI 3, female).

A second SU agreed, and said he had questioned whether recovery was relevant to him during a period when he was not experiencing any improvement in his mental health. His criticism of the term’s irrelevance to him at that time was qualified by his belief that the promise of recovery prevented his mental health from deteriorating.

“I felt like that for years, that I wasn’t getting any better. What was this recovery about? I still felt unwell. Now looking back I think at least it stopped me going backwards. Even though I didn’t feel like I was going forwards” (SU 4, male).

**Recovery conceptualisations change throughout a person’s life**

A SU in the second focus group discussed how his conceptualisations of recovery had changed over time, due to his own experiences of psychosis. He had previously believed that recovery meant complete eradication of symptoms, whereas now with ten years experience of psychosis he believed that recovery meant being able to live a functioning life.

“If you had asked me that question ten years ago I would probably say for the symptoms to be gone - that would have been my idea of recovery. My viewpoint now - that I am able to live a functioning life” (SU 4, male).

**Summary**

Conceptualisations of recovery were constructed in a number of different ways by different focus group participants. Recovery was seen in the following ways: accepting one’s psychosis and
coping with continuing difficulties; a process of normalisation and regaining social functioning; avoiding hospital admissions and medication; a three stage process of firstly returning to social functioning, then eradicating symptoms, and finally coming off treatment; an individual journey based on optimism; removing socially constructed forms of disability; as a devalued, formulaic and unrealistic concept; and as a conceptualisation which changes throughout a person’s life.

Recovery was defined variously as acceptance of and coping with psychosis, as a process of normalisation, or as an avoidance of psychiatric interventions. Each of these conceptualisations could be synthesised together to form three points along a recovery process spectrum, where acceptance is an initial stage in the recovery process, followed by normalisation, with independence from intervention as an endpoint. This synthesised conceptualisation bears a resemblance to the three stage recovery process as conceptualised by one of the GP participants. The GP described the three stages as follows: an initial stabilisation after an acute episode, followed by a return to pre-illness levels of social functioning, eventually leading to no further need for treatment. Recovery was also seen as a non-prescriptive individual journey of trial-and-error, which incorporated the possibility of changes based on each person’s life experiences. For some focus group participants, this conceptualisation of recovery was hopeful and optimistic, whereas for others there was a fear that it might lead to an unrealistic promise or an over-expectation of recovery. Although focus group participants provided clear conceptualisations of recovery, the term was also described as being misunderstood and devalued in NHS settings through a lack of clarity and consistency regarding the meaning of recovery.

7.2 Barriers to promoting recovery in primary care

Prevalence of psychosis in primary care
One GP reported that she did not frequently see SUs who experienced psychosis, and that there was a perception of primary care not being the part of the health service which was best equipped to deal with psychosis.
“I think a lot of GPs don't see patients with hearing voices on a regular basis, maybe it's once every six weeks or so, if that” (GPS 1, female).

From the SUs’ perspective there was some agreement, with one SU stating that he never presented with psychosis problems to his GP surgery. He only went to his GP for repeat prescriptions. The idea that responsibility for psychosis lies with the psychiatrist rather than the GP was reiterated.

“Basically I never see my GP. The only time I see my GP is to go for prescriptions, after that as far as I know my GP has no say in whether I can change my med or whether I can't change my med, it is all down to the psychiatrist” (SU 3, male).

Discontinuity of care
SUs sometimes saw more than one GP about their psychosis-related problems, especially if the practice they were registered with was a large one. A SU in the first focus group had visited a number of GPs in her local practice, and she was unsure of how much information was transferred from one GP to the next through case notes. She was worried about the possible lack of communication between GPs regarding important information.

“One problem that I have with the GP, anytime you go to see the GP it's a different one because it's a practice. There are four or five different doctors. When you go and see a different, one and I might have told Dr X; I might have told her something and I thought that I’ve already told her when I haven't told her. I mean, I don’t know what they do in the files, if they write down what we talked about you know, after you leave”
(SU 1, female).

One of the GPs in this focus group admitted that GPs could do more to make continuity of care more of a priority, by making it easier for SUs to see the same GP each time they visit a practice.

“I think this thing about seeing a different doctor each time, I think we are making that unnecessarily hard. I think we should work harder to get round that. Something like at the moment, we in our practice we do actually try and oversee our own patients. So if you are seeing
one doctor you will hopefully only see him” (GPwSI 2, male).

Some discontinuity of care was unavoidable, such as when a GP was sick or on holidays, or when a GP moved away from one practice to work in a different location. One of the GPs in the first focus group gave an example of this occurring – a GP in his practice had built up a relationship with a SU, but the GP then left that practice. He pinpointed the main problem he saw with discontinuity of care, which was that the relationship between SU and GP needs to be built up over time.

“She developed quite a close relationship with one lady doctor at the practice, but unfortunately she left, so there was a bit of a gap, and although she had been my patient for a while, it's taken me a little bit of time to build up a relationship again with her” (GPwSI 2, male).

Another GP in the same focus group agreed that GPs moving between practices was a problem. She also felt that SUs contributed to the discontinuity of care problem, as they moved around in terms of which GP practices they were registered with.

“One of the issues that we have is the fluctuation in personnel in the GP practice and also patients and people who come in with a long history of mental health and have perhaps been dotted around various GPs” (GPS 1, female).

One of the SUs in this focus group agreed that he moved his care around between GPs. He justified his decision to move around between GPs by saying that he was attempting to find a GP that provided care that was of a sufficient standard for his requirements.

“I kept changing, like four or five doctors there, I kept changing because the first one wasn't good enough, the second one didn't seem to care that much, so I started going round, and this doctor that I've got now he's the best one” (SU 2, male).

The problem of discontinuity of care may be exacerbated by problematic appointment systems, especially in crisis situations. One GP talked about situations where SUs wanted to see their GP
in a crisis or an emergency, but an appointment was not available for that day. This meant that the SU could not be seen on that day, or at best, could only be seen for a brief consultation. “I think the appointment system doesn’t help either, because often if somebody has mental health issues and is in crisis and want to be seen that day, we haven’t always got appointments available and because often the ones that are available are at the end of surgery, that you are not going to have the time” (GPS 1, female).

Medication
Medication was a major issue for SUs in both focus groups in terms of being a barrier to recovery in primary care. As mentioned above, one SU defined recovery as being able to avoid anti-psychotic medication. Numerous side-effects of anti-psychotic medications were listed by SUs. “Dehydration, and I find it difficult to get to the weight I want. It affects my thyroid in a negative way” (SU 2, male).

SUs felt that anti-psychotic medication was the only form of treatment on offer from GPs. “I was forced to start taking medication and I really had been convinced it would be the best way forward. It wasn’t until I actually stopped taking medication I actually started to feel I was getting my mind back into a position where I could take control over the direction I was taking” (SU 5, male).

GPs tended to disagree with SUs about anti-psychotic medication being a major barrier to recovery in primary care. For most GPs, medication was seen as useful and necessary rather than problematic, with negative issues only arising where SUs did not continue with the medication as prescribed.

“She wasn’t convinced that she needed them (anti-psychotics) long term, so she then stopped. And then the process was trying to…it was quite clear that actually if she did take the tablets then she could actually return pretty well to normal” (GPS 2, male).
A unique aspect of focus groups is their facilitation of discussion between participants. It allows participants to experience the perspectives of others regarding the issue under discussion. In the first focus group, a discussion took place involving two SUs and a GP regarding the prescription of medications for psychosis in primary care. The SUs criticised the lack of alternatives to medication. The GP came to understand their viewpoint, and took on board the perspective of the SUs, while at the same time trying to explain the constraints on her which led to medication often being the only option available to her.

“I can see the perception as someone coming to see a GP, that it always seems that we are ready to prescribe very readily. Yes they’re stressed and they have plucked up the courage to come in and tell us about it. But often our hands are tied because we know there is a long waiting list, the referral system isn’t the best in the world and the argument is that maybe you just get a very brief telephone assessment and no real support. So sometimes a prescription is used to help alleviate distress, while we get other things mobilised” (GPS 1, female).

In the second focus group, this view of seeing medication as a stop-gap measure was echoed by another GP.

“We offer medication because we don’t feel we’ve got timely access. I’d like to see from primary care better access to things like occupational therapy. There are some things that are quite difficult to access from primary care – day services, occupational therapy to help people think about, to get them back into education, leisure, voluntary work, whatever” (GPwSI 3, female).

A conflict arose in the first focus group, when the stop-gap justification was given by a GP as the reason for prescribing medication so frequently. A SU rejected this reasoning, questioning why then in her experience was the medication never reviewed after its initial prescription.

“But then when you are on that medication, they keep you on it for like months and years. They don’t seem to review it” (SU 1, female).

**Diagnosis and language issues**
The diagnosis of mental health problems was seen as problematic and a barrier to promoting recovery. The issue of labelling and stereotyping was identified as a barrier by two SUs in the first focus group, although in a secondary care setting rather than in primary care. One SU described his experience of being treated by a psychiatrist as a diagnosis rather than as a person. “They don’t see us personally, they speak nicely but they don’t see us as a person, they are very cold. They just see you as a, oh, he’s got this or he’s my bipolar case” (SU 2, male).

This point was immediately agreed upon by a second SU. “Just see us as a diagnosis” (SU 3, male).

A problem associated with diagnosis in primary care was encountered by one of the GPs in the first focus group. She spoke of difficulties she had dealing with SUs who had multiple or inconsistent diagnoses in their case notes. She reasoned that inconsistent diagnoses may be caused by the changing diagnostic fashions of the medical profession, and also by the changing presentations of SUs over their lifespan.

“The label that's put on the mental health often changes in the years with fashion with the diagnosis, but also with the different presentations as they go through life with this condition. It is very difficult to put a name on a condition and also each individual that has that umbrella of that condition presents in a different way and manages it in a different way” (GPS 1, female).

The language used to frame psychosis was another related issue discussed by both SUs and GPs in the first focus group. A SU felt that psychosis was more adequately described as a condition rather than illness. Framing psychosis as an illness was seen as a barrier to promoting recovery in primary care.

“The biggest step to recovery is acceptance of your condition. I am not saying acceptance as an illness, accepting it as a condition and the way you are at the time” (SU 1, female).

A GP then agreed with this point. He also believed that framing psychosis as a condition rather than an illness was more likely to promote recovery in primary care. He explained that the
language of illness entailed a pessimistic attitude towards the likelihood of recovery, which could act as a self-fulfilling prophesy. On the other hand, a condition was something which could be improved by the GP and SU working collaboratively together to find ways of alleviating problems.

“As a GP, if I said it was a language of illness then it almost is a prophesy that you will never get better, you are always going to be my patient with an illness. Whereas if you talk about condition then it’s something that we can recognise, but we are working together to; so you are dealing with it” (GPwSI 1, male).

However, the GP also admitted that the reframing of psychosis as a condition would be a challenge for GPs, as they deal primarily with physical illness and generally use the language of illness.

“You are basically saying I don’t have an illness, I have a condition. I think that’s an interesting challenge for general practitioners because a lot of the time it is very easy to slip into the language of illness” (GPwSI 1, male).

The GP proposed a helpful way of explaining to GPs the importance of language in connection with psychosis. He compared the use of the word “condition” to describe psychosis with the use of the word “condition” to describe long-term physical conditions such as diabetes, rheumatoid arthritis and skin diseases which GPs deal with regularly in primary care.

“We deal with a lot of people who have got quite long-term conditions, not just mental health ones, like diabetes…rheumatoid arthritis, skin diseases…those are examples where people have to live with conditions” (GPwSI 1, male).

**Secondary care**

It was reported in both focus groups that participants had encountered difficulties in accessing secondary care mental health services and that this proved to be a major barrier to promoting recovery from psychosis in primary care. This was a complaint common to both GPs and SUs.
One SU in the second focus group spoke of his six month wait to access secondary care services following a GP referral.

“Going into the GP’s office, help, I need help. Okay, we’ll send off a letter, and you don’t get an appointment for six months. And so I’m waiting six months, and in a couple of weeks things can spiral out of control” (SU 5, male).

A GP in the same focus group also discussed the problems he had experienced in attempting to gain access to services for SUs. He blamed access difficulties on the financial constraints of the NHS, and the belief amongst NHS management that access to services should be made difficult for primary care to obtain. The GP felt that cost-cutting measures such as attempts to reduce referrals may actually lead to cost increases in the longer-term.

“There’s this perception that we’ll do whatever we can to cut costs and try and make it as difficult as possible for people to access services...But the GPs come back and say, "If we’d been able to refer them first they wouldn’t have got into secondary services so the overall cost would have reduced”...I think if GPs had a little bit more access into other parts of the system, it would take some of the burden off secondary services” (GPS 2, male).

Another barrier to accessing secondary care services was the threshold levels for severity of psychosis which needed to be met. A GP felt such thresholds sometimes resulted in SUs who were recovering well, then being denied access to useful and suitable services because they were deemed “too well”. This in turn resulted in their mental health deteriorating to the point where they were again allowed to access the services they had been previously denied. This characteristic of secondary care services was referred to as “the loop” by the GP.

“I suppose again it's about the level of provision, isn’t it? But the thing that always strikes me as ironic is that there are people who are on the way to being a bit better than they were, but because they're better they don’t reach a threshold for services. And yet in some ways they're at a stage where they could make maximum use of the services that are there...It's going right back round the loop again, and it's almost like when you've fallen below a threshold you stop being
eligible for things that would actually help you now where they couldn't have done six months ago, which seems to me a load of nonsense” (GPwSI 3, female).

In addition, the unresponsive nature of some secondary care services was criticised by a GP in the first focus group.
“The services that are offered often don't react when we ask for help” (GPS 1, female).

Sometimes GPs themselves did not know who to contact in order to access secondary care services, which became a barrier to recovery for those SUs going to their GP with psychosis.
“The issue was about not knowing who to ring up, what was the phone number of the intervention service, how do you access the mental health service” (GPwSI 1, male).

Lack of interest and negative attitudes amongst some GPs towards psychosis
One GP in the first focus group made the point that many GPs feel that they do not have the resources available to them to deal adequately with psychosis in primary care. This led to SUs being referred on, and not dealt with in a primary care setting. The resources which GPs felt they lacked included consultation time.
“I think there's a lot of fear from the medical profession that we don't have the time to help you” (GPS 1, female).

Another GP in that focus group felt that GPs also lacked confidence in how to deal with psychosis which stemmed from a lack of knowledge about psychosis.
“Maybe there is an argument for all GPs not rushing to wash their hands or being afraid to tackle mental health problems, but find more confidence and more knowledge and do more basic stuff rather than just cart them straight off” (GPwSI 2, male).

This genuine lack of resources amongst many GPs was supplemented by a lack of interest in psychosis amongst other GPs. A GP gave the example of him being the only GP at an important
mental health conference, as well as the example of none of his GP colleagues being aware of the government’s mental health policy.

“I went to a conference on New Horizons. New Horizons is the government’s ten-year plan for mental health for the whole country, one of these consultation things. Two hundred and fifty people in the room - I was the only GP there” (GPwSI 2, male).

There was a discussion in the first focus group regarding interest in psychosis amongst GPs, with one GP arguing that it was unrealistic to expect GPs to have a large amount of knowledge or interest in specific areas such as psychosis, when their role was that of a generalist rather than a specialist.

“GPs are general practitioners for a reason. We are not specialised, we are general practitioners” (GPwSI 1, male).

However, it was also argued that this lack of knowledge or interest in psychosis amongst some GPs meant that some GPs were unaware of the range of services available for psychosis both within the NHS and also in the voluntary and community sector. This issue was brought up by a SU in the second focus group.

“There's a lot of good stuff out in the voluntary sector as well. I think if GPs or people involved with people's care, without wishing to put all the buck on you of course, would benefit from knowing not only what was available through NHS or other projects” (SU 4, male).

A GP in the first focus group felt that alongside a lack of knowledge or interest in psychosis amongst some GPs, there was an even greater problem regarding some GPs who held negative attitudes or prejudices against SUs experiencing psychosis. This problem was seen as a barrier to recovery from psychosis in primary care, and the GP assigned the cause of such negative attitudes to the training provided to medical students and young doctors.

“I think that there are other issues beyond knowledge and part of it is attitude. Attitude is the thing I am really keen to get at, the attitudes of young doctors as they come through particularly
is the key, because I think it is the attitude when you are young that determines how behave when you get older” (GPwSI 1, male).

**Summary**

Focus group participants mentioned many different barriers to the promotion of recovery from psychosis in primary care. These barriers included a perceived lack of prevalence of psychosis in primary care services, discontinuity of care, anti-psychotic medication, issues related to diagnostic labels and language, difficulties in accessing secondary care, a lack of interest, knowledge and resources on the part of some GPs, and the negative attitudes held by some GPs towards mental health problems.

These barriers are related to each other in different ways, and the alleviation of one barrier may lead to solutions for related barriers. For example, both GPs and SUs agreed that some SUs do not often seek out their GP for assistance with psychosis because GPs are perceived as not playing a major role in psychosis care. It was also reported that many GPs lack knowledge about psychosis and about the services that are available to SUs. This lack of knowledge may result in, and/or be a result of the minor role that many GPs currently have in terms of psychosis care. An increase in the knowledge of GPs could be related to an enhanced role for GPs, and vice versa.

Similarly, the reported lack of knowledge and interest in psychosis amongst some GPs could affect the problem reported by SUs of psychosis being framed as an illness, and the diagnostic labelling that goes with that framing. If the interest of GPs in psychosis was stimulated, this might lead to a greater awareness of SUs’ experiences, as well as a more appropriate use of language by GPs from a SU perspective.

How psychosis is framed linguistically and intellectually may also affect the use of anti-psychotic medication by GPs. If psychosis is framed by GPs as an illness using the biomedical model, then anti-psychotic medications seem the most appropriate treatment. However, the use of anti-
psychotic medication was seen as a problem by a number of SUs in the focus groups. For some, recovery itself was defined as independence from anti-psychotic medications. For others, the recovery process only began at the point where anti-psychotic medication stopped. However, even though some GPs were aware of this problem, and validated the experiences of SUs, GPs often felt that they were left with no other option apart from prescribing anti-psychotic medication in the short-term. This was because GPs felt that they lacked the resources and time required to deal with psychosis, and they found it difficult to access any alternative services through secondary care. Similarly, some GPs’ lack of knowledge regarding the services available in the NHS and the voluntary and community sector may have led to an increased use of medication. Addressing barriers to recovery such as poor access to secondary care services and the lack of GP knowledge and resources might lead to a reduction in other barriers to recovery such as the use of anti-psychotic medication.

Discontinuity of care was identified as a barrier to recovery from psychosis in primary care. Discontinuity was seen as a problem in itself as it led to doubts in the mind of one SU regarding whether her experiences and needs were being adequately transferred from one GP to the next via case notes. However, discontinuity of care may also be related to other barriers such as difficulties in building rapport between GPs and SUs. If there is a lack of rapport or a lack of understanding of the SU’s perspective, this may make it more difficult for some GPs to see beyond the diagnosis to the SU’s experience. This may in turn lead to negative attitudes amongst GPs towards mental health problems, which was identified as another barrier to recovery in psychosis.

7.3 Recovery-orientated services at the level of individual GPs

Pleasant manner and listening skills of GPs
SUs felt that recovery from psychosis in primary care could be aided by GPs who had a personable manner, were caring and respectful, and listened to the concerns of SUs. One SU in the first focus group felt that his GP helped to promote his recovery by listening to his concerns
and then trying new interventions to assess their efficacy, as well as signposting local day centres and support groups.

“Well he changed my medication for a start off, he'll try something else, he'll try something different that will help more and he'll do that and listen to me for a bit. He's got a nice manner, he seems to care even though he is a very busy, a very busy guy. He's got his own surgery so he is a very busy guy but he will listen to me for five or ten minutes. He's told me to get in touch with things, but nothing has come of it, like been registered at day centres or getting support” (SU 2, male).

**Continuity of care with the family**

There was a consensus in both focus groups that although continuity of care in primary care could be problematic, it generally provided better continuity of care than secondary care. This continuity of care allowed GPs and SUs to build up an interpersonal rapport over time, which helped to promote recovery from psychosis. One GP mentioned that this interpersonal rapport built up through continuity of care may prove useful in promoting recovery, particularly if the GP in question has an interest in psychosis or mental health more generally.

“You've got a good rapport with somebody because you've been in the practice a long time and have a particular interest in mental health” (GPwSI 1, male).

The same GP also felt that GPs had a particular advantage in being able to promote recovery in primary care because they often knew the families or carers of SUs with psychosis. Families and carers of SUs often live with the SU who has psychosis, and would also share the same GP. It was much less likely that psychiatrists or other mental health professionals working in secondary care would know families and carers to the same degree. This level of family knowledge gave GPs a greater insight into the background of the SU, as well as facilitating greater rapport-building opportunities with family members and carers.

“I knew the whole family and the whole family had a whole range of challenging issues over the years...if you know your family and patients well it is a very different relationship” (GPwSI 1, male).
Summary

These findings highlight the important role which SUs feel that GPs can play in promoting recovery from psychosis. SUs felt that recovery from psychosis in primary care could be aided by GPs who had a personable manner, were caring and respectful, and listened to the concerns of SUs. GPs agreed with this, with one GP saying that interpersonal rapport built up through continuity of care was very useful in promoting recovery. It was also felt that the likelihood of recovery could be enhanced if GPs had a particular interest in psychosis or in mental health generally. GPs have a particular advantage in being able to promote recovery in primary care because they often know the families or carers of SUs with psychosis, as the family members often share the same GP.

SUs discussed the many positive attributes of GPs and possible roles which they could provide in promoting recovery from psychosis. In one focus group, resistance was initially evident from some GPs to the idea that GPs had an important part to play in promoting recovery from psychosis. However, throughout the focus group SUs continued to highlight the importance of GPs, with one SU describing how a 5 or 10 minute consultation with a GP could be beneficial. This led to an acceptance by GPs that they had a potentially important role to play in promoting recovery. This example highlights the importance of the focus groups as a means of facilitating interaction between different viewpoints, and how those viewpoints may be informed and influenced by each other.

7.4 Recovery-orientated services at the level of the primary care system

Holistic care

In the second focus group, a SU spoke of the ability of GPs to see beyond SUs’ mental health diagnoses because unlike psychiatrists, GPs provided physical health care. The SU also contrasted GPs favourably with psychiatrists in terms of GPs’ relative lack of interest in “box
ticking” regarding mental health. There was an overall consensus that because GPs are involved in both the mental and physical health of SUs, this generally helps promote recovery from psychosis in primary care. There was a desire amongst participants to retain this holistic approach to health inherent in the primary care system, alongside the retention of continuity of care which leads to a more personalised approach.

“When you go to see a GP they've also seen you when you've had a cold, so they're not just going to start ticking boxes on the mental health side of things. And they do have a sort of...more of an insight into you as a person beyond the illness which you don't seem to get with psychiatry” (SU 5, male).

**Early Detection**

One SU felt that GPs already had an important role to play in terms of recovery from psychosis, because they may be in a good position to detect the early warning signs of relapse. GPs’ regular contact with SUs in relation to physical symptoms may allow GPs to observe shifts in a SU’s psychological well-being. However, the SU qualified this by saying that GPs would find it more difficult to fulfil this early detection role if there was not a great deal of contact between the GP and the SU, because this would leave the GP without a baseline of psychological well-being with which to compare the SU’s current mental state.

“For them to pick up on my early warning signs, when I'm becoming unwell, it can be a bit of a difficult one. Unless you've really seen a client that's come in regularly to see you, you can then go, ‘Oh, actually there's a little slip from last time I saw you’” (SU 4, male).

**Help finding alternative interventions**

Primary care was seen as an ideal place to provide SUs with information about interventions other than anti-psychotic medications. There was a consensus amongst SUs that they would like GPs to provide more help in this regard. GPs also agreed that more could be done on their part to enhance the amount of information they held and could provide regarding alternative interventions.

“It's about help finding alternatives” (SU 5, male).
In the other focus group, SUs also conveyed their desire for GPs to provide alternatives to medication. One SU felt that interventions could be tailored by GPs to fit the needs of each individual SU. However, that SU’s previous experiences involved receiving a one-size-fits-all medication prescription from GPs. She then went on the list a number of possible alternative interventions.

“Talking therapy or counselling or some sort of, other alternative treatment might be considered...like acupuncture and hypnosis and various others, reflexology, may alleviate symptoms or just increase the mental state of well being, and it doesn’t always have to be a prescription and 'come back in three months'. All aspects should be covered, especially like CBT, cognitive behavioural therapy, that's not offered to a lot of people” (SU 1, female).

**Primary care acts as a bridge between consultants and SUs**
Primary care can play a useful role in promoting the recovery of SUs from psychosis by enhancing communication between SUs and secondary care professionals. A GP in the second focus group felt that sometimes misunderstandings occurred between SUs and hospital consultants because they did not listen to each other properly. In this scenario, the GP may be in a position to act as a communication bridge in order to bring the message of one side to the attention of the other.

“The second role I think of is as a bridge between the hospital consultants and the patient. Sometimes the relationship between the hospital and the patient can be good, but sometimes people are obviously not understanding each other particularly well. Maybe the patient’s said something about side effects, whatever, which the consultant has ignored or sometimes it’s some message that the consultant has been trying to get to the patient which they’ve not kind of understood. And so acting as a kind of bridge to help that communication” (GPS 2, male).

**Primary care environment is local, easily accessed, safe, and non-stigmatised**
The psychiatric hospital environment was described as frightening and “dysfunctional” by a SU in the second focus group. A GP in that focus group agreed, and said that primary care is more amenable to promoting recovery from psychosis in that sense because it represents an environment that is local, easily accessed, safe, and non-stigmatising.

“I think that those non-hospital (locations) are easy accessible, sort of safe places to be. Again, it’s about flexibility without having to go through such big hoops” (GPwSI 3, female).

Primary care was contrasted favourably with secondary care regarding continuity of care as well as frequency of access to care. One SU talked about the frequency with which he saw his GP, and the knowledge that the GP had about him as a person, and contrasted that with his much less frequent consultations with psychiatrists.

“You see them (psychiatrists) for about an hour a year or something like that, and they just fob you off. Psychiatrists don’t care about you as an individual, they don’t give a toss, he doesn’t know you. He sees you for about an hour and a half a year” (SU 2, male).

Another area where primary care was contrasted favourably with secondary care was regarding the reduced expectations of recovery in secondary care. One GP mentioned that when psychosis is treated as a chronic problem in secondary care, psychiatrists do not expect the SU to recover, and do not invest as much time or effort into trying to promote recovery.

“Classic chronic condition, where you have no expectations that anything should happen. Come back, everything is okay, see you in six months” (GPwSI 1, male).

**Summary**

It was reported that some GPs saw beyond mental health diagnoses because they were involved in both the mental and physical health of SUs. This was regarded as an aid to promoting recovery from psychosis in primary care. Focus group participants wished for a retention of this holistic approach to health which was seen as inherent in the primary care system. GPs’ regular contact with SUs in relation to physical symptoms may also allow GPs to observe shifts in a SU’s psychological well-being. As a result, GPs may also be in a good position to detect the early
warning signs of the onset of an episode of psychosis. In addition to their role as physical health practitioners, GPs may also be able to detect early signs of psychosis due to the local and accessible nature of primary care.

A recovery-oriented primary care service would remain local and accessible as this provides a non-stigmatising environment in contrast to secondary care services which are often hospital-based. Local and personalised care might also have a greater ability to take account of individual SUs’ social and cultural contexts and personal preferences.

Recovery-oriented primary care services could facilitate enhanced communication between SUs and secondary care professionals. In addition, GPs could attempt to improve their own communication channels with secondary care, as both GPs and SUs felt this needed to be improved upon.

An important feature of any recovery-oriented primary care service in the future would involve the provision of interventions other than anti-psychotic medications. Psychological therapies and other alternative interventions were deemed desirable by both SUs and GPs during the focus groups. Such interventions could be provided directly in a primary care setting, or GPs could increase their awareness of how to access such interventions through NHS secondary care services or through the voluntary and community sector.

7.5 Introducing change to primary care

Education and training
There was a consensus that the provision of bespoke mental health training and education for GPs was one way of promoting a recovery-orientated approach to psychosis. One GP felt that training should be targeted at a small number of more specialised mental health GPwSIs, and that an increase in the number of GPwSIs would be useful. However, another GP believed that all GPs needed to take responsibility for improving their knowledge of psychosis.
“All GPs should have better understanding of mental health” (GPwSI 2, male).

Methods mentioned by GPs for increasing the mental health knowledge and skills sets of GPs included top down change in the form of training run by PCTs. Education could be provided in the form of detailed courses such as mental health degrees or certificates, as well as e-learning. One example of the latter form of education was given by a GP who suggested the use of podcasts on GP learning forums which involved SUs describing their experiences of psychosis. “Using multimedia, there is no reason why something like this couldn't be done as a podcast, somebody who is a service user describing what their experience is, and that used as a new learning tool” (GPwSI 1, male).

It was suggested by a GPwSI that training could also be approached from the bottom up, with local clinical leaders or champions stimulating the interest of local GPs in recovery from psychosis and advising them on key things to prioritise in terms of what they could learn. “There's opportunities I think for local clinical leadership and GPwSIs to take more responsibility” (GPwSI 2, male).

However, it was noted by a GP in the same focus group, that GPs are already inundated with information about mental health issues and other health issues generally. She felt that it is very difficult to decide which information was most important to digest, and this meant that GPs often read what was already of interest to them. It was suggested that if a GP does not already have a particular interest in psychosis, it would be unrealistically optimistic to expect them to seek out or assimilate information about recovery from psychosis. “I think we get information overload don’t we, we are all busy doing surgery, visits etcetera and on top of that we get professional learning and information being e-mailed to us and sent by post. It’s very difficult to filter what's most important, what's your priority” (GPS 1, female).

In order to overcome this problem of lack of interest in mental health, it was suggested by a GP in the second focus group that the uptake of training in recovery from psychosis could be
incentivised through the revalidation process for existing GPs, e.g. audits of care as well as perhaps through the introduction of new indicators in the “Quality and Outcomes Framework”. “You have to demonstrate an advantage, you have to. I think you do it in as many ways as you can think of, because there isn’t one simple way. And I think that, well, we were talking about a quality and outcomes framework earlier and about what are incentives for people” (GPwSI 3, female).

Awareness of mental health services
The lack of awareness amongst some GPs about how mental health services operate was mentioned by GPs in both focus groups. It was felt that along with knowledge about psychosis, and attitudes towards psychosis, a major issue that needed to be addressed was the lack of awareness which some GPs had about the services available to them. A GP in the first focus group felt that knowing somebody who works in mental health services such as a CPN, on a face-to-face basis, could facilitate GPs’ awareness of available mental health services.

“So just simply knowing who to ring up and how to engage with the specialist mental health service is incredibly important, and of course that’s when you get down to the structures, how we set up services in the primary care. If we have a CPN who we know quite well, who is actually familiar, who used to work in your surgery, and you are meeting over coffee quite frequently - it’s a very different relationship to one where you are ringing up a single point of access, where you have no idea who you are talking to. You may be faced with ten phone calls, and there is no sense of you feeling confident that you know, and they don’t know you either. You are just a stereotypical GP who is not really coping. So I think how we set up the systems to support the middle ground general practice is really important” (GPwSI 1, male).

A GP in the second focus group made the same point about GPs not always being aware of the mental health services which are available to them. She proposed that representatives of those services should frequently visit practices and update GPs about available mental health services. She believed that GPs had a lot of information and knowledge about services, but that the most important thing was to build working links with individuals within those services. She spoke of
mental health service representatives who meet with GPs once but then disappear. This was deemed insufficient in terms of that representative or service building up a relationship with the GP.

“You get people coming in and they meet you once and then they disappear. It's those working links that you get to know the person, you get to know what they can do, what they can offer, and then that plants the seed in your mind that, well, I've got this situation so I know X can advise me about that. And it's about getting new habits in place. But doing it in a personal way I think. Because we've got all the information” (GPwSI 3, female).

**Change GPs’ attitudes through collaboration with SUs: “Education not medication”**

Although all GPs agreed that education and training could be a useful way of promoting a recovery-minded approach to psychosis amongst GPs, one of the GPs in the first focus group felt that it was a change in GPs’ attitudes that was required, rather than supplying GPs with more knowledge.

“It is one thing to have knowledge, but attitudes eat knowledge for breakfast. If you've got the wrong attitudes then you can have all the knowledge in the world, but it won't really work and I think there is an issue about stigma, discrimination and stereotypes that starts off with, probably before medical school, but certainly happens in medical school where you can acquire stereotypes of patient conditions” (GPwSI 1, male).

It was generally felt that a potentially influential way of changing attitudes towards psychosis amongst GPs, was to expose medical students and junior doctors during their initial training to people experiencing psychosis. People experiencing psychosis could then share their experiences of psychosis with those students and junior doctors.

“Exposure to people who have had long-term mental conditions would be what I'd try and create in services, and conversations between people who have conditions and doctors” (GPwSI 1, male).
There was a consensus that qualified GPs could learn about recovery promotion from having conversations with SUs, in the same way that medical students could learn from SUs at an earlier stage in their careers. GPs could work collaboratively with SUs to learn what it’s like to deal with the health system. It was felt that this could affect the attitudes of GPs towards SUs and recovery from psychosis. One SU had previously given presentations to mental health professionals about her personal experience of psychosis.

“Giving talks, personal account of how I came to hear voices, slides. There were psychiatrists, CPNs, social workers, psychologists, mental health workers” (SU 1, female).

This SU’s experience of presenting her personal account to mental health professionals led her to believe that carrying out a similar educational program with GPs could be beneficial in terms of changing attitudes. She summed up this belief as follows: “Education not medication” (SU 1, female).

However, that SU also felt that such attitudinal changes are not easily achieved and require much time and effort.

“I understood that they couldn't just wave a magic wand. They can’t solve it over night, these things. You can't move mountains. These sort of things take time” (SU 1, female).

Another SU proposed a similar method for bringing about attitudinal change amongst GPs towards recovery from psychosis. He felt that SUs could travel around meeting with GPs in order to canvass them for their support in promoting recovery from psychosis. This SU had no previous experience of providing educational presentations or of political activism. He felt that it would be beneficial if SUs travelled in groups when they were meeting with GPs, in order to provide mutual support for one another.

“Little canvassing in groups, in a group scenario, the tighter and smaller the better” (SU 2, male).
One GP expressed an interest in attending and observing a SU peer support group, having had little knowledge about their existence prior to the focus group discussion. She felt that GPs could also learn more about SUs’ experiences of psychosis by attending such a group.

“What about this group that you go to? The support group, the listening group. Just to be a GP observing what goes on in that forum would be hugely helpful” (GPS 1, female).

**GP supervision**

Two GPs in the first focus group felt that GPs generally could be encouraged to promote recovery from psychosis through engaging in supervision of each other’s work. Problematic psychosis-related consultations could be discussed with other GPs who might have more experience of mental health issues. One of the GPs gave the example of her own practice which had weekly clinical supervision meetings, enabling all the GPs to discuss their consultations and share advice. These meetings also facilitated the input of other GPs in the practice who may have been working with family members of a SU experiencing psychosis.

“In my practice we have a weekly clinical supervision meeting, where all the practitioners come for an hour. It's been running for nearly three years now. I chair it each week and it is hugely helpful. If you've got somebody, for example, somebody with a mental health issue and you've got the family that have been involved perhaps. Other members of that (supervision) group may be dealing with other members of that family. Perhaps we can coordinate care, not just mental health issues but end of life issues etcetera. So it is a huge help, but it doesn't happen across the board” (GPS 1, female).

It was felt that GP peer supervision could facilitate the sharing of information between GPs, as well as engendering a more self-reflective approach amongst GPs. However, there was a consensus amongst GPs that regular supervision groups or other GP peer support groups are rare.

“One of the things that GPs are generally not good at doing is building on their own supervision of their own day-to-day work. So building supervision let's me think about what's happened in the consulting room. A group of professionals getting together and talking about what had happened
that day, things that have stood out. So I think reflective practice is another very key way of getting at attitudes” (GPwSI 1, male).

Summary

A variety of different methods were suggested for introducing change into primary care services. Education and training could be provided in a top-down manner which might involve university modules or courses or PCT training. Alternatively, education and training might also be provided in a bottom-up manner by local champions of recovery-oriented primary care mental health services. There was no consensus on who should be provided with training. Some GPs felt that all GPs should take part in recovery training, while others felt that only GPwSIs should be trained, but that there should be an increase in the numbers of GPwSIs.

SUs proffered another method of introducing change which was via SU-led training for GPs. SUs would share their experience of psychosis and of mental health services with GPs, and GPs would be able to learn from those experiences. This is a plausible method as one of the SUs who participated in the focus group had already carried out similar training with mental health professionals. It could also be a useful method for tackling many of the barriers to promoting recovery because it exposes GPs directly to a SU’s actual experience of psychosis and services from a SU’s perspective. This might help to address barriers such as the lack of interest in mental health amongst some GPs and the negative attitudes held by some towards mental health problems.

Changes might also be introduced with the aid of reflective peer supervision groups for GPs. These groups would allow GPs to share their experiences and knowledge about psychosis with each other. It would facilitate the exchange of knowledge between GPs about where to access appropriate mental health services. GPs might be able to gain support from their peers if they felt they were experiencing difficulty with a particular case. It might also allow GPs to be more self-reflective about their own relationship with SUs during consultations, and allow GPs to improve on skills such as building rapport. Reflective peer supervision groups are an integral part of the
weekly work schedule for clinical psychologists and psychotherapists. However, such groups are not part of GP culture generally. A more widespread introduction of reflective peer supervision groups for GPs might prove beneficial as a method of promoting recovery from psychosis in primary care.

**Conclusion**

Recovery was conceptualised in a number of different ways. Some of these recovery conceptualisations were of a social or functional nature, such as accepting and coping with continuing difficulties, or returning to one’s own normal pre-morbid social functioning. Some conceptualisations stressed the individual nature of recovery - an individual journey based on optimism, or a conceptualisation which changed throughout a person’s life. Recovery was also conceptualised by one SU as the attainment of independence from the mental health service, from hospital admissions, and from medication. A GPS combined three separate conceptualisations or stages of recovery into one overarching conceptualisation – recovery as a three stage process of firstly returning to social functioning, then eradicating symptoms, and finally coming off treatment. In addition, recovery was seen as a means of removing socially constructed forms of disability. Recovery was also criticised by some focus group participants for variously being a devalued, a formulaic, or an unrealistic concept.

A number of different factors were mentioned which were perceived to be barriers to the promotion of recovery from psychosis in primary care. Some GPs felt that they did not see many people presenting to primary care with psychosis, and that they were relatively inexperienced in this area. There was feeling that lack of interest, knowledge and resources on the part of some GPs were also barriers to recovery promotion, and that this was further amplified by the negative attitudes towards mental health which some GPs were felt to have. Discontinuity of care and the use of anti-psychotic medications within primary care were also identified as by some participants as being potential barriers to recovery. Issues related to diagnostic labels and
language in primary care, and difficulties in accessing secondary care from primary care, were also reported by some participants as barriers to recovery from psychosis.

Recovery from psychosis in primary care could be aided by GPs who displayed particular interpersonal skills and attitudes such as having a personable manner, being caring and respectful, and listening to the concerns of SUs. Interpersonal rapport between the GP and the SU, which was built up through continuity of care was also perceived as an important aid to promoting recovery. In many instances, GPs knew the families or carers of SUs with psychosis, as family members often shared the same GP. This was seen as a help to GPs who were attempting to promote recovery in primary care. In addition, it was also felt that recovery could be enhanced if GPs had a particular interest in psychosis or in mental health generally.

Apart from the actual or potential personal characteristics of individual GPs which were identified as being helpful in promoting recovery, the characteristics of recovery-orientated services at the level of the primary care system were also identified. The primary care system in general was reported as being in a position to promote recovery in a number of ways: providing holistic care which covered physical health as well as mental health; facilitating early detection of psychosis; helping SUs to find alternative possible interventions; acting as a communication bridge between consultants and SUs; and providing care in a setting which was local, accessible, safe, and non-stigmatised.

In order to overcome the potential barriers to promoting recovery in primary care, the introduction of a number of changes to primary care were identified. It was felt that additional training for GPs on recovery from psychosis, and on enhancing GPs’ knowledge of how the mental health system operates more generally, would be changes which might prove beneficial in promoting recovery in primary care. It was felt that the attitudes of GPs towards recovery from psychosis could be changed through direct collaboration with SUs. The possibility of more GPs becoming involved in reflective peer supervision was also identified as a potential way of promoting recovery from psychosis in primary care.
The following chapter will discuss the findings of the focus groups and the findings of the interviews. The findings presented in the previous three results chapters will form the basis of a new theoretical model which will also be presented in the following chapter. This theoretical model of recovery from psychosis in primary care will also be informed by the findings of the CIS (Chapter 2). In addition, the relevance of the Conceptual Framework (Chapter 3) to the findings will be discussed.
Chapter 8

Discussion
Introduction
In this final chapter the findings from the empirical study are summarised. A new theoretical model of recovery from psychosis in primary care is presented and discussed. The PhD’s findings are discussed in the context of the critical interpretive synthesis, the conceptual framework within which this study was located, and the original objectives of the PhD. Following this, the limitations of the study are considered. Finally, the implications of this research are examined in terms of future practice, policy and research.

8.1 Summary of empirical findings

(a) GPs’ views on recovery in primary care
GPwSIs and GPSs shared a number of views regarding recovery from psychosis. Almost all interviewees discussed the continuity of care afforded by primary care which may aid recovery. The importance of social support networks for promoting recovery, the ability of GPs to support the families of SUs, and the importance of enhancing communication channels between primary and secondary care for the promotion of recovery were also described by many GPwSIs and GPSs.

Continuity and Immediacy
Many GPs felt that continuity and immediacy of support were key elements of GPs’ roles in promoting recovery, and that good continuity was unique to primary care. It was felt that primary care was also able to successfully communicate this continuous availability of support to SUs. Stable and genuine relationships were fostered between SUs and primary care professionals because of this continuity over time, in addition to allowing GPs to gain a better understanding of SUs’ family and social circumstances. Primary care was contrasted with secondary care by many GPs who believed that secondary care was less well equipped to offer continuity of care to SUs. Meetings with secondary care professionals were reported as often being brief or infrequent, and this was felt to be particularly the case if a SU had recovered to a certain degree. The lack of continuity of secondary care which some SUs experienced was believed at times to prevent the
development of genuine relationships, which then was perceived to lead to the disengagement of SUs from secondary care services. GPs often felt frustrated and burdened when continuity of care and engagement broke down in other areas of the health service.

**Social Support Networks**

Most GPwSIs and GPSs felt the availability of adequate social support networks for SUs was an important factor in the promotion of recovery, and that social support was generally provided by families, friends, communities, and employers. If a SU lacked social support, this was believed to be a potential risk factor for relapse, and a barrier to recovery. It was felt by some GPs that SUs could be helped to expand their social support networks through interventions, with GPwSIs in particular having referred or sign-posted SUs to organisations in the community, such as community gardening projects and befriending schemes. Some GPs believed that recovery could be promoted by encouraging SUs to create fulfilling friendships through an increased involvement in their own interests and hobbies. Some GPs also felt that they could provide educational interventions to promote a greater understanding of psychosis, and enable members of SUs’ social support networks to overcome their own fears regarding psychosis. It should be noted that only GPwSIs reported the possibility of GPs intervening to enhance social support networks. Many GPSs recognised the importance of social support networks for recovery, but ultimately did not propose any interventions which GPs could potentially implement to enhance such social support. However, the continuity of care provided by GPSs may in itself represent one aspect of a SU’s social support network. GPSs may enhance the social support available to SUs through this provision of continuity of care, alongside the targeted interventions to enhance social support networks reported by some GPwSIs.

**Supporting Families**

GPwSIs and GPSs felt uniquely placed to support the families and carers of SUs experiencing psychosis, and this role related to their continuous provision of care over a long period of time. This enabled GPs to build trusting relationships with families, and was seen as a way of promoting recovery. GPs felt they could support families in a number of ways: providing families
with information about psychosis and treatment options; promoting an understanding, patient, optimistic and hopeful approach towards psychosis and recovery; listening to the concerns and pressing issues of families; and facilitating the involvement of families in decisions regarding treatment. GPs felt they were also more trusted by families and SUs because GPs were seen to be relatively removed from treatment and sectioning decisions. This meant that GPs were sometimes relied on by families to provide an independent analysis of the situation, or to provide information to families regarding decisions made by secondary care services. Some GPs believed that it was part of their role to inform families about alternative sources of social support for themselves and for the SU. GPs who wished to contact SUs after they had disengaged with primary care services, could often rely on the SU’s family as alternative contact route and source of information. GPs also reported that families could often recognise the early warning signs associated with a relapse, and relay this information to their local GP.

**Primary/Secondary Care Interface**

There was a feeling amongst many GPwSIs and GPSs that communication channels with psychiatrists could be improved, and that both GPs and psychiatrists could display a greater interest in engaging and working closely with one another, with the recovery of SUs in mind. Many GPs expressed dissatisfaction with the referral process, and had difficulty in accessing secondary care services for SUs who were not deemed “unwell enough”. Consistent and prompt support from and access to psychiatrists was desired by GPs, particularly GPs who felt less confident about their knowledge and skills regarding psychosis.

However, there were a number of marked differences between GPwSIs and GPSs. For example, differences were evident in how recovery was conceptualised, how anti-psychotic medications were interpreted, how much confidence and expertise GPs felt they had in promoting recovery, and the importance placed on comorbid drug and alcohol use as a barrier to recovery.

**Recovery Conceptualisations**
GPSs more frequently emphasised biomedical recovery, symptomatic recovery, a return to mental stability, and the efficacy of anti-psychotic medications as a way of producing this recovery outcome. GPwSIs were more likely to speak of adequate functional or social recovery which included a return to being involved in community activities, such as education, employment, independent living, and having fulfilling interpersonal relationships. This functional conceptualisation did not tend to emphasise symptom suppression, but rather tended to focus on optimising the SU’s state of wellbeing despite their possible continuing experience of psychosis-related symptoms. Conceptualisations of social recovery amongst GPwSIs tended to involve the idea that social support and inclusion were key factors in promoting recovery. Families and GPs could both potentially have roles to play in promoting social support and ultimately social recovery. For some GPwSIs, functional recovery also involved a reduction in anti-psychotic medication.

**Medication**

Anti-psychotic medication was seen as an efficacious tool for the promotion of recovery by all GPSs, and adherence to medication was believed to be necessary for the maintenance of stability by some GPwSIs also. However, most GPwSIs expressed reservations about anti-psychotic medications such as their side-effects. Most GPwSIs also felt that there were other useful ways of promoting recovery apart from medication, such as family and social support, and psychological interventions. By contrast, ensuring that SUs complied with medication prescriptions was seen as a central factor in promoting recovery, from the perspective of GPSs. While some GPwSIs also felt that non-compliance was an important barrier to recovery, such non-compliance tended to be seen as understandable due to the serious side-effects often associated with anti-psychotic medication.

**Expertise**

GPSs and GPwSIs tended to differ according to their perceived respective abilities to promote recovery from psychosis. GPSs generally felt inadequately skilled and knowledgeable about psychosis, whereas GPwSIs felt more confident in this regard. GPSs felt ill-equipped to carry out
assessments, to prescribe medication, to carry out a “section” under the Mental Health Act, or to manage psychosis on a long-term basis. GPSs perceived themselves as lacking expertise because they reported encountering relatively few people with psychosis. GPSs reported that they had not received specialist training in psychosis, and felt more reliant upon psychiatrists for suggestions and advice. On the other hand, GPwSIs tended to express more confidence in working with SUs, especially SUs who were somewhat recovered and were no longer in contact with secondary care services.

**Drug Misuse**

Misuse of illicit drugs was seen by many GPSs to be a common cause of psychosis, with the onset of psychosis resulting from the behaviours of SUs. Drug use was also seen as an important barrier to recovery by many GPSs. The focus on illicit drug use was congruent with the biochemical explanatory framework for psychosis adopted by most GPSs. By contrast, comorbid drug and alcohol use was not emphasised as a causal factor or a barrier to recovery by GPwSIs. Instead, GPwSIs tended to focus on alternative ways of promoting functional recovery.

**(b) SUs’ views on recovery in primary care**

There was a consensus evident amongst many of the interviewed SUs regarding how recovery from psychosis could be best promoted in primary care. The four main themes which emerged were as follows: a preference for a psychosocial or “whole-person” approach to recovery; a desire for greater SU autonomy and input into consultations and treatment plans; a wish for GPs to have greater responsibility for providing psychosis care, alongside more training for GPs in this area; and a desire for more GPs to acknowledge social barriers to recovery such as stigma and exclusion.

**“Whole person” approach to recovery**

Most SUs conceptualised recovery as a process involving psychosocial factors, and wished to see this approach applied to the promotion of recovery in primary care. This would involve primary care giving greater recognition to social and psychological factors as well as physical ones, in
order to form a “whole person” approach to recovery. Many SUs felt that GPs were engaged primarily in promoting a biomedical approach to recovery which emphasised symptoms, diagnoses, brain chemistry, and medication-based treatments. Criticism of anti-psychotic medications was reported due to their side-effects, their perceived inability to promote recovery or prevent relapse, and the perceived inappropriateness of treatments being focused solely on brain chemistry. There was an expectation amongst some SUs that GPs could do more to discuss the potential side-effects of medications with SUs, along with providing information regarding alternative non-pharmaceutical interventions. These alternatives might include psychological therapies, local peer-supported services, SU groups, or nutritional advice.

“Fobbed off” by GPs
An inability to influence one’s own treatment plan during consultations with GPs was a problem encountered by many of the SUs interviewed. Many GPs were criticised for not listening properly to the needs of SUs, for not communicating empathically during consultations, and for the rushed nature of consultations. Some SUs reported the feeling that they posed problems which GPs found difficult to deal with, and were “fobbed off” with prescriptions or referred on to psychiatrists. SUs often felt disempowered by their lack of choice or input in the decision making process, and wished for more input into what form their treatment plans took so that their individual needs could be met. Apart from addressing unique personal requirements, having input into the decision-making process might help build a sense of autonomy and empowerment. This enhanced sense of autonomy could in itself play a part in the recovery process, and could be facilitated by GPs.

Shift responsibility to primary care
An interest was expressed by many SUs in shifting responsibility for their care from secondary to primary care, alongside greater access to GPwSIs. This desire for a shift to primary care was partly due to a feeling amongst SUs that primary care could more readily promote recovery as a result of the greater continuity of care and access to GPs. Many SUs also reported having a more positive relationship with their GP than with their psychiatrist. For example, it was felt that GPs
tended to be more willing to take on board the input of SUs when making treatment decisions. In addition, the primary care setting was seen as less stigmatizing. Many SUs wished to either see GPs take on the main responsibility for psychosis care, or for GPs to become more involved in the promotion of recovery from psychosis alongside psychiatrists. There was a desire to see GPs and psychiatrists working together in a more collaborative manner. An alternative approach proposed by one SU was for psychiatrists to hold their clinics in GP practices. There was a belief held by some SUs that GPs would not wish to become more involved in the provision of care for psychosis. There was also a desire amongst many SUs for more training in mental health to be provided for GPs, and to see more GPs becoming mental health GPwSIs.

**Stigma and Exclusion**

The stigma related to having a psychiatric diagnosis and a medicalised identity was reported by many SUs to be a barrier to recovery from psychosis, and there was a wish to see more GPs acknowledge social barriers to recovery such as stigma, prejudice, social exclusion and misunderstandings of what mental illness is. Sources of such misunderstandings included friends, acquaintances, family members, employers and the police. The accommodation provided for SUs was reported by many to be of poor quality and in socially disadvantaged areas, where it was a struggle to cope with the environment. It was felt that psychosis could be exacerbated if SUs shared their living space with other people experiencing psychosis, as was often the case with supported housing arrangements. Housing and employment problems were reported by many SUs to be barriers to recovery, and there was a feeling that GPs could do more to attend to these social elements of recovery. A greater awareness amongst GPs of local community groups or peer-support groups, and a greater willingness to signpost SUs in the direction of such groups, was desired by many SUs. Such groups were identified as key promoters of recovery, and it was felt that SUs’ involvement in groups and activities could be encouraged by GPs in a primary care setting.

(c) Findings of mixed focus groups
The focus groups served two primary functions: to validate previous interview responses, and to generate new data. Some recovery conceptualisations and factors were originally only discussed by a small number of interview participants, and did not feature prominently in the interview results chapters. However, some of those themes were subsequently emphasised to a greater degree during the mixed focus group discussions, and were reported as part of the focus group findings. Themes which were emphasised by participants during the mixed focus groups are summarised below.

**Recovery conceptualisations**

A number of recovery conceptualisations were reported by both SUs and GPs during the two mixed focus groups, which validated previous interview findings. Recovery was seen by many participants to be social or functional in nature. For example, recovery was conceptualised as accepting and coping with continuing symptoms, as well as returning to a pre-morbid levels of social functioning. The individual nature of recovery was emphasised by some participants. For example, recovery was seen as an individual journey based on optimism, or as a conceptualisation which changed throughout a person’s life due to a person’s changing circumstances and experiences. One SU saw recovery as being able to live independently of mental health services and medication.

Novel recovery conceptualisations were also generated during the focus groups. Three separate conceptualisations or stages of recovery were accommodated into one overarching conceptualisation by a GPS. According to this conceptualisation, recovery could be seen as a three stage process consisting of an initial return to social functioning, followed by an eradication of symptoms, and finally by an ability to end treatment. In addition, recovery was seen by some as the removal of a socially constructed form of disability. There was also criticism of services that used the term “recovery” in an unrealistic or formulaic manner, which led to a devaluation of the term’s meaning.

**Barriers to recovery**
There were a number of barriers to promoting recovery from psychosis in primary care which were emphasised during the focus groups, and which validated the findings of interviews with SUs and GPs. There was a feeling amongst some GPs that there were not many people with psychosis attending their practices, and that this did not lend itself to GPs becoming more experienced and confident when it came to promoting recovery from psychosis. It was felt that some GPs lacked the sufficient amount of interest, knowledge or resources required to promote recovery. Some GPs were even felt to hold negative attitudes towards mental health, which would be a significant barrier to recovery promotion in primary care. Both SUs and GPs felt that sometimes care in primary care was discontinuous, due to either SUs moving between practices, or to practices being large in size. This discontinuity was seen as a potential barrier to recovery. Some SUs also saw the prescription of anti-psychotic medication in primary care as a barrier to recovery. Both SUs and GPs recognised the importance of diagnostic labels and language use in primary care, with incorrect usage being seen as a barrier to recovery. A further barrier discussed in the focus groups was GPs’ difficulties in securing access to secondary care services for SUs.

Factors promoting recovery
A number of factors originally discussed during the interviews with individual SUs and GPs, were validated as a result of further discussions during the mixed focus groups. Certain personal characteristics of individual GPs were identified as being helpful for the recovery of SUs from psychosis. For example, it was reported that GPs promote recovery by displaying particular interpersonal skills and attitudes such as having a personable manner, being caring and respectful, and listening to the concerns of SUs. An important factor in the promotion of recovery was the interpersonal rapport built up between the GP and the SU, often through years of continuity of care. GPs were also felt by participants to have a unique perspective within the NHS, in that the families or carers of SUs were often also registered with the same GP as the SU. This allowed GPs to gain an understanding of the SU’s familial context, as well as enabling the GP to communicate more readily with family members if required. If a particular GP had an interest in psychosis or in mental health, this was seen as an additional positive factor in aiding a SU’s recovery in primary care.
Apart from the characteristics of individual GPs, certain characteristics of recovery-orientated services at the level of the primary care system were also identified during the focus groups. The primary care system was seen as being in a position to provide holistic care which covered the physical health as well as the mental health of SUs. In addition, primary care could facilitate the early detection of psychosis, help SUs to find alternative possible interventions, act as a communication bridge between consultants and SUs, and provide care in a setting which was local, accessible, safe, and non-stigmatised.

**Potential Interventions**

There were a number of changes to primary care identified by focus group participants which could be implemented in order to help overcome potential barriers to promoting recovery. The identification of barriers to implementing recovery-oriented services in primary care was an issue which was specifically focused on during the focus groups. The new themes which were emerged from the focus groups are summarised here. For example, GPs could be provided with further training in mental health, and in recovery from psychosis specifically. The setting up of reflective peer supervision networks was proposed as a possible method for raising awareness of recovery from psychosis amongst GPs. Peer supervision in psychosis was not readily available to a majority of the GPs who participated in the focus groups, and this proposal was universally welcomed by all GPs. It was also felt that the attitudes of some GPs towards psychosis needed to be changed, and that direct collaboration between SUs and GPs might prove effective in this regard. In particular, there was agreement amongst focus group participants on the potential for change which might be brought about through SU-led training for GPs. This training might involve SUs presenting their personal recovery experiences to GPs.

8.2 Theoretical Model: Recovery from Psychosis in Primary Care

*Incorporating the Critical Interpretive Synthesis*
This PhD developed a new theoretical model of recovery from psychosis in primary care (see Figure 1 below). This theoretical model incorporated the findings of the PhD’s empirical work, as well as the outcomes of the CIS of previous literature. As suggested by the findings of the critical interpretive synthesis, recovery was conceptualised as a continuum, where recovery was seen as a process, as a program of care, or as an outcome. The new theoretical model had a primary care focus, and recovery conceptualisations were viewed as running along such a continuum. SU autonomy was maximised at one end of the spectrum, and this end of the continuum was marked by notions of recovery as a process. This was where SUs had the greatest influence over their own recovery plans. Concepts associated with recovery as an outcome were situated at the opposite end of the spectrum, where SU autonomy was minimised, and biomedical influences were greatest. However, it should be noted that the primary reason for developing this theoretical model was for the social or clinical utility it might provide in guiding future service provision. The model’s social and clinical utility takes priority over questions of conceptual and causal accuracy, and the model is tentative in nature.

**New conceptualisations of recovery**

As a result of interviews and focus groups with GPs and SUs focusing on the primary care context, six recovery concepts were situated along this continuum. Two such concepts were mapped onto “recovery as a process”:

- User-led recovery as an individual journey which is based on optimism
- Recovery as the removal of socially constructed forms of disability

A further three recovery concepts were mapped onto recovery as a program of care:

- Social Inclusion and Support
- Alternatives to anti-psychotic medication
- Whole-person approach to recovery

Finally, the concept of recovery as an eradication of symptoms, with its associated biomedical philosophical underpinning, was mapped onto recovery as an outcome.
Factors and Interventions

Further findings of the empirical work with GPs and SUs were also subsequently mapped on to this recovery continuum. For example, the theoretical model (see Figure 1) illustrates the numerous factors which have been reported in the data to promote recovery from psychosis in primary care settings. These facilitators of recovery have been linked to the conceptualisations of recovery and the barriers to recovery that are also related to such facilitators. Finally, potential interventions aimed at primary care settings have been identified from the data, and linked to the barriers which they aim to overcome.

Differences between SUs’ and GPs’ views

Conceptualisations of recovery as a process were reported primarily by SUs. For example, SUs were more likely to describe recovery as a journey based on optimism, and that recovery could be promoted by having greater SU autonomy and empowerment. A SU in one of the mixed focus groups first raised the idea of having SU-led training for GPs on recovery from psychosis, and this intervention proposal was subsequently welcomed by the GPs participating in that focus group. SUs were also more likely to report a desire to receive care in the less stigmatising primary care environment.

GPwSIs and SUs both frequently conceptualised recovery as a program of care. Many SUs noted the importance of providing alternatives to medication in primary care. SUs and GPwSIs both noted the importance of social inclusion and social support to SUs’ recovery. During interviews and focus groups, SUs emphasised the importance of peer-support networks as a key element of this social support. During the focus groups, GPwSIs heard about the importance of such peer-support for SUs. GPwSIs talked about the role of GPs in signposting support groups and other services for SUs, but also mentioned that some GPs lacked an awareness of such local groups.

GPSs tended to be the research participants who were most likely to conceptualise recovery as an outcome which consisted of a cessation of psychotic symptoms. For GPSs, medication compliance was emphasised as a key factor in promoting recovery. Based on the empirical data,
GPSs’ conceptualisations of recovery tended to be located towards the “outcome” end of the continuum, SUs’ conceptualisations were more likely to be located towards the “process” end of the continuum, and GPwSIs’ conceptualisations were often located between those two poles, with a focus on recovery as a program of care. However, there were differences evident in the responses of individual participants within each of these three groups. Not all SUs, GPwSIs, or GPSs expressed views which were consistent with other participants from their particular participant “group”. In addition, some participants conceptualised recovery using two, or sometimes even all three, of the recovery conceptualisation categories described in the theoretical model.

The theoretical model below attempts to represent the themes which emerged from the empirical data in a clear and parsimonious manner. The model links the reported factors and interventions to the particular conceptualisations of recovery with which they were most commonly associated in the data.
### Figure 1: Theoretical model of recovery from psychosis in primary care

<table>
<thead>
<tr>
<th>Recovery Continuum</th>
<th>Recovery Concepts in Primary Care Context</th>
<th>Factors Promoting Recovery in Primary Care</th>
<th>Factors Hindering Recovery in Primary Care</th>
<th>Potential Interventions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recovery as a Process</td>
<td>User-led, individual journey, based on optimism</td>
<td>Autonomy, choice, and empowerment for SUs in treatment decisions</td>
<td>Lack of autonomy for SUs, leading to feelings of disempowerment</td>
<td>Provide training for GPs aimed at enhancing GPS’ knowledge of, and attitudes towards recovery from psychosis. Training for GPs to be provided by SUs, to exemplify the need for SU input, and collaboration</td>
</tr>
<tr>
<td></td>
<td>Removal of socially constructed forms of disability</td>
<td>Less stigmatising environment of primary care</td>
<td>GPs not listening to or “fobbing off” SUs</td>
<td>Reinforce amongst GPs an awareness of the important role which primary care can play in promoting recovery</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Shift a greater degree of responsibility for recovery from psychosis to primary care from secondary care</td>
</tr>
<tr>
<td>Recovery as a Program of Care</td>
<td>Social Inclusion and Support</td>
<td>Signposting of peer-supported groups and services by GPs</td>
<td>Increase access to GPwSIs</td>
<td></td>
</tr>
<tr>
<td>-------------------------------</td>
<td>-----------------------------</td>
<td>------------------------------------------------------</td>
<td>------------------------</td>
<td></td>
</tr>
<tr>
<td>Alternatives to anti-psychotic medication</td>
<td>Enhancement of SUs’ social support networks by GPs</td>
<td>GPs lacking awareness of local groups and services</td>
<td>Raise GPs’ awareness of local services and groups by encouraging service managers and group organisers to visit GP practices</td>
<td></td>
</tr>
<tr>
<td>Whole-person approach to recovery</td>
<td>Advocacy provided by GPs, often independent from sectioning process</td>
<td>GPs lack knowledge of, confidence with, or interest in psychosis</td>
<td>Establish GP peer supervision forums</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Families of SUs and GPs work together in collaboration, often having built up a trusting relationship over time through continuity of care</td>
<td>SU disengaging from GPs or from other mental health services</td>
<td>Facilitate continuity of care within practices where feasible, paying particular attention to continuity in larger practices</td>
<td></td>
</tr>
<tr>
<td>Recovery as an Outcome</td>
<td>Eradication of symptoms</td>
<td>Cessation of substance misuse by SUs</td>
<td>Encouraging GPs to alert SUs to seriousness of potential side-effects of medication before and during treatment</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Medication compliance</td>
<td>Continued substance misuse</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Medication non compliance</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
8.3 Relevance of Conceptual Framework

A synthesised conceptual framework was employed in this PhD to inform the empirical investigation. This framework was based on four strands of thought - social constructionism, postpsychiatry, positive psychology, and autonomy enhancement. Each of these approaches was reflected to some degree in the experiences of GPs and SUs who contributed to this research.

Social constructionism argues that people construct their own beliefs and truths, and that these constructions are coloured by the experiences of those individuals themselves. Rather than there being an objective truth as modernism would purport, instead social constructionism argues that there are a myriad of subjective truths. This was reflected by the empirical data, which found that recovery in primary care was conceptualised in a number of different ways, by a number of different individual participants whose views may have been shaped by different personal experiences and professional backgrounds. Indeed, one of those reported conceptualisations of recovery explicitly referred to the personal nature of the recovery process which individual SUs may experience.

Postpsychiatry critiques mental health services which emphasise professional expertise and the application of technologies to problems, especially if this is given priority over ethical considerations. Postpsychiatry calls for an approach which considers the values of SUs and involves SUs in the development of services. Postpsychiatry was highly relevant to the findings of the empirical work of this PhD. SU-led training was identified as being an intervention in primary care which could help to enhance recovery-oriented services. Not only would this approach to training GPs involve direct SU involvement, but it would also enable GPs and SUs to work more closely and collaboratively together. The values and experiences of SUs would be expressed and communicated to GPs. These values could inform future service provision, alongside the knowledge and training which GPs already bring to primary care services.
Postpsychiatry was also found to be relevant through its identification of the role of the critical professionals’ movement in bringing about change in mental health services. It was evident from the responses of some GPwSIs that they were critical of current primary care mental health services and practices. Those GPwSIs were advocates of introducing a recovery-oriented approach to primary care on a more widespread basis, and may represent a burgeoning critical GP movement which might increase calls for further collaboration with SUs in the future.

GPwSIs, with their special interest in mental health, and their awareness of recovery-oriented services, would appear to be the most likely drivers of such change in primary care. Providing SUs with enhanced access to GPwSIs was also identified as a potential intervention which might overcome barriers to recovery in primary care.

Positive psychology was adopted as part of the conceptual framework for this PhD. As with social constructionism and postpsychiatry, it placed value on individuals’ subjective experiences. It also emphasised the importance of positive attributes at the group level, as well as at the individual level. These attributes included citizenship, responsibility, and participation in one’s own community and society. There were clear parallels with the empirical data, where recovery was viewed by many to mean enhanced social functioning. This reported social aspect of recovery included being able to participate in activities with family and peers, engaging in hobbies, education or work, and having fulfilling relationships. There was also a particular emphasis on the role of primary care in this regard. GPs were seen as a key part of the community, who were in a position to help improve the social support networks of SUs. However, it was felt that some GPs needed to be provided with more information about local services, support groups, and other activities where SUs could be signposted to. A strengths-based positive psychology approach to recovery in primary care was found to be important, and optimism was reported as being a key element of the recovery process for SUs.

The autonomy enhancement approach was the fourth strand of this PhD’s conceptual framework. In a similar manner to postpsychiatry, the autonomy enhancement approach calls for greater SU involvement and collaboration with clinicians. The input of SUs into their own care is paramount
according to this approach. This was reflected in the data, as many SUs spoke of their wish for a greater sense of autonomy over the treatment they received in primary care. SUs spoke of wanting to be listened to by the GPs instead of being “fobbed off”, which was the experience of some SUs. SUs wished for the provision of alternatives to anti-psychotic medication in primary care, especially when medication was not proving helpful. Some GPs emphasised the importance of medication compliance for achieving recovery, even if this was against the wishes of SUs. This approach ran counter to an autonomy enhancement approach. SU-led training on recovery might enable GPs to be aware of alternative primary care interventions apart from medication.

8.4 Meeting the research objectives

As previously outlined in Chapter 1, this PhD had the following objectives:

1. Explore meanings and definitions of recovery from psychosis for individual SUs.
2. Explore meanings and definitions of recovery from psychosis for individual GPs.
3. Explore SUs’ personal experiences of recovery in the context of primary care.
4. Explore GPs’ personal experiences of working with psychosis in their own practices.
5. Identify factors which promote recovery in primary care.
6. Identify factors which hinder recovery in primary care.
7. Identify potential interventions which aim to enhance the provision of GP services for SUs who have experienced psychosis.

This PhD had a number of objectives at the outset. Objectives number 1 & 2 aimed to explore the meanings and definitions of recovery from psychosis which were held by SUs and GPs respectively. This process of exploring definitions was initiated by carrying out a CIS of existing conceptualisations of recovery. The outcome of this synthesis of quantitative, qualitative, and theoretical studies was that recovery could be categorised in the following ways: recovery as an outcome, recovery as a program of care, and recovery as a personal process. For the first time, recovery as a personal process was identified as a clearly separate construct, whereas previously, constituent elements of this new construct had been included as part of “user-led” or
“psychosocial rehabilitation” notions of “recovery”. The synthesis also identified the following factors which influence how recovery is conceptualised: the personal identity/professional socialisation of those who created them, as well as the historical, cultural, and geographical environment in which they were conceptualised. The outcome of the synthesis highlighted the importance of social constructionism as a guiding theoretical framework for this PhD. This subsequently informed the choice of methodology for the collection of empirical data, as modified grounded theory was also based on a social constructionist framework.

The CIS succeeded in outlining and synthesising previous meanings and definitions of recovery from psychosis. However, a limitation of this synthesis was that previous conceptualisations did not make reference to the primary care context. This was due to a lack of previous research focusing on recovery in primary care. This PhD’s subsequent empirical work set out to redress this problem by exploring the meanings and definitions of recovery from psychosis in a primary care context, which were held by GPs and SUs. The empirical research was successful in identifying the different ways in which recovery in a primary care context could be conceptualised by GPs and SUs.

Objectives number 3 & 4 aimed to explore SUs’ personal experiences of recovery in primary care, and GPs’ personal experiences of working with psychosis in their own practices respectively. The logic underlying this was that by exploring the first-hand experiences of the research participants, it would be possible to simultaneously facilitate the identification of factors which either promoted or hindered recovery in primary care (objectives number 5 & 6). Core elements of the role of the GP were identified as central to the promotion of recovery in primary care – providing continuity of care, developing rapport, enhancing the social support networks of SUs, and supporting the families of SUs. GPs were identified as being particularly adept at promoting recovery if they displayed particular interpersonal skills such as listening respectfully and taking on-board the needs of SUs, as well as having a positive and optimistic attitude towards psychosis, and acknowledging the stigma and exclusion that many SUs had faced. However, a number of barriers to recovery in primary care were also identified – communication difficulties
at the primary/secondary care interface, differing prioritisations of medication as a treatment, the lack of confidence amongst some GPs in working with psychosis, the lack of interest in mental health amongst some GPs, and SUs reporting that had felt “fobbed off” by some GPs.

Finally, objective number 7 of this PhD aimed to identify potential interventions which might overcome barriers to recovery from psychosis, and help to promote recovery-oriented services in primary care. This objective was successfully achieved, and a number of potential interventions were identified. One potential intervention could involve user-led training in recovery from psychosis for GPs, with a particular focus on GP-SU collaboration, and changing attitudes towards psychosis. Other interventions identified included the provision of reflective peer supervision groups for GPs, and greater access to GPwSIs for SUs.

**Contribution of new knowledge to the literature**

This PhD was undertaken as a response to the perceived lack of input from primary care in providing recovery-oriented services for psychosis, as well as the lack of research on this topic to-date. This PhD aimed to address these issues by exploring the personal experiences of GPs and SUs in this area.

This PhD employed the relatively new method of the CIS, and applied it to a review of existing conceptualisations of recovery for the first time. This review of “recovery” resulted in the synthesis of a new construct - “recovery as program of care”.

The different ways in which recovery from psychosis was conceptualised in a primary care context were identified for the first time. The meanings which GPs and SUs associated with recovery in primary care were explored and identified through the empirical research carried out for this PhD.

As evidenced by the results of the literature search and the CIS, previous studies which identified factors promoting recovery and hindering recovery from psychosis, had focused on secondary
care settings. However, this PhD identified factors promoting and hindering recovery in a primary care setting for the first time. In addition, this PhD explored potential interventions aimed at promoting recovery in a primary care setting for the first time.

This PhD formulated a theoretical model of recovery from psychosis in primary care based on the empirical evidence collected for this PhD, and the themes which emerged from the data. This model identified the relationships between factors which promoted or hindered recovery from psychosis, as well as identifying potential interventions which might overcome such barriers to recovery in primary care.

This PhD has provided constructive recommendations for potential future interventions based on the collaborative discussions of GPs and SUs in mixed focus groups. It is envisaged that the future adoption of such interventions might help to further promote recovery from psychosis in primary care.

8.5 Limitations of the PhD

There were a number of limitations to this study which should be noted. Some of the limitations are present in qualitative studies generally, especially in modified grounded theory studies. These limitations will be outlined first. There were also other limitations which were specific to this PhD. These study-specific limitations will be outlined in the context of the stage of the research process to which the limitations were most relevant.

One of the most basic criticisms of qualitative research is that it cannot prove causality between two or more variables or factors. There is no statistical or quantitative basis to the findings of qualitative studies, and thus such studies are unable to prove or disprove theoretical hypotheses. This is a given for all qualitative research. This PhD involved an exploratory study rather than a hypothesis-testing one.
The CIS was employed as a means of synthesising differing conceptualisations of recovery which already exist in the literature. This PhD critiqued these previous conceptualisations of recovery, and examined how such conceptualisations were related. However, the CIS has limitations as a method for reviewing previous literature. It is created by a subjective author. Although the CIS output was grounded in evidence, differing subjective interpretations of that evidence were possible. As a result of this inherent subjectivity, CIS is not a reproducible review method. The CIS combined different conceptualisations and interpretations from previous publications which led to a synthesis of information, but also led to generalisations and a loss of the uniqueness of individual interpretations.

Researcher bias may be present in all forms of qualitative research due to the subjective nature of the qualitative research process. In line with the modified grounded theory approach (Charmaz, 2006), this PhD acknowledged the importance of researcher bias during the empirical data collection and analysis stages. Attempts were made to limit such bias, but it was also noted that systematically avoiding all bias would not be possible.

As previously discussed in Chapter 4, modified grounded theory has attracted criticism for its potential limitations. These potential limitations include the possibility that researchers might force or shoe-horn data to fit their own perspectives, the lack of prescriptive guidelines or rules for data analysis, and the denial of the existence of a single conceptual reality.

There were number of limitations specifically related to this PhD. The recruitment of GPs to the interview part of the study resulted in a large differential in response rates between GPwSIs and GPSs. The response rate to participation requests from GPwSIs was 77% (17/22), whereas the response rate from GPSs was 5% (7/148). GPs with a special interest in mental health were much more likely to participate in the research possibly because they have a greater level of interest in the research topic. Similarly, the 5% of GPSs who did respond positively to participation requests may have exhibited self-selection bias, and may also have had a greater personal interest in mental health than those GPSs who did not respond.
The difference in GP response rates may also have been partly attributable to the different recruitment methods used with the two groups. GPwSIs were invited in person by the interviewer to participate, as they were attending a master’s degree course in mental health. However, GPSs were invited by letter. In addition, GPwSIs were not required to fax or post a response sheet to the interviewer in order to confirm their interest in participation, whereas GPSs were. These considerations may have been additional psychological, physical and time barriers to participation for GPSs. GPwSIs also had more time available to participate as they were attending a university course on the day of their interview, and were not directly involved in additional time-consuming clinical work.

The sample of SUs who were interviewed only included SUs living in community settings, and no SUs currently in psychiatric wards were interviewed. This means that the sample was not representative of all SUs who have experienced psychosis. Also, the sample included a number of SUs who were involved in mental health peer support groups or user-led groups. Some user-led groups have a political or campaigning element to their ethos, which may involve a resistance to biomedical notions of mental illness. Interviewees who were involved in user-led groups may be more likely to articulate such views compared to SUs who are not involved in such groups. The inclusion of a number of participants who were involved with peer-support groups or SU-led groups may have affected the generalisability of the findings beyond the sample used in the study. However, the study also included SUs who were not involved in user-led groups. This allowed a broad range of SU perspectives to contribute to the research.

SUs who participated in the study did not have their diagnosis medically verified for the purpose of the study. SUs included in the sample either had a self-reported diagnosis of schizophrenia, a self-reported diagnosis which involved psychosis, or were living in supervised accommodation which was designed specifically for those with a psychosis-related diagnosis. These diagnoses were not verified, as it was deemed intrusive to attempt to access each SU’s medical notes. It was also felt that an attempt to access medical notes might undermine the building of trust and rapport.
between the researcher and the SU. For similar reasons, no diagnostic interview such as the “Structured Clinical Interview I for the Diagnostic and Statistical Manual of Mental Disorders-IV” was undertaken. If the interviewer could not believe a SU’s self-reported diagnosis, then it would follow that the research would be rendered less meaningful as the interviewer could not credibly believe the SU’s views on anything else, including recovery from psychosis.

The findings of the focus groups were limited by participants potentially finding it difficult to disclose sensitive personal information in a group situation. Some participants may have felt more inhibited than others and may have contributed relatively less to the discussion. This is a limitation faced by all focus group research. In addition, the potential effect of participants’ social positions on disclosure in mixed focus groups should be noted. In this PhD research, GPs may have been perceived to have had greater power due to the relative social positions of the participants. This may have led to feelings of inhibition amongst SUs. The possibility that GPs might provide socially desirable responses should also be noted. The facilitating moderator did attempt to encourage universal participation within the focus group, but there was no guarantee that this could prove to be a completely effective counter measure. However, the focus group transcripts suggested that this was not a significant problem in practice.

There were a small number of participants in the focus groups. Three GPwSIs, two GPSs, and five SUs participated in the focus groups. This made the task of differentiating results based on group identity difficult. Due to this consideration, the results of the focus group were reported for GPs as a single coherent group, rather than as two sub-groups (GPwSI and GPS). The factor primarily responsible for this problem was the practicalities of the selection process for recruiting participants to the focus groups. The focus groups required even numbers of GPs and SUs, and GPs needed to be represented in each focus group by both GPSs and GPwSIs. Seven GPSs had originally been interviewed, and all were invited back to the subsequent focus groups. Of those seven GPSs, only two were able to attend the focus groups at times and dates that also suited other participants (including GPwSIs and SUs).
The focus groups may also have been limited by the tendency of participants to avoid direct conflict during their discussions. SUs frequently criticised psychiatrists during the focus group discussions. Those criticisms appeared credible. Criticisms of GPs were much less common. This may have been due to SUs’ better experiences of receiving care from GPs, but it may have also been due to reluctance on the part of SUs to directly criticise GPs whilst in their presence. There was also a tendency amongst GPs to contrast themselves with psychiatrists. This may be a natural comparison to make, as it was comparing key medical professionals in primary and secondary mental health care. However, it may also have served as a self-protective function amongst GPs, especially if GPs noted that SUs were criticising psychiatrists. In this social scenario, psychiatrists may have provided a convenient scapegoat for both SUs and GPs.

8.6 Implications for Practice

The findings of this current study have a number of implications for future practice. The results of this PhD indicated that many GPs did not feel confident in their own knowledge and skills regarding psychosis. It was also felt that the negative attitudes of some GPs towards psychosis, and recovery from psychosis needed to be attended to. These issues were particularly problematic for GPSs. A potential future intervention for these problems was also identified during this research study. This intervention would involve the provision of training for GPs. The training would aim to enhance GPs’ knowledge of recovery from psychosis, as well as addressing negative attitudes towards psychosis and recovery. This training would be delivered by SUs who have experienced their own process of recovery from psychosis. GPs would be able to learn from SUs about what promoted and did not promote recovery from psychosis. SUs have been described as “experts by experience” (McLaughlin, 2009), and can claim to hold a particular form of expert knowledge based on one’s own experience of accessing and using health services. This SU-led training would focus primarily on primary care issues in relation to psychosis care, and would emphasise the importance of primary care to the recovery process. The training provision would be led by SUs, as this would exemplify the need for greater SU input in psychosis care and reinforce amongst GPs an awareness of the important role which primary care
can play in promoting recovery for SUs. An educational intervention for GPs relating to first episode psychosis which involved direct SU input was reported by GPs to have been a valuable opportunity to gain insight from SUs (Lester et al., 2005b).

The training would aim to address negative GP attitudes towards psychosis and recovery by bringing GPs and SUs into contact with one another, based on the contact hypothesis of Allport (1954). The contact hypothesis suggests that social contact between majority and minority group members would reduce prejudice, especially when participants have a mutual goal and are backed by institutional and social support. The resultant positive attitudes are generalised to all members of the out-group, beyond the out-group members with whom contact has occurred. However, Desforges et al. (1991) found that intergroup contact is beneficial only if participants have an opportunity to get to know one another personally, and that this contact can be facilitated through structured guided interaction which disconfirms a negative stereotype. Such an approach would be appropriate and practicable in a SU-led training scenario.

GPs’ lack of confidence in their own mental health knowledge and skills might be ameliorated by a process of knowledge sharing between GPs. The idea of having a top-down psychiatrist-led approach to training GPs in recovery from psychosis was not universally welcomed by GPs. The idea of having GP peer support groups gained more favour. Peer supervision groups are common practice in certain mental health professions, for example in clinical psychology. In primary care, Balint Groups provide a recognised model upon which psychosis peer supervision groups could be based. Balint (1957) outlined a model for postgraduate GP education which involved reflective group discussion of cases by groups of GPs or GP trainees. The Balint Group was subsequently adopted by the Royal College of General Practitioners as a key element of modern postgraduate training for GPs in the UK. These discussion groups promote “patient-centred medicine”, consist of 6-12 doctors with one or two leaders, usually last for one to two hours each, and meet regularly for one or more years. One member will volunteer to discuss a case, in the form of telling the story of their work with a patient, without case notes. The subsequent group discussion is reflective, focusing on feelings elicited in the doctor during this work, and the
relationship between the doctor and patient. Balint Groups are non-directive and GPs are not instructed by their colleagues regarding what should be done. Instead, the aim is the facilitation of GPs’ understanding of the patient under discussion.

The results of this PhD suggest that many GPs were not aware of many of the available mental health services and peer support groups for SUs in their local area. It is widely recognised that GPs generally have a busy work schedule, and find it difficult to set aside time to research the existence or the availability of such services and groups. The implication of this finding is that local service managers and group organisers might find it helpful to liaise more frequently with GPs in their area, and visit GP practices to inform them of current services. This would apply to both NHS mental health services and third sector organisations and would help GPs to be more aware of beneficial local services to which they could signpost or refer SUs. This might then increase SUs’ choice, and facilitate increased empowerment, autonomy, and support networks.

There was a desire amongst SUs generally to see GPs become more involved in psychosis care, and there was an awareness of how GPs were often in an advantageous position to promote recovery. The implication of this for practice is that SUs would ideally like to see a shift in responsibility for psychosis care from secondary care to the less stigmatised setting of primary care. This shift might entail increasing the required threshold levels for SUs to be accepted into secondary care services such as community mental health teams, in terms of symptom severity or functional impairment. Alternatively, it might mean that SUs are stepped-down to primary care services more quickly, or at a higher threshold than at present. This would lead to a greater number of SUs being seen primarily by their GP or a GPwSI. This increasingly stepped-down approach for SUs who are on a recovery pathway would tie-in with current moves towards recovery-oriented mental health services (Shepherd, Boardman & Slade, 2008) and the increased government investment in primary care mental health services as exemplified by the “Improving Access to Psychological Therapies” initiative (Department of Health, 2008).
An increased number of GPwSIs would mean that SUs would find it easier to access GPwSIs, either in the GP practice where they are registered, or in a neighbouring GP practice located within the same PCT or GP consortium. The role of the GPwSI was first formalised in 2000 with the publication of the NHS Plan (Department of Health, 2000), based on the need to take pressure off secondary care services and transfer chronic disease management to primary care. Guidelines for the appointment of mental health GPwSIs (Department of Health & Royal College of General Practitioners, 2003) specified the roles and competencies which mental health GPwSIs should have. The role was developed primarily for the assessment and treatment of common mental health problems such as depression and anxiety, although serious mental health problems such as psychosis were also covered in this document. Mental health GPwSIs are required to have knowledge, skills, and competencies which may be applied to psychosis care provision. For example, GPwSIs are required to have a “good knowledge of serious mental health problems, including assessment, treatment, and significance of Care Pathway Approach” and “knowledge of basic psychological/psychosocial skills, such as problem solving, brief intervention, motivational interviewing, basic CBT skills, working with families, behavioural therapy”, as well as attitudes in keeping with a recovery approach such as an ability to “provide patient-centred care” (p.4). Increasing the number of GPwSIs, and placing more emphasis on recovery from psychosis within the context of GPwSI-based care would be one potential method of meeting the needs of SUs as reported in this PhD. This particular approach would require training and resources to be focused on a smaller number of more specialised mental health GPs, and would not necessitate the training of all or most GPs in recovery principles. Increasing the number of GPwSIs, and improving SUs’ access to GPwSIs, might prove popular as a potentially more cost-effective approach. It might also prove more beneficial to SUs recovering from psychosis, as SUs could access a local GP who would also be highly proficient in psychosis care.

A German study has found that a brief 10 hour mental health training program for non-specialised GPs covering CBT for anxiety did not result in clinically significant or cost effective outcomes for SUs who were subsequently seen by those GPs for anxiety (König et al., 2009). Spreading mental health training resources wide and thin for GPs without a special interest in
mental health may not prove successful, particularly if the training provided is brief. The provision of training for GPwSIs might prove more cost-effective than training all GPs in recovery principles. However, it must be noted that neither approach may be as cost-effective as specialist care from hospital outpatient clinics. Coast et al. (2005) found that dermatology services provided by GPwSIs were more accessible and preferable for patients, but were not as cost-effective as specialist hospital services because patients seen in specialist clinics could be seen by junior hospital staff as well as consultants, and junior staff had lower salaries than GPwSIs.

However, in order for GPs to successfully promote recovery for SUs in primary care, a number of issues would first need to be addressed. The first three recommendations already mentioned in this section (SU-led training for GPs, Balint Group-style peer supervision, enhancing GPs awareness of available services) would need to be implemented beforehand in order for GPs to be equipped with the necessary knowledge, skills, attitudes, and support to be able to successfully promote recovery from psychosis in a primary care setting. Any shift in responsibility to primary care would need to be carefully planned and monitored. This shift in responsibility to primary care might also be facilitated by increasing the ease of access with which GPs could contact secondary care professionals such as consultant psychiatrists for advice when required as part of an approach involving consultation-liaison psychiatry. This might involve a GP having a question about a SU’s mental health and consulting with a psychiatrist. In addition, the psychiatrist might liaise between the GP and the patient. Consultation-liaison psychiatry has recently been described as follows:

“This can be consultative, collaborative, or integrated as a core feature of the care of patients being treated in the non-mental health setting. The scope necessarily includes psychiatric collaboration or integration in support of mental health care services provided in primary care and specialty care settings” (Leentjens et al., 2011)

Continuity of care was identified by both SUs and GPs as an important factor which promotes recovery in primary care. Continuity of care may have a number of meanings, so it must be made
clear that the continuity of care reported by participants in this current study referred to the continuity of care which is generally associated with primary care. The primary care conceptualisation of continuity refers to the longitudinal and personal relationship between an individual clinician and a patient, which extends beyond specific episodes of illness (Haggerty et al., 2003). This continuity is associated with an affiliation between clinician and patient, which fosters communication, trust, and a sustained sense of responsibility (Freeman & Hjortdahl, 1997). This relational continuity associated with primary care differs from the informational continuity and management continuity which is associated with the team-based structures of mental health services, where care provided by different professionals is coordinated through a common care plan. The relational and longitudinal continuity reported in this PhD was not always possible due to the inevitable geographical movement of both SUs and GPs. Another factor which was reported as a potential barrier to continuity was the size of some GP practices. Larger practices with more SUs and GPs tend to have a reduced level of continuity, as a particular GP was not always available to see a particular SU. In such cases continuity may have been traded off for access. This PhD found that continuity of care is particularly important for SUs experiencing psychosis. An implication of this finding is that recovery might be promoted more effectively in primary care, if a concerted effort to facilitate continuity of care was made for SUs experiencing psychosis. For example, a SU might be enabled to request a consultation with a specific GP.

This PhD indicated that in situations where GPs are involved in prescribing or maintaining anti-psychotic medications, all GPs should be encouraged to alert SUs to the potential severity of side-effects, both before and during medication-based treatment. GPs could be encouraged to emphasise the potential seriousness of side-effects during SU-led recovery training. Previous research on the views of SUs regarding anti-psychotic medication has found that SUs believe that there is an overuse of medication in the psychiatric treatment of psychosis (Rogers & Pilgrim, 1993).

8.7 Implications for Future Research
The findings of this PhD have a number of implications for future research in the area of recovery from psychosis in primary care settings. These implications are outlined below:

This PhD investigated the viewpoints of GPs and SUs regarding recovery from psychosis in primary care. Primary care mental health services are provided by other health professionals in addition to GPs, for example by practice nurses, clinical psychologists, high intensity CBT therapists, counsellors, and psychological wellbeing practitioners. All of these professionals could be asked to participate in future research, so that their experiences of promoting recovery from psychosis in primary care may be explored. Psychiatrists, CPNs, social workers, and other care coordinators working in secondary care services might also be asked to provide their perspectives on recovery from psychosis in primary care, as they constitute a key element of psychosis care provision in the NHS.

This PhD was exploratory and hypothesis-building. However, further research is required to test the hypothesis of the working model which resulted from this PhD. As this PhD involved a qualitative investigation, further quantitative research might assess the potential correlational or causal relationships between recovery processes or recovery outcomes and the factors which were reported to either promote or hinder recovery. A correlational study would involve the observation of naturally-occurring bivariate relationships between promotional factors or barriers on the one hand, and recovery outcomes or processes on the other. Recovery in these future studies might be operationalised according to any or all of the different conceptualisations reported here. A factor analysis might be conducted to assess the degree to which elements or factors are loaded onto each conceptualisation of recovery.

A number of potential interventions were reported in this PhD. These interventions could be piloted to assess their efficacy and acceptability to both SUs and professionals in primary care. The list of potential interventions include: SU-led training in recovery from psychosis for GPs; increasing access to peer supervision groups for GPs; managers of organisations which provide
services for psychosis visiting GPs more frequently to raise awareness of those services amongst GPs; increasing numbers of GPwSIs; improving access to consultant psychiatrists for GPs through consultation liaison schemes; enhancing continuity of care especially in larger GP practices; and the flagging of the potential seriousness of side-effects associated with anti-psychotic medication in advance of prescription by GPs. Each of these interventions could initially be run as small-scale pilots. If some or all of these pilots proved successful, it might then be possible to run larger follow-up trials to assess the impact of such interventions. It is important to note the multitude of factors reported by participants as having an important impact on recovery from psychosis in primary care. The complex interaction of factors, as well as the importance of context, means that complex interventions involving several components will be required (Medical Research Council, 2000). A phased approach to the development and evaluation of such complex interventions has previously been suggested (Campbell et al., 2000). According to this phased approach, the first stages of developing complex interventions involve examining the existing theory, followed by identifying the components of the intervention. This could then followed by exploratory trials, definitive randomised controlled trials, and long term implementation.

8.8 Implications for Policy

The findings of this PhD will now be discussed in terms of implications for future healthcare policy, particularly in the context of the UK Government’s and the Department of Health’s recent policy proposals.

Health and Social Care Bill (2011)
The UK Coalition Government published a White Paper called “Liberating the NHS: Equity and Excellence” (Department of Health, 2010). This set out the Department of Health’s plans for changing the way NHS services are commissioned. Following on from the publication of the White Paper, the Government outlined draft proposals for legislation in the form of the “Health
and Social Care Bill” (Department of Health, 2011a), which reiterated the White Paper’s proposals.

The first stated goal of the White Paper was for patients to have more choice and control over their own treatment. The policy’s emphasis on patients having greater informed choice and control over their own healthcare decisions is congruent with the findings of this PhD. This PhD found that SUs would welcome greater control over their own care regarding primary care psychosis services, and the recovery model promotes such an approach. The Government’s policy aim of improving SU patient choice and control may be welcomed by SUs based on a straightforward initial assessment of the policy document. The current policy climate suggests that the findings of the present research may be acceptable to healthcare policy-makers, commissioners, and providers, as the research reports that SUs would like greater input into decision-making about psychosis in primary care.

The second aim of the Government’s White Paper reform proposals was to ensure that the measurement of success would be focused on clinical outcomes rather than process targets. This aim is very broad and sweeping in terms of how it was expressed in the White Paper. If this approach is to be applied to all areas of health care, including psychosis, then it would mean that success would be defined by clinical outcomes. This raises the question regarding what the clinical outcomes for psychosis might be. The conceptual framework of this PhD has shown that the way in which recovery or success is defined depends on who you ask. The social, cultural, and historical context in which such clinical outcomes are defined are also important in shaping definitions. The White Paper’s rejection of “bureaucratic” process targets may be partly based on the frustration of healthcare professionals and managers with such targets (Cosker, 2004). However, it should be noted that some SUs in this PhD valued the process associated with recovery, more than recovery as a measurable clinical outcome. The value of the journey or the process of recovery may not be taken account of if the White Paper’s proposals are implemented. The clinical outcomes that are to be measured have not been specified for individual diagnoses or problems. The White Paper explicitly states that mental health outcomes may require different
criteria from physical health clinical outcomes, and this also reflects the findings of this PhD. The inclusion of criteria such as "patient-reported outcomes" and "the broader experience patients have of the treatment and care they receive" would allow SUs accessing primary care psychosis care to communicate their personally-defined outcomes and experiences, in line with the desires of SUs as expressed in the findings of this PhD (p.22).

The White Paper proposes that the control of healthcare budgets and the responsibility for commissioning services would be shifted to GP consortia, and that PCTs and Strategic Health Authorities would be disbanded. As a result of this, GPs would have direct control over commissioning services from secondary care providers. There would be an increased onus on GPs, practice managers, and the decision-making boards of GP consortia to be aware of the needs of SUs experiencing psychosis. The potential introduction of GP commissioning to the NHS increases the need for GPs to have the knowledge and attitudes which best help to promote recovery for SUs experiencing psychosis. This would allow GPs to commission services with the best interests of SUs experiencing psychosis in mind. GP consortia would also have the power to fund training programs for GPs regarding psychosis and recovery.

A recent survey of 500 GPs found that only 31% of GPs felt prepared to take on commissioning for mental health services compared to 75% for diabetes and asthma (Rethink, 2010). In addition, 42% of GPs reported that they lacked knowledge about specialist services needed for people with psychosis. A GP “pathfinder” consortium in Ipswich called Ipscom has already begun training all their GP practices in issues related to mental health, including alcohol screening and an emotional planning program for children with conduct disorder (Snell, 2011). This is part of Ipscom’s attempt to upskill GPs, so that GPs have the skills to commission mental health services. This indicates that there is scope for the implementation of SU-led training in recovery from psychosis across GP practices in each GP consortium. This training would impact on the care SUs receive directly in primary care from GPs, as well as the services available to SUs in secondary care where services would also be commissioned by GPs. There is also scope for increasing the numbers of GPwSIs as a result of the commissioning proposals, as a substantial majority of GPs
(63%) want each GP consortium to have a mental health lead (Rethink, 2010). The provision of mental health leads for each GP consortium would help promote a recovery agenda within primary care. The greater collaboration between practices as a result of being part of a single consortium might also promote the possibility of sharing skills and sharing GPwSI provision across practices.

A shift to primary care was reported as being an element of a preferred approach to recovery for SUs in this PhD. There are indications that current policy may also be moving in this direction. For example, the Joint Commissioning Panel for Mental Health (2011) stated that one likely consequence of GP commissioning would be a shift in responsibility for mental health services and psychosis care from secondary care to primary care. In addition to this shift to primary care, the Joint Commissioning Panel for Mental Health (2011) also identified the need for a greater focus on recovery, and the promotion of independence and choice. Again, these were also issues highlighted by the findings of this PhD.

As well as providing opportunities for promoting recovery from psychosis in primary care settings, the commissioning reforms also contain potential threats to promoting recovery within primary care. For example, the Rethink (2010) survey found that 31% of GPs believe mental health services are most at risk of cuts. This indicates that GPs may not prioritise mental health services when making commissioning decisions. In addition, more than half of GPs (54%) said they found people with severe mental illness hardest to engage with. GPs’ negative attitudes towards SUs, or negative experiences with SUs, might hinder the promotion of recovery in primary care, and underlines the need for training aimed at addressing the attitudes of GPs.

*Mental Health Strategy (2011)*

The Department of Health’s “Mental Health Strategy” (2011) does not frequently refer to potential role of primary care in providing services for psychosis. This is an important omission to note, as it may reflect a lack of recognition of primary care’s potential amongst policy-makers. However, the “Mental Health Strategy” does aim to address, in a more general sense, many of the
barriers to recovery from psychosis which were reported in the findings of this PhD. For example, the current Governmental mental health policy calls for a greater emphasis on approaches which support choice, personalised care, and recovery. It also envisages more decisions about people's mental health will be made locally, which reflects the findings of this PhD.

The policy document also aims to create a situation where mental health is given parity of esteem alongside physical health. The policy also acknowledges that this will require a change in public and professional attitudes, and a reduction in institutionalised discrimination. The recognition that the negative attitudes of some health professionals towards mental health need to be addressed echoes the findings of this PhD regarding the attitudes of some GPs.

The “Mental Health Strategy” also points towards the need for SUs experiencing severe mental health problems to receive care in the least restrictive environment possible. Again, this potentially allows for SUs to receive high quality care and treatment in the less stigmatised, less restrictive and more accessible setting of GP practices.

Importantly, the “Mental Health Strategy” recognised the difficulties that some SUs have experienced in terms of effectively transferring between services when required, and in terms of organisational barriers encountered. This aim of the policy reflects the findings of this PhD regarding problems in communication across the primary/secondary care interface, and the problem of the ensuring of continuity of care within GP practices.

“Services should be designed around the needs of individuals, ensuring appropriate, effective transition between services when necessary, without age-based, professional or organisational barriers and attitudes getting in the way” (p.26).

The “Mental Health Strategy” recognised the important knowledge and understanding of psychosis and other mental illnesses which GPs already have, particularly in the context of issues
facing the local population. According to the Strategy, GP consortia are perceived to be well placed to understand the mental health problems experienced by people in the local community. The commissioning role of GP is anticipated to facilitate greater communication between GPs, secondary care professionals, SUs, and families regarding what works best for all stake-holders in mental health services.

Although the Government’s current mental health policy does not specifically refer to the role of primary care in promoting recovery from psychosis, the most recent policy document does highlight the important roles which GPs may have regarding the commissioning and provision of mental health services. It also highlights a number of general barriers to promoting mental well-being, which this PhD found to be specifically applicable to promoting recovery from psychosis in a primary care setting.

Conclusion

This PhD began with the idea of exploring how a recovery approach to psychosis might be applied to primary care settings. GPs and SUs were asked to contribute their conceptualisations of recovery, and how recovery could be promoted or hindered in primary care settings. The analysis of the empirical data has highlighted the complex nature of the issues involved in promoting recovery in primary care. The number of factors involved, as well as the number of existing barriers to recovery, may pose a daunting prospect for clinicians and policy-makers to overcome. Fortunately, the theoretical model generated by this PhD, does clearly map out the interventions which may be required to overcome such obstacles. None of the barriers to implementing a recovery approach in primary care appear insurmountable. Perhaps these barriers require a step-by-step approach, addressing one barrier at a time. The findings of this PhD have shown that primary care does have an important role to play in promoting recovery from psychosis, and the lives of SUs could be enhanced if such a recovery approach was adopted in those settings.
REFERENCES


Crossley, M. (2002). ‘Could you please pass one of those health leaflets along?’: exploring health, morality, and resistance through focus groups. *Social Science and Medicine, 55*, 1471-1483.


Kitzinger J. (1994). The methodology of focus groups: the importance of interaction between research participants. *Sociology of Health, 16*(1), 103-21.


Snell, J. (2011). Can GP consortiums benefit services? Examining if these early 'pathfinders' have the skills to commission mental health services. *The Guardian Newspaper, 6 April 2011*.


APPENDIX 1
NICE GUIDANCE ON SCHIZOPHRENIA (2009)

1. Develop and use practice case registers to monitor the physical and mental health of people with schizophrenia in primary care.

2. GPs and other primary healthcare professionals should monitor the physical health of people with schizophrenia at least once a year. Focus on cardiovascular disease risk assessment as described in 'Lipid modification' (NICE clinical guideline 67) but bear in mind that people with schizophrenia are at higher risk of cardiovascular disease than the general population. A copy of the results should be sent to the care coordinator and/or psychiatrist, and put in the secondary care notes.

3. People with schizophrenia at increased risk of developing cardiovascular disease and/or diabetes (for example, with elevated blood pressure, raised lipid levels, smokers, increased waist measurement) should be identified at the earliest opportunity. Their care should be managed using the appropriate NICE guidance for prevention of these conditions.

4. Treat people with schizophrenia who have diabetes and/or cardiovascular disease in primary care according to the appropriate NICE guidance.

5. Healthcare professionals in secondary care should ensure, as part of the CPA, that people with schizophrenia receive physical healthcare from primary care as described in recommendations 1–4.

6. When a person with an established diagnosis of schizophrenia presents with a suspected relapse (for example, with increased psychotic symptoms or a significant increase in the use of alcohol or other substances), primary healthcare professionals should refer to the crisis section of the care plan. Consider referral to the key clinician or care coordinator identified in the crisis plan.

7. For a person with schizophrenia being cared for in primary care, consider referral to secondary care again if there is:
   • poor response to treatment
• non-adherence to medication
• intolerable side effects from medication
• comorbid substance misuse
• risk to self or others.

8. When re-referring people with schizophrenia to mental health services, take account of service user and carer requests, especially for:
• review of the side effects of existing treatments
• psychological treatments or other interventions.

9. When a person with schizophrenia is planning to move to the catchment area of a different NHS trust, a meeting should be arranged between the services involved and the service user to agree a transition plan before transfer. The person’s current care plan should be sent to the new secondary care and primary care providers.
APPENDIX 2
DATABASES USED IN LITERATURE SEARCH

The following databases were searched using **OVID**:

- ACP Journal Club
  1991 - August 2007
- Cochrane Central Register of Controlled Trials
  1991 – August 2007
- Cochrane Database of Systematic Reviews
  1991 – August 2007
- Database of Abstracts of Reviews of Effects (EBM Reviews)
  1991 – August 2007
- AMED (Allied and Complementary Medicine)
  1985 – August 2007
- British Nursing Index and Archive
  1985 – August 2007
- CINAHL (Cumulative Index to Nursing & Allied Health Literature)
  1982 – August 2007
- EMBASE
  1980 – August 2007
- Health and Psychosocial Instruments
  1985 – August 2007
- HMIC Health Management Information Consortium
  September 2007
- International Pharmaceutical Abstracts
  1970 – August 2007
- MEDLINE
  1950 – August 2007
- MEDLINE In-Process & Other Non-Indexed Citations
Similarly, **ISI Web of Science** was used to access the following databases:

- Science Citation Index Expanded
  1945 – August 2007
- Social Sciences Citation Index
  1956 – August 2007
- Arts and Humanities Citation Index
  1975 – August 2007
APPENDIX 3
PAPERS INCLUDED IN THE CIS

Quantitative Studies

1. Harrison et al. (2001)
“Recovery from psychotic illness: a 15- and 25-year international follow-up study”
British Journal of Psychiatry

This is an extensive research study undertaken into schizophrenia outcomes world-wide. It is a cross-cultural study. It was funded by the WHO and was published in a high impact journal. It generally adopts a clinical/biomedical theoretical framework in its approach to recovery. This paper is frequently cited in research papers in the area of recovery from psychosis.

“Do Patients with Schizophrenia Ever Show Periods of Recovery? A 15-Year Multi-Follow-up Study”
Schizophrenia Bulletin

This paper was chosen as it is a recent empirical study of long-term recovery outcomes for patients with schizophrenia. It a longitudinal study spanning 15 years and also adopts a clinical/biomedical framework.

Qualitative Studies

3. Ng, Pearson, Lam, Law, Chiu, Chen (2008)
“What does recovery from schizophrenia mean? Perceptions of long-term patients”
International Journal of Social Psychiatry
This paper was chosen because it is a study of the meaning of recovery from schizophrenia from the perspective of Chinese SUs.

“An empirical conceptualization of the recovery orientation”
Schizophrenia Research

This research study was chosen because it is an empirical investigation of what the recovery orientation consists of. SUs were surveyed and four components of recovery were identified through a confirmatory factor analysis: empowerment, hope, knowledge, and life satisfaction.

5. Lester, Tritter, Sorohan (2005a)
“Patients’ and health professionals’ views on primary care for people with serious mental illness: focus group study”
British Medical Journal

This paper was chosen as it includes research about psychosis in a primary care setting. It includes the views of both SUs and professionals. Some of these views are implicitly related to either the user-led or the biomedical models of recovery from psychosis. This research paper was published in a high impact journal.

“The importance of personal medicine: A qualitative study of resilience in people with psychiatric disabilities”
Scandinavian Journal of Public Health

This paper was chosen as it is written by a renowned expert on user-led perspectives regarding recovery from psychosis. The author is a SU, a clinical psychologist, and an academic. The focus of the study is user-defined perspectives on recovery.
7. **Ridgway (2001)**

“ReStorying Psychiatric Disability: Learning from First Person Recovery Narratives”
Psychiatric Rehabilitation

This paper was chosen because it examines first person accounts of recovery from psychiatric disability. Four service-users’ narratives were examined, and were used as the basis for the development of a user-led perspective on what recovery entails.

**Theoretical Papers**

8. **Davidson, Schmutte, Dinzeo, Andres-Hyman (2008)**

“Remission and Recovery in Schizophrenia: Practitioner and Patient Perspectives”
Schizophrenia Bulletin

This is a theoretical article which explores the concepts of “remission”, “being in recovery”, and “recovery from” schizophrenia. It traces the history of these notions and investigates them from both practitioner and patient perspectives. This paper was also chosen because it was published very recently (i.e. 2008), and so includes the most up-to-date research.


“Scientific and Consumer Models of Recovery in Schizophrenia: Concordance, Contrasts, and Implications”
Schizophrenia Bulletin

This is a theoretical article looking at different notions of recovery in schizophrenia. It was chosen because it examines scientific and user-led concepts of recovery, and possibilities for integration of user-led notions of recovery with evidence-based practice are explored.
“The process of recovery from schizophrenia”
International Review of Psychiatry

This paper was chosen to represent psychosocial approaches to recovery. One of the authors (Anthony) is frequently cited in articles related to recovery from psychosis, as a previous paper of this author (Anthony, 1993) has been credited with presenting one of the most widely accepted definitions of “recovery” based on a psychosocial rehabilitation perspective.

“The rediscovery of recovery: open to all”
Advances in Psychiatric Treatment

This article was chosen as it is a theoretical paper from a UK perspective. It examines different definitions of recovery, how recovery might be measured, and what a recovery-based service might look like.

“Rethinking Social Recovery in Schizophrenia: What a Capabilities Approach Might Offer”
Social Science and Medicine

This paper was chosen as it represents an anthropological view of recovery. This paper is critical of the user-led recovery perspective, and offers an alternative theoretical framework – a “capabilities” approach.

“Recovery from mental illness as an emergent concept and practice in Australia and the UK”
International Journal of Social Psychiatry
This theoretical paper was chosen because it looks at the history of how a user-led model of recovery grew in popularity in Australia and in the UK, in terms of both policy and practice. The advantages and disadvantages of the model are examined. It is written from the perspective of a social worker.

“Recovery from schizophrenia and the role of evidence-based psychosocial interventions”
Expert Review of Neurotherapeutics

This paper was chosen as it represents the psychosocial view of recovery from psychosis, and it presents possible evidence-based psychosocial interventions.

“Patients-reported outcomes in schizophrenia”
British Journal of Psychiatry

This paper was chosen because it is a review of the various different concepts which have been measured as a part of patient-reported outcomes in schizophrenia. “Recovery” is one of the outcome concepts included in this review. The journal is also a high impact one.

“Implementing Recovery Oriented Evidence Based Programs: Identifying the Critical Dimensions”
Community Mental Health Journal

This theoretical paper was chosen because it attempts to conceptualise the specifics of what a recovery-oriented mental health program might entail.
APPENDIX 4
CIS FINDINGS: OUTPUT TABLE

The details of the 16 papers in the CIS are included here. The table below outlines the methodological approaches, authors’ backgrounds, first/second order, and third order “recovery” constructs of each paper, as well as the implications of the synthesised findings for future research and applied purposes.

<table>
<thead>
<tr>
<th>Methodological Approach</th>
<th>Authors’ Backgrounds</th>
<th>Constructs of recovery as described by the authors’ of each paper (these are first order constructs if described directly by SUs or health professionals, and are second order constructs if described by social scientists)</th>
<th>Third order constructs for recovery identified (with parallel constructs in terms of general theoretical orientation, in brackets)</th>
<th>Implications for future research</th>
<th>Implications for future educational interventions aimed at GPs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Harrison et</td>
<td>International</td>
<td>Principal</td>
<td>- Absence of symptoms</td>
<td>Recovery as</td>
<td>Inform GPs on</td>
</tr>
<tr>
<td>Study</td>
<td>Design</td>
<td>Investigator Details</td>
<td>Outcome Focus</td>
<td>Importance of Conceptualisation</td>
<td></td>
</tr>
<tr>
<td>------------------------</td>
<td>---------------------------------</td>
<td>--------------------------------------------------------------------------------------</td>
<td>---------------------------------------------------</td>
<td>---------------------------------</td>
<td></td>
</tr>
<tr>
<td>al. (2001)</td>
<td>Longitudinal outcome study using 18 different cohorts</td>
<td>Investigator is a psychiatrist based in the UK. Second author is an anthropologist based in the USA. Individual studies mostly undertaken by psychiatrists based in each locality.</td>
<td>Absence of social disability</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>an <strong>Outcome</strong> (Biomedical)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
| Harrow, Grossman, Jobe, Herbener (2005) | Longitudinal outcome study | Three clinical psychologists and a medical doctor based in the USA. | Absence of symptoms  
- No psychiatric rehospitalisation  
- Adequate psychosocial functioning | Recovery as an **Outcome** (Biomedical)  
Explore the opinions of GPs and SUs regarding the usefulness of conceptualising recovery as an outcome where absence of symptoms/social disability are measured, particularly in a primary care context. | Inform GPs on SUs opinions regarding the conceptualisation of recovery as an outcome. |
| **Ng, Pearson, Lam, Law, Chiu, Chen (2008)** | Focus group was carried out with 8 SUs, and different dimensions of recovery were generated | Five psychiatrists and one social worker, all based in Hong Kong | - Cessation of antipsychotic medication  
- Disappearance of symptoms  
- Employment  
- Good familial relationships  
- Independent living | Recovery as an **Outcome** (User-led) | Inform GPs on SUs opinions regarding the conceptualisation of recovery as an outcome where absence of symptoms, cessation of medication, employment, rehospitalisations, and psychosocial functioning are measured | Outcome where absence of symptoms, rehospitalisations, and psychosocial functioning are measured |
| **Resnick, Fontana, Lehman, Rosenheck (2005)** | Surveys covering 1076 SUs were analysed, identifying any items which reflected recovery themes | Two psychologists, a medical doctor and a psychiatrist, all based in the USA | (A) - Belief that hope for the future can be developed - Participate in meaningful activities - Exercise self-determination - Live in a society without stigma and discrimination - Development of spirituality - A sense of identity - Choice - Social relationships - Availability of peer support - Feelings of independence and (B) | Recovery as a **Personal Process** (Psychosocial Rehab, User-led) | Explore the opinions of GPs and SUs regarding the usefulness of conceptualising recovery as a personal process with an emphasis on hope for the future, participation in meaningful activities, and exercising self-determination | Inform GPs on SUs opinions regarding the conceptualisation of recovery as a personal process with an emphasis on hope for the future, participation in meaningful activities, and exercising self-determination |

| **Employment, familial relationships and independence of living** | **are noted** | **are noted** | **are noted** | **are noted** | **are noted** | **are noted** | **are noted** | **are noted** | **are noted** |

"Resnick, Fontana, Lehman, Rosenheck (2005)" Surveys covering 1076 SUs were analysed, identifying any items which reflected recovery themes. Two psychologists, a medical doctor and a psychiatrist, all based in the USA, explored the opinions of GPs and SUs regarding the usefulness of conceptualising recovery as a personal process with an emphasis on hope for the future, participation in meaningful activities, and exercising self-determination.
autonomy

- Supported employment may promote empowerment
- Peer supported services may help to foster hope
- Assertive community treatment which may help consumers maximise their housing opportunities
- Family psycho-education may improve life satisfaction

Recovery as a Program of Care
(Psychosocial Rehab, User-led)

Explore the opinions of GPs and SUs regarding the usefulness of conceptualising recovery as a program of care including supported employment, peer support, assertive community treatment and family psycho-education

Inform GPs on SUs opinions regarding the conceptualisation of recovery as a program of care including supported employment, peer support, assertive community treatment and family psycho-education

Lester, Tritter, Sorohan

Focus group

GP, sociologist and SU in the

- Enabling patient choice in treatments
- Offering talking and alternative

Recovery as a Program of Care (User-

Explore the opinions of GPs and SUs regarding

Inform GPs on SUs opinions regarding the
<table>
<thead>
<tr>
<th>Year</th>
<th>Method</th>
<th>Country</th>
<th>Key Findings</th>
<th>Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>(2005)</td>
<td>Participatory action design was used to analyse 29 interviews with SUs/“survivors”</td>
<td>UK</td>
<td>Therapies as well as medication - Discussing future educational and work opportunities - Support from family, friends, and other patients - GPs were found to perceive psychosis as a lifelong condition, whereas SUs emphasised the importance of optimism and hope for recovery</td>
<td>the usefulness of conceptualising recovery as a program of care in which patient choice is enabled, talking therapy is offered, optimism/hope is emphasised, and future work and education options are discussed</td>
</tr>
</tbody>
</table>

Deegan (2005) | Clinical psychologist/ex-SU in the USA | - Unique process for each person - Activities that give life meaning and purpose - Activities that raise self-esteem - Activities that decrease symptoms | Recovery as a Personal Process (User-led) | Explore the opinions of GPs and SUs regarding the usefulness of conceptualising recovery as a personal process |

Inform GPs on SUs opinions regarding the conceptualisation of recovery as a personal process |
| **Ridgway (2001)** | Examined four women’s first-hand accounts of psychiatric disability and recovery. Common themes and patterns identified. Grounded theory developed | A social worker/ex-SU based in the USA | - Activities that avoid unwanted outcomes such as hospitalization | - Reawakening of hope after despair  
- Breaking through denial and achieving understanding and acceptance  
- Moving from withdrawal to engagement and active participation in life  
- Active coping rather than passive adjustment  
- No longer viewing oneself primarily as a person with a personal process  
with an emphasis on activities that give meaning, raise self-esteem and decrease symptoms | Inform GPs on SUs opinions regarding the conceptualisation of recovery as a personal process emphasising reawakening of hope, active participation in life, reclaiming a positive sense of self, and moving |
psychiatric disorder and reclaiming a positive sense of self
- Moving from alienation to a sense of meaning and purpose
- A complex and nonlinear journey
- Not accomplished alone, the journey involves support and partnership

| Recovery as a Program of Care (User-led) | Explore the opinions of GPs and SUs regarding the usefulness of conceptualising recovery as a program of care which amplifies resilience and is | Inform GPs on SUs opinions regarding the conceptualisation of recovery as a program of care which amplifies resilience and is |

(B) - Helping systems can which amplify resilience and support recovery
- Avoid socially segregated programs which serve as entrapping niches that reinforce social stigma, reduce access to self, and moving from alienation to a sense of meaning and purpose from alienation to a sense of meaning and purpose
<table>
<thead>
<tr>
<th><strong>Davidson, Schmutte, Dinzeo, Andres-Hyman (2008)</strong></th>
<th>Theoretical paper</th>
<th>Four clinical psychologists in the USA</th>
<th>normative feedback and resources, encourage passive adjustment, and solidify social withdrawal</th>
<th>resilience and is not socially segregated</th>
<th>not socially segregated</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Bellack (2006)</strong></td>
<td>Theoretical paper</td>
<td>Clinical psychologist based in the USA</td>
<td>Recovery as a <strong>Personal Process</strong> (User-led)</td>
<td>Explore opinions of GPs and SUs regarding the usefulness of conceptualising recovery as a personal process which includes a self-determined pursuit of dignified and meaningful life in a community</td>
<td>Inform GPs on SUs opinions regarding the conceptualisation of recovery as a personal process which includes a self-determined pursuit of a dignified and meaningful life in a community</td>
</tr>
<tr>
<td>USA</td>
<td>(SU)</td>
<td>Recovery as a Program of Care (User-led)</td>
<td>the usefulness of conceptualising recovery as a program of care which is characterised by an emphasis on a user-led personal process which is non-linear, strengths-based, person-centred, and supported by peers</td>
<td>conceptualisation of recovery as a program of care which is characterised by an emphasis on a user-led personal process which is non-linear, strengths-based, person-centred, and supported by peers</td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td></td>
</tr>
<tr>
<td>- Individualized and person-centered</td>
<td>- Holistic: mind, body, spirit, and community</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Empowered consumers exercising choice</td>
<td>- Nonlinear: not a step-by-step process</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Holistic: mind, body, spirit, and community</td>
<td>- Strengths-based</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Nonlinear: not a step-by-step process</td>
<td>- Peer support</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Strengths-based</td>
<td>- Respect: Community, systems, and societal acceptance and appreciation of consumers</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Peer support</td>
<td>- Consumers have personal responsibility for their own self-care and journeys of recovery.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Respect: Community, systems, and societal acceptance and appreciation of consumers</td>
<td>- Motivating message that people can and do overcome barriers</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Consumers have personal responsibility for their own self-care and journeys of recovery.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Spaniol, Wewiorski, Gagne, Anthony (2002)</strong></td>
<td>Open-ended interviews with 12 SUs were conducted every four to eight months over a period of four years</td>
<td>Four psychologists in the USA</td>
<td>Recovery as a <strong>Personal Process</strong>/Recovery as a <strong>Program of Care</strong> (User-led, Psychosocial Rehab)</td>
<td>Explore the opinions of GPs and SUs regarding the usefulness of conceptualising recovery as a personal process of emotional and physical healing, developing new meaning and purpose in one’s life, developing explanatory frameworks for understanding psychosis, and moving into productive and valued by society</td>
<td>Inform GPs on SUs opinions regarding the conceptualisation of recovery as a personal process of emotional and physical healing, developing new meaning and purpose in one’s life, developing explanatory frameworks for understanding psychosis, and moving into productive and valued by society</td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td></td>
<td>- A process of healing physically and emotionally, of adjusting one’s attitudes, feelings, perceptions, roles and goals in life</td>
<td>- The development of new meaning and purpose in one’s life. This represents a holistic approach to recovery</td>
<td>- Developing an explanatory framework for understanding the psychosis experience</td>
<td>- Getting some control over the illness itself</td>
<td>- Moving into roles that are meaningful, productive and valued by society</td>
</tr>
<tr>
<td>Author(s)</td>
<td>Type</td>
<td>Setting</td>
<td>Description</td>
<td>Inform GPs on SU's opinions regarding the conceptualisation of recovery as a personal process of discovering how to live with enduring symptoms</td>
<td></td>
</tr>
<tr>
<td>-----------------</td>
<td>-----------------</td>
<td>-----------------------------</td>
<td>-----------------------------------------------------------------------------</td>
<td>-----------------------------------------------------------------------------------------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td>Roberts, Wolfson (2004)</td>
<td>Theoretical paper</td>
<td>Two consultant psychiatrists based in the UK</td>
<td>(A) - A process of personal discovery, of how to live (and to live well) with enduring symptoms and vulnerabilities</td>
<td>Recovery as Personal Process (User-led) Explore the opinions of GPs and SU's regarding the usefulness of conceptualising recovery as a personal process of discovering how to live with enduring symptoms</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>(B) - Shift of professional’s role from authority to coach</td>
<td>Recovery as a Program of Care (User-led) Explore the opinions of GPs and SU’s regarding the usefulness of conceptualising recovery as a program of care</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>- Focus on significance of hope and optimism</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>- Medication based on choice, not compliance</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
| - Right to failure and dignity of risk embraced  
| - Promote self-management  
| - Hospital should be a “springy safety net”, not necessitating “long-term involvement and monitoring” after a crisis has been resolved  
| - Patient is an expert in their own experience  
| - Value ethnicity and diversity  
| - Supported employment schemes available  
| - Doctors should communicate in accessible language.  |

| emphasising the GP’s role as that of a coach, and the SU as an expert in their own experience, focusing on hope and optimism, medication based on choice, the right of the SU to fail, self-management, valuing diversity, making supported employment available, and GPs communicating in accessible language  |

| GP’s role as that of a coach, and the SU as an expert in their own experience, focusing on hope and optimism, medication based on choice, the right of the SU to fail, self-management, valuing diversity, making supported employment available, and GPs communicating in accessible language  |
| **Hopper (2007)** | Theoretical paper | Medical anthropologist based in the USA | **(A)** - Rebuilding a functional self—a person apart from the reality of illness  
- Persisting sense of casualty may do daily battle with a struggling sense of agency  
- Transformation may be spiritual for some | Recovery as a **Personal Process** (User-led) | Explore the opinions of GPs and SUs regarding the usefulness of conceptualising recovery as a personal process where a functional self is rebuilt, and transformation may be spiritual | Inform GPs on SUs opinions regarding the conceptualisation of recovery as a personal process where a functional self is rebuilt, and transformation may be spiritual |

<p>| <strong>(B)</strong> - Social recovery consists of independent living and gainful employment | Recovery as an <strong>Outcome</strong> (Psychosocial Rehab) | Explore the opinions of GPs and SUs regarding the usefulness of conceptualising recovery as an outcome which consists of independent living | Inform GPs on SUs opinions regarding the conceptualisation of recovery as an outcome which consists of independent living |</p>
<table>
<thead>
<tr>
<th><strong>Ramon, Healy, Renouf (2007)</strong></th>
<th>Theoretical paper</th>
<th>One social worker/clinical psychologist based in the UK, and two social workers based in Australia</th>
<th>(A) - Not about returning to pre-illness state - Forging a new way of living controlled by the newly found self-agency of users - Recovery is from the trauma of psychosis, treatment, stigma, lack of skills and opportunities for valued activities - Inter-dependency with other users, and self-help - Hope is a core component - Developing one’s own coping strategies - Systematic effort, with risk</th>
<th>Recovery as a <strong>Personal Process</strong> (User-led)</th>
<th>independent living and gainful employment</th>
<th>and gainful employment</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Explore the opinions of GPs and SUs regarding the usefulness of conceptualising recovery as a personal process in which emphasises self-agency, forging a new way of life, hope, developing one’s own coping strategies, systematic effort, risk taking, the right to fail, and a</td>
<td>Inform GPs on SUs opinions regarding the conceptualisation of recovery as a personal process in which emphasises self-agency, forging a new way of life, hope, developing one’s own coping strategies, systematic effort, risk taking, the right to fail, and a</td>
</tr>
</tbody>
</table>
taking
- Right to fail
- Term “recovery” partly created and adopted by SUs, and has transformative implications
- Move from a deficit to a strengths model

right to fail, and a movement from a deficit model to a strengths model

<table>
<thead>
<tr>
<th>(B)</th>
<th>Early and active use of medication</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Psychosocial interventions</td>
</tr>
<tr>
<td></td>
<td>Attending to individuals’ social and cultural environments</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Recovery as a Program of Care (Psychosocial Rehab)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Explore opinions of GPs and SUs regarding the usefulness of conceptualising recovery as a care program including early and active use of medication, psychosocial interventions, and attending to</td>
</tr>
</tbody>
</table>

Inform GPs on SUs opinions regarding the conceptualisation of recovery as a program of care including early and active use of medication, psychosocial interventions, and attending to
<p>| <strong>Corrigan (2006)</strong> | Theoretical paper | Clinical psychologist based in the USA | (A) - Focus on the future, psychological well-being, personal empowerment, and goal orientation - Concerned with sense of meaning in life and personal comfort rather than being symptom free and without disabilities - Validation of personhood - Recognition of common humanity - Tolerance for individual differences | Recovery as a Personal Process (User-led) | Explore the opinions of GPs and SUs regarding the usefulness of conceptualising recovery as a personal process focusing on the future, psychological well-being, personal empowerment, and a sense of meaning in life | Inform GPs on SUs opinions regarding the conceptualisation of recovery as a personal process focusing on the future, psychological well-being, personal empowerment, and a sense of meaning in life |</p>
<table>
<thead>
<tr>
<th>Program of Care (Psychosocial Rehab)</th>
<th>Recovery as a Personal Process</th>
<th>McCabe, Saidi, Priebe (2007)</th>
</tr>
</thead>
<tbody>
<tr>
<td>opinions of GPs and SUs regarding the usefulness of conceptualising recovery as a program of care including strategic medication management, illness management, supported employment, and assertive community treatment</td>
<td>Explore the opinions of GPs and SUs regarding</td>
<td>Review of theoretical constructs</td>
</tr>
<tr>
<td>Inform GPs on SUs opinions regarding the conceptualisation of recovery as a program of care including strategic medication management, illness management, supported employment, and assertive community treatment</td>
<td>A psychologist, a health</td>
<td>- Three phases of recovery</td>
</tr>
<tr>
<td>- Overcoming sickness</td>
<td>- Discovering and fostering self-</td>
<td></td>
</tr>
<tr>
<td>- Strategic medication management</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Illness management</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Supported employment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Assertive community treatment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Services to families</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Services for people with dual diagnoses</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
| **Farkas, Gagne, Anthony, Chamberlin (2005)** | Theoretical paper | Three psychologists and one former service-user/survivor based in the USA | - Program oriented towards the SU  
- Program should have involvement of SU  
- Choice emphasised  
- Growth potential of SU emphasised | Recovery as a Program of Care  
(Psychosocial Rehab) | Explore the opinions of GPs and SUs regarding the usefulness of conceptualising recovery as a program of care oriented towards SUs’ choices | Inform GPs on SUs opinions regarding the conceptualisation of recovery as a program of care oriented towards the choices of the SU | 307 |
APPENDIX 5
INTERVIEW TOPIC GUIDE FOR GPs

1. What does psychosis mean to you?
2. What does recovery from psychosis mean to you?
3. What do you consider to be the typical prognosis and trajectory of someone with a diagnosis of psychosis?
4. What factors do you think are relevant to influencing the prognosis of psychosis?
5. Is the term recovery a useful one for you and your practice? If so, how would you define recovery from psychosis?
6. Can you recall a patient you have encountered where you felt that they recovered particularly well from psychosis?
7. What indicated to you that the patient had recovered?
8. Why do you believe the patient recovered so well? What factors do you feel promoted recovery?
9. How did the patient deal with this episode?
10. Can you recall a patient you have encountered where you felt that they did not recover particularly well?
11. What indicated to you that the patient had not recovered?
12. Why do you believe the patient did not recover so well? What factors do you feel hindered recovery?
13. How did the patient deal with this episode?
INTERVIEW TOPIC GUIDE FOR SUs

1. Can you tell me what the nature of your mental health problems are? Is this the way in which you think other people like your GP see your problems?
2. What are the things that you think have a) helped or b) made your mental health worse in the past? Are there any particular things in the past that in your opinion have helped prevent your mental health getting worse?
3. Does the term psychosis mean anything to you?
4. Does the term recovery from psychosis mean anything to you?
5. Can you recall an episode of psychosis from which you recovered particularly well?
6. What indicated to you that you had recovered?
7. Why do you believe you recovered so well? What factors do you feel promoted recovery?
6. How did your GP deal with this episode? Who else was involved at this time and how were they involved?
7. Can you recall an episode of psychosis from which you did not recover particularly well?
8. What indicated to you that you had not recovered?
9. Why do you believe you did not recover so well? What factors do you feel hindered recovery?
10. How did your GP deal with this episode?
FOCUS GROUP TOPIC GUIDE

First Half

1. Let’s first of all begin by taking a few minutes to think of a time when you’ve either experienced psychosis personally, or have worked with a service user who has had psychosis. In particular, try to recall a time when you recovered particularly well, or where a service user with psychosis you were seeing recovered particularly well. What promoted their recovery? (Social support? Insight? GPs avoiding fatalism?)
   10 minutes

2. Now try to recall a time when you didn’t recover particularly well, or when you were seeing a patient with psychosis who didn’t recover well?
   What hindered their recovery? (Drug abuse? Medication non-compliance?)
   10 minutes

3. What does recovery from psychosis mean to you? (Functional, Symptoms?)
   10 minutes

4. What do GPs provide that promotes recovery at the moment?
   (Signposting services? Advocacy? Supporting families? Continuity? Listening to SU?)
   10 minutes

Second Half

Focus: Envisaging Future Services

1. What could GPs do to promote recovery in an improved, future service?
   Attitudinal change?
   Early Intervention,
More education, training for GPs,
GP-GP forums to exchange experiences,
GP-Psychiatrist direct contact/communication?
GP-SU comms,
SU input/Patient-centred approach,
Shift from 2\textsuperscript{nd} to primary care, SUs trust GPs more
GPs perception of their own lack of expertise,
Awareness of wider societal context – stigma/jobs/family,
Nutrition,
Peer supported services,
Medication side effects,
Therapeutic optimism,
Continuity of care (conflicting GP/SU perceptions)
Other?

\textit{20 minutes}

2. How would this work in practice? How would it be implemented?
Training for GPs
Psychiatrists encouraged to communicate more effectively
Other?

\textit{10 minutes}

3. What are the barriers to implementing this primary care service?
Time constraints,
Financial constraints,
Lack of expertise
Lack of interest
Other?

\textit{10 minutes}
APPENDIX 6

Participant Information Sheet
A study of service users’ and general practitioners’ experiences of recovery from psychosis in primary care medicine.

Interview – GPs

We would like to invite you to take part in an interview as part of this study on experiences of recovery from psychosis in primary care medicine. Before you decide you need to understand why these interviews are being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about taking part in an interview if you wish.

Ask us if there is anything that is not clear or if you would like more information – there are contact details at the end of page 2. Take time to decide whether or not you wish to take part.

You are invited to take part in an informal interview as part of this study which is investigating the meaning of recovery from psychosis in primary care medicine for service-users and general practitioners. The experiences of both groups will be explored. Your interview will help us understand your experiences and thoughts about recovery from psychosis.

What is the purpose of the interview?
We want to find out about:
• your experiences of psychosis in primary care
• what recovery from psychosis means to you
• what collaboration between GPs and service users means to you
• the advantages and disadvantages of such collaboration
• how you think collaboration might be facilitated

Why have I been chosen?
You are being approached to take part in an interview because you have experience seeing and treating people with a diagnosis of psychosis as a GP. Your views on recovery from psychosis, and how it might be enhanced, are therefore highly valued.

Do I have to take part?
It is up to you to decide. We will describe what will be involved in the interview and go through this information sheet with you; we will then give you a copy. We will invite you to sign a consent form to show you have agreed to take part.

What will happen if I choose to take part?
Interviews are a good way of learning in detail about people’s thoughts about a subject. If you agree to take part, you will be asked to attend an interview. Each interview will take approximately 1 hour to conduct. A member of the research team will conduct the interview. The interview will be semi-structured, which means that some of the questions asked will be pre-planned, but the interview will also be like an informal conversation in that the discussion’s direction will depend on what you would like to talk about.

The researcher will ask questions regarding your experience of providing primary care services related to psychosis, as well as your views on what recovery from psychosis means to you. You will also be asked to recall your encounters with an individual patient who you felt recovered particular well, and with a patient who you felt did not recover particularly well. Thinking about specific patients who have and have not recovered, prior to the interview, would be helpful.

These interviews will give you the opportunity to discuss your experiences and help the researchers to understand what worked and didn’t work in a primary care setting. The sessions will be tape-recorded so they can be typed up to make sure that there is an accurate record of the discussion.
What are the possible risks of taking part?
Some people may find it distressing to discuss their past experiences of treating people with a mental health problem. You do not have to answer any questions that you do not feel comfortable answering.

What are the possible benefits of taking part?
You may or may not experience some benefit from taking part in an interview. These sessions may give you the opportunity to impart your knowledge and experience related to providing services for patients with a diagnosis of psychosis. Your thoughts on this matter would contribute to our research, the findings of which may be ultimately applicable to real-world primary care settings.

What if there are any problems?
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 (see below for contact details). If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from the Trust.

If any emotional issues arise during the course of the study, and you would like to see someone about them, you can contact any of the following organisations for help. All these counselling services/support groups have offices in Manchester:

- Self-Help Services: 0161 226 7727
- Rethink Manchester: 0161 245 3268
- MIND Manchester: 0161 272 8204
- 42nd Street (under 25’s): 0161 832 0170
- Age Concern Counselling (over 65’s): 0161 833 3944
- NHS Direct (phone line open 24 hours): 0845 46 47

Will my taking part in the study be kept confidential?
All information which is collected about you during the course of the research will be kept strictly confidential. The interviews will be typed up and then read and re-read by members of the research team. The tapes will then be destroyed. When reporting the findings of the study, we may use direct quotes from you. If so, we will use an ID number so that your identity is protected. Information collected in the study will be stored in locked filing cabinets and on password protected databases.

What will happen if I don’t want to carry on with the study?
You can withdraw from the study at any time. All you have to do is notify the researcher of your decision.

What will happen to the results of the research study?
Results from the study may be published in medical, psychiatric or social science journals, without using any information that could identify staff or patients.

Who is organising and funding the research?
This research is being run and funded by the National Primary Care Research and Development Centre, located in the School of Community Based Medicine, University of Manchester. This research centre receives most of its external funding from the Department of Health.

Who has reviewed the study?
This study has been reviewed and given favourable opinion by North Manchester NHS Research Ethics Committee, on behalf of the Greater Manchester Primary Care Research Governance Partnership.

Further information and contact details
If you have any questions regarding the study, please contact a member of the research study team at the National Primary Care Research & Development Centre, Williamson Building, Oxford Road, University of Manchester.

- Seamus Ryan, PhD student  seamus.ryan@postgrad.manchester.ac.uk  0777 2497613
- Professor Helen Lester  helen.lester@manchester.ac.uk  0161 2757602
- Professor Anne Rogers  anne.rogers@manchester.ac.uk  0161 2757607
Consent Form

A study of service users’ and general practitioners’ experiences of recovery from psychosis in primary care medicine.

Interview – GPs

Centre number:
Staff Identification number for this study:

Please tick each box

1. I confirm that I have read and understood the information sheet for the above study and have had the opportunity to ask questions.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason, without my medical care or legal rights being affected.

3. I understand that my comments may be used in reports on this study and that these will be anonymous. I give permission for this.

4. I understand the interviews will be tape recorded

5. I agree to take part in the above study

Name of Participant ___________________________ Date __________ Signature ___________________________

Name of Person taking consent (if different from researcher) ___________________________ Date __________ Signature ___________________________

Name of Researcher ___________________________ Date __________ Signature ___________________________
Participant Information Sheet

A study of service users’ and general practitioners’ experiences of recovery from psychosis in primary care medicine.

Interview – Service Users

We would like to invite you to take part in an interview as part of this study on experiences of recovery from psychosis in primary care medicine. Before you decide you need to understand why these interviews are being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about taking part in the interview if you wish.

Ask us if there is anything that is not clear or if you would like more information – there are contact details at the end of page 2. Take time to decide whether or not you wish to take part.

You are invited to take part in an informal interview as part of this study which is investigating the meaning of recovery from psychosis in primary care medicine for service users and general practitioners. The experiences of both groups will be explored. The interview will help us understand your experiences and thoughts about recovery from psychosis.

What is the purpose of the interview?
We want to find out about:
• your experiences of psychosis in primary care
• what recovery from psychosis means to you
• what collaboration between GPs and service-users means to you
• the advantages and disadvantages of such collaboration
• how you think collaboration might be facilitated

Why have I been chosen?
You are being approached to take part in the interview because you have experience of accessing psychosis-related services through your GP in the NHS. Your views on recovery from psychosis, and how recovery might be enhanced, are therefore highly valued.

Do I have to take part?
It is up to you to decide. We will describe what will be involved in the interview and go through this information sheet with you; we will then give you a copy. We will invite you to sign a consent form to show you have agreed to take part.

What will happen if I choose to take part?
Interviews are a good way of learning in detail about people’s thoughts about a subject. If you agree to take part, you will be asked to attend an interview. Each interview will take approximately 1 hour to conduct. A member of the research team will conduct the interview. The interview will be semi-structured, which means that some of the questions asked will be pre-planned, but the interview will also be like an informal conversation in that the discussion’s direction will partly depend on what you would like to talk about.

The researcher will ask questions regarding your experience of primary care services related to psychosis, as well as your views on what recovery from psychosis means to you. You will also be asked if you can recall an episode of psychosis from which you felt that you recovered particularly well, and an episode of psychosis from which you felt you did not recover particularly well and GPs who were helpful and not so helpful. These interviews will give you the opportunity to discuss your experiences and help the researchers to understand what was helpful and what was not helpful, in a primary care setting. The sessions will be tape-recorded so they can be typed up to make sure that there is an accurate record of the discussion.
What are the possible risks of taking part?
Some people may find it distressing to discuss their past experiences of mental health problems. You do not have to answer any questions that you do not feel comfortable answering.

What are the possible benefits of taking part?
You may or may not experience some benefit from taking part in this interview. This interview may give you the opportunity to tell us about your experiences of recovery from psychosis in primary care services. Your thoughts on this matter would contribute to our research, the findings of which may be ultimately applicable to real-world primary care settings.

What if there are any problems?
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 (see below for contact details). If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from the Trust.

If any emotional issues arise during the course of the study, and you would like to see someone about them, you can contact any of the following organisations for help. All these counselling services/support groups have offices in Manchester:

Self-Help Services: 0161 226 7727
Rethink Manchester: 0161 245 3268
MIND Manchester: 0161 272 8204
42™ Street (under 25’s): 0161 832 0170
Age Concern Counselling (over 65’s): 0161 833 3944
NHS Direct (phone line open 24 hours): 0845 46 47

Will my taking part in the study be kept confidential?
All information which is collected about you during the course of the research will be kept strictly confidential. The interviews will be typed up and then read and re-read by members of the research team. The tapes will then be destroyed. When reporting the findings of the study, we may use direct quotes from you. If so, we will use a number rather than your name so that your identity is protected. Information collected in the study will be stored in locked filing cabinets and on password protected databases.

What will happen if I don’t want to carry on with the study?
You can withdraw from the study at any time. All you have to do is notify the researcher of your decision.

What will happen to the results of the research study?
Results from the study may be published in medical, psychiatric or social science journals, without using any information that could identify staff or patients.

Who is organising and funding the research?
This research is being run and funded by the National Primary Care Research and Development Centre, located in the School of Community Based Medicine, University of Manchester. This research centre receives most of its external funding from the Department of Health.

Who has reviewed the study?
This study has been reviewed and given favourable opinion by North Manchester NHS Research Ethics Committee, on behalf of the Greater Manchester Primary Care Research Governance Partnership.

Further information and contact details
If you have any questions regarding the study, please contact a member of the research study team at the National Primary Care Research & Development Centre, Williamson Building, Oxford Road, University of Manchester.

- Seamus Ryan, PhD student seamus.ryan@postgrad.manchester.ac.uk 0777 2497613
- Professor Helen Lester helen.lester@manchester.ac.uk 0161 2757602
- Professor Anne Rogers anne.rogers@manchester.ac.uk 0161 2757607
Consent Form

A study of service users’ and general practitioners’ experiences of recovery from psychosis in primary care medicine.

Interview – Service Users

Centre number:
Staff Identification number for this study:

Please tick each box

1. I confirm that I have read and understood the information sheet for the above study and have had the opportunity to ask questions.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason, without my medical care or legal rights being affected.

3. I understand that my comments may be used in reports on this study and that these will be anonymous. I give permission for this.

4. I understand the interview will be tape recorded

5. I agree to take part in the above study

Name of Participant ___________________________ Date ______________ Signature ___________________________

Name of Person taking consent ___________________________ Date ______________ Signature ___________________________
(if different from researcher)

Name of Researcher ___________________________ Date ______________ Signature ___________________________
We would like to invite you to take part in a focus group as part of this study on experiences of recovery from psychosis in primary care. Before you decide you need to understand why these focus groups are being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about taking part in the focus groups if you wish.

Ask us if there is anything that is not clear or if you would like more information – there are contact details at the end of page 2. Take time to decide whether or not you wish to take part.

You are invited to take part in a focus group (group discussion) as part of this study which is investigating the meaning of recovery from psychosis in primary care for service users and general practitioners. The experiences of both groups will be explored. The focus group will help us understand your experiences and thoughts about recovery from psychosis.

**What is the purpose of the focus groups?**
We want to find out about:
- your experiences of psychosis in primary care
- what recovery from psychosis means to you
- what collaboration between GPs and service-users means to you
- the advantages and disadvantages of such collaboration
- how you think collaboration might be facilitated

**Why have I been chosen?**
You are being approached to take part in the focus group because as a GP you will have provided care for people with a psychosis. You have also taken part in a recent interview about this matter. Your views on recovery from psychosis, and how it might be enhanced, are therefore highly valued.

**Do I have to take part?**
It is up to you to decide. We will describe what will be involved in the focus groups and go through this information sheet with you; we will then give you a copy. We will invite you to sign a consent form to show you have agreed to take part.

**What will happen if I choose to take part?**
Focus groups are a good way of learning in detail about people’s thoughts about a subject. If you agree to take part, you will be asked to attend a focus group which will include other GPs, as well as service users who also have experience of accessing primary care services. We will do a check beforehand so that none of the GPs attending your focus group will have come into contact with any of the service-users through the NHS previously. The presence of both service-users and GPs will allow us to talk about how the process of recovery from psychosis is seen from different peoples’ points of view.

Each focus group will take approximately 1 hour. Each group will have approximately six people. Half the people attending the focus group will be fellow GPs, the other half will consist of service users. Two members of the research team, one of whom is a GP and researcher who is experienced in running focus groups, will run the groups. That person will ask questions regarding your experience of providing primary care services related to psychosis, as well as your views on what recovery from psychosis means to you. These groups will give you the opportunity to discuss your experiences and help the researchers to understand what worked and didn’t work in a primary care setting. The sessions will be tape-recorded so they can be typed up to make sure that there is an accurate record of the discussion.
What are the possible risks of taking part?
Some people in the group may find it distressing to discuss their past experiences of living with or treating people with mental health problems. You do not have to answer any questions that you do not feel comfortable answering.

What are the possible benefits of taking part?
You may or may not experience some benefit from taking part in these focus groups. These sessions may give you the opportunity to hear about other service users’ and general practitioners’ thoughts and experiences in a way that you may find helpful.

What if there are any problems?
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 (see below for contact details). If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from the Trust.

If any emotional issues arise during the course of the study, and you would like to see someone about them, you can contact any of the following organisations for help. All these counselling services/support groups have offices in Manchester:

<table>
<thead>
<tr>
<th>Organisation</th>
<th>Contact Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-Help Services</td>
<td>0161 226 7727</td>
</tr>
<tr>
<td>Rethink Manchester</td>
<td>0161 245 3268</td>
</tr>
<tr>
<td>MIND Manchester</td>
<td>0161 272 8204</td>
</tr>
<tr>
<td>42nd Street (under 25’s)</td>
<td>0161 832 0170</td>
</tr>
<tr>
<td>Age Concern Counselling (over 65’s):</td>
<td>0161 833 3944</td>
</tr>
<tr>
<td>NHS Direct (phone line open 24 hours)</td>
<td>0845 46 47</td>
</tr>
</tbody>
</table>

Will my taking part in the study be kept confidential?
All information which is collected about you during the course of the research will be kept strictly confidential. The focus group sessions will be typed up and then read and re-read by members of the research team. The tapes will then be destroyed. When reporting the findings of the study, we may use direct quotes from you. If so, your words will be attached to an ID number so your identity is protected. Information collected in the study will be stored in locked filing cabinets and on password protected databases.

What will happen if I don’t want to carry on with the study?
You can withdraw from the study at any time. All you have to do is notify the researcher of your decision.

What will happen to the results of the research study?
Results from the study may be published in medical, psychiatric or social science journals, without using any information that could identify staff or patients.

Who is organising and funding the research?
This research is being run and funded by the National Primary Care Research and Development Centre, located in the School of Community Based Medicine, University of Manchester. This research centre receives most of its external funding from the Department of Health.

Who has reviewed the study?
This study has been reviewed and given favourable opinion by North Manchester NHS Research Ethics Committee, on behalf of the Greater Manchester Primary Care Research Governance Partnership.

Further information and contact details
If you have any questions regarding the study, please contact a member of the research study team at the National Primary Care Research & Development Centre, Williamson Building, Oxford Road, University of Manchester.

- Seamus Ryan, PhD student seamus.ryan@postgrad.manchester.ac.uk 0777 2497613
- Professor Helen Lester helen.lester@manchester.ac.uk 0161 2757602
- Professor Anne Rogers anne.rogers@manchester.ac.uk 0161 2757607
Consent Form

A study of service users’ and general practitioners’ experiences of recovery from psychosis in primary care medicine.

Focus Groups – GPs

Centre number:
Staff Identification number for this study:

Please tick each box

1. I confirm that I have read and understood the information sheet for the above study and have had the opportunity to ask questions.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason, without my medical care or legal rights being affected.

3. I understand that my comments may be used in reports on this study and that these will be anonymous. I give permission for this.

4. I understand the focus groups will be tape recorded

5. I agree to take part in the above study

________________________________________  ________  __________________________
Name of Participant                        Date                        Signature

________________________________________  ________  __________________________
Name of Person taking consent             Date                        Signature
(if different from researcher)

________________________________________  ________  __________________________
Name of Researcher                        Date                        Signature
Participant Information Sheet

A study of service-users’ and general practitioners’ experiences of recovery from psychosis in primary care medicine.
Focus Groups – Service Users

We would like to invite you to take part in a focus group as part of this study on experiences of recovery from psychosis in primary care. Before you decide you need to understand why these focus groups are being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about taking part in the focus groups if you wish.

Ask us if there is anything that is not clear or if you would like more information – there are contact details at the end of page 2. Take time to decide whether or not you wish to take part.

You are invited to take part in a focus group (group discussion) as part of this study which is investigating the meaning of recovery from psychosis in primary care for service-users and general practitioners. The experiences of both groups will be explored. The focus group will help us understand your experiences and thoughts about recovery from psychosis.

What is the purpose of the focus groups?
We want to find out about:

- your experiences of psychosis in primary care
- what recovery from psychosis means to you
- what collaboration between GPs and service-users means to you
- the advantages and disadvantages of such collaboration
- how you think collaboration might be facilitated

Why have I been chosen?
You are being approached to take part in the focus group because you will have experience of going to your GP. You have also taken part in a recent interview about this matter. Your views on recovery from psychosis, and how it might be enhanced, are therefore highly valued.

Do I have to take part?
It is up to you to decide. We will describe what will be involved in the focus groups and go through this information sheet with you; we will then give you a copy. We will invite you to sign a consent form to show you have agreed to take part.

What will happen if I choose to take part?
Focus groups are a good way of learning in detail about people’s thoughts about a subject. If you agree to take part, you will be asked to attend a focus group which will include other service users who also have experience of accessing primary care services, as well as GPs. We will do a check beforehand so that none of the GPs attending your focus group will have come into contact with any of the service-users through the NHS previously. The presence of both service-users and GPs will allow us to talk about how the process of recovery from psychosis is seen from different peoples’ points of view.

Each focus group will take approximately 1 hour. Each group will have approximately six people. Half the people attending the focus group will be fellow service users, the other half will consist of GPs. Two members of the research team, one of whom is a GP and researcher who is experienced in running focus groups, will run the groups. That person will ask questions regarding your experience of primary care services related to psychosis, as well as your views on what recovery from psychosis means to you. These groups will give you the opportunity to discuss your experiences and help the researchers to understand what worked and didn’t work in a primary care setting. The sessions will be tape-recorded so they can be typed up to make sure that there is an accurate record of the discussion. You will receive £15 for the time you have given.
What are the possible risks of taking part?
Some people in the group may find it distressing to discuss their past experiences of living with or treating people with mental health problems. You do not have to answer any questions that you do not feel comfortable answering.

What are the possible benefits of taking part?
You may or may not experience some benefit from taking part in these focus groups. These sessions may give you the opportunity to hear about other service users' and general practitioners' thoughts and experiences in a way that you may find helpful.

What if there are any problems?
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 (see below for contact details). If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from the Trust.

If any emotional issues arise during the course of the study, and you would like to see someone about them, you can contact any of the following organisations for help. All these counselling services/support groups have offices in Manchester:

Self-Help Services: 0161 226 7727
Rethink Manchester: 0161 245 3268
MIND Manchester: 0161 272 8204
42nd Street (under 25's): 0161 832 0170
Age Concern Counselling (over 65's): 0161 833 3944
NHS Direct (phone line open 24 hours): 0845 46 47

Will my taking part in the study be kept confidential?
All information which is collected about you during the course of the research will be kept strictly confidential. The focus group sessions will be typed up and then read and re-read by members of the research team. The tapes will then be destroyed. When reporting the findings of the study, we may use direct quotes from you. If so, your words will be attached to an ID number so your identity is protected. Information collected in the study will be stored in locked filing cabinets and on password protected databases.

What will happen if I don't want to carry on with the study?
You can withdraw from the study at any time. All you have to do is notify the researcher of your decision.

What will happen to the results of the research study?
Results from the study may be published in medical, psychiatric or social science journals, without using any information that could identify staff or patients.

Who is organising and funding the research?
This research is being run and funded by the National Primary Care Research and Development Centre, located in the School of Community Based Medicine, University of Manchester. This research centre receives most of its external funding from the Department of Health.

Who has reviewed the study?
This study has been reviewed and given favourable opinion by North Manchester NHS Research Ethics Committee, on behalf of the Greater Manchester Primary Care Research Governance Partnership.

Further information and contact details
If you have any questions regarding the study, please contact a member of the research study team at the National Primary Care Research & Development Centre, Williamson Building, Oxford Road, University of Manchester.

- Seamus Ryan, PhD student  seamus.ryan@postgrad.manchester.ac.uk 0777 2497613
- Professor Helen Lester  helen.lester@manchester.ac.uk 0161 2757602
- Professor Anne Rogers  anne.rogers@manchester.ac.uk 0161 2757607
Consent Form

A study of service-users’ and general practitioners’ experiences of recovery from psychosis in primary care medicine.

Focus Groups – Service Users

Centre number:
Staff Identification number for this study:

Please tick each box

1. I confirm that I have read and understood the information sheet for the above study and have had the opportunity to ask questions.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason, without my medical care or legal rights being affected.

3. I understand that my comments may be used in reports on this study and that these will be anonymous. I give permission for this.

4. I understand the focus groups will be tape recorded

5. I agree to take part in the above study

Name of Participant __________________________ Date __________ Signature ______________

Name of Person taking consent (if different from researcher) __________________________ Date __________ Signature ______________

Name of Researcher __________________________ Date __________ Signature ______________
APPENDIX 7
CODING OF GP INTERVIEWS

1. Psychosis conceptualisations
   1.1 Detachment from reality
   1.2 Denial
   1.3 Lack of insight
   1.4 Fantasy world
   1.5 Unrealistic goals
   1.6 Can’t connect
   1.7 Financial problems
      1.7.1 Debt
      1.7.2 Not claiming benefits
   1.8 Bipolar/Psychosis – categories questioned
   1.9 Physical symptoms
      1.9.1 Physical Symptoms at episode onset
      1.9.2 Sleeping stops, overactive, hypomanic
   1.10 Distressing to witness impaired Ps
   1.11 Negative symptoms
      1.11.1 Apathy
      1.12 Awful condition
         1.12.1 Hopeless
      1.12.2 Cycles of repeated investigations
      1.12.3 Long term psychosis
      1.12.4 Ps deprived of so much
   1.13 Positive conceptualisations
      1.13.1 Bipolar disorder cases – complete recovery/positive outcome
   1.14 Positive symptoms
      1.14.1 Hallucinations
      1.14.2 Paranoia
1.14.3 Delusions
1.14.4 Bizzare thoughts/behaviours

2. **Recovery/Prognosis**
   2.1 Functional recovery
      2.1.1 Relationships
         2.1.1.1 Positive outcomes
         2.1.1.2 Negative outcomes
      2.1.2 Employment
         2.1.2.1 Positive outcomes
         2.1.2.2 Negative outcomes
      2.1.3 Accommodation
         2.1.3.1 Positive outcomes
         2.1.3.2 Negative outcomes
   2.2 Symptomatic recovery
      2.2.1 Positive symptomatic outcomes
      2.2.2 Negative symptomatic outcomes
   2.3 Varied prognostic spectrum
   2.4 Factors affecting recovery
      2.4.1 Resilience

3. **Role of GPs**
   3.1 Physical Health
      3.1.1 Looking after physical health of Ps, as well as mental
      3.1.2 Physical Symptoms at psychosis episode onset
      3.1.3 Annual Check-up
         3.1.3.1 Leads to awareness of diabetes
      3.1.4 Lifestyle
         3.1.4.1 Look proactively at P’s lifestyle.
         3.1.4.2 Lifespan
3.2 Mental Health

3.2.1 Generalists

3.2.2 Stress for GPs - when left holding a stressful situation.

3.2.10 Onset of psychosis not that common in general practice

3.2.11 Watching natural history of Ps

3.2.12 Conflict: GP-Patient

3.3 Treatment

3.3.1 Treatment routes

3.3.1.1 GPs carry out treatment.

3.3.1.2 Treatment initiated and carried out by others

3.3.1.3 GPs initiate treatment if P unwilling to go to hospital/psychiatrist

3.3.1.4 GPs look after non-engaged Ps

3.3.1.5 GPs carry on monitoring if Ps well enough, and don’t want to see services

3.3.1.6 Potential to intervene early and change its course (Early Intervention)

3.3.1.7 Experience – Lack of experience of referral to EI services

3.3.1.7 Liaison advice received by GP in relation to Ps who won’t go to services

3.3.1.8 Shared care – GP & Psychiatrist. Meet together. Manage problems.

3.3.2 Medication

3.3.2.1 Meds positive

3.3.2.2 Meds negative

3.3.2.3 Risks associated with medication

3.3.2.4 Monitor levels of medication

3.3.2.5 Meds for sleep/stress/pre-empting episodes

3.3.2.6 Meds refused

3.3.2.7 GP not advocating meds as only way

3.4 Value of Primary Care
3.4.1 Continuity of care
3.4.1.1 Knowing P in a longitudinal sense
3.4.2 Knowing whole person
3.4.4 Limited contact with psychiatric services, even when going
3.4.5 GPs talk of prevention/”early intervention” vs Psychiatrists talk of “late intervention”/not being ill enough
3.4.6 Universality of having and seeing a GP (regardless of condition or involvement of other professionals)

3.4 Social Issues

4. Role of other professionals

4.1 Relationship with Psychiatrists
4.1.1 Engagement of Psychiatrists with GPs
4.1.1.1 Positive relationship
4.1.1.2 Remote psychiatrists, difficult for GPs
4.1.2 Engagement of GP with Psychiatrist
4.1.3 Sense of working together. Collaboration

4.2 Resources/Support
4.2.1 Limited resources (people) available in psychiatric services that can help
4.2.1 Inconsistent support to GP surgeries
4.2.1.1 Support and Liaison – better for GPs, carers, patients
4.4.1 P has limited contact with psychiatric services, even when going

4.3 Access to secondary care
4.3.1 Families find this lack of access to secondary care difficult.
4.3.2 Access to mental health team/psychiatrist/care-coordinator is down to pot luck
4.3.3 Timing of access
4.3.3.1 GPs talk of prevention/"early intervention”
4.3.3.2 Contrast: Psychiatrists talk of “late intervention”/not being ill enough
   (Conflict between Perceived Need vs. Lack of Diagnosis/Risk)

5. **Role of Family**
   5.1 Families give help to GPs
      5.1.1 Mother recognised onset
      5.1.2 Family provides information about Ps
   5.2 Family receive help from GPs
   5.3 Families give help to Ps
      5.3.1 GPs work with families and carers, supporting carers to support Ps
      5.3.2 Parental support needed for survival
   5.4 Families receive help from P
      5.4.1 P looked after 2 parents through terminal illness

6. **Changes desired by GPs**
   6.1 Better Liaison
   6.2 Rapid Access to advice
   6.3 Access to stepping Ps back into services quickly
      6.4.1 Relationship with psychiatrist – more engagement, less remote
      6.4.2 Desire for closer working relationships
   6.5 GPs need to be aware of Early Intervention
APPENDIX 8
CODING OF SU INTERVIEWS

1. Changes in Primary Care desired by SUs
   1.1 GP talk to patient more and clarify, not just give meds
   1.2 Give alternative routes, info, guidance
   1.2.1 Info leaflets in surgery about mental health
   1.3 Respect the person: better bedside manner
   1.4 Listen and ask the right questions
   1.5 Shared Care: GPs need to work with psychiatrists, and include patients in decisions
   1.5.1 Currently ferried between GP and psychiatrist
   1.6 More mental health training for GPs

2. Conceptualisations of Psychosis
   2.1 Severe mental health problems
   2.1.1 Doctors: "Chronic mental illness"
   2.2 Caused by social isolation
   2.3 Symptoms that affect your everyday life
   2.3.1 Auditory hallucinations
   2.3.2 Social isolation, Not leaving house, Agoraphobia
   2.3.3 Regression
   2.3.4 Not eating properly
   2.3.5 Depression
   2.3.6 Visual hallucinations
   2.3.7 Reality: Not knowing what's real
   2.3.8 Transfixed on certain thing, controls their life
   2.4 Calls herself "a voice hearer"
   2.5 Live life as Rachel, not a mental health patient
   2.6 Disability, not illness
   2.7 Conflicting diagnoses by docs: anxiety, psychosis, borderline personality
3. **Role of GP**

3.1 **MEDICATION**: Prescribe, repeats

3.1.1 Side effects

3.1.1.1 Weight gain

3.1.1.2 Jaw Locked

3.1.1.3 Spasms - unable to walk properly

3.1.1.4 Drowsy at work, stopped meds, relapse, lost job

3.1.1.5 Sedated by tranquilisers in morning, hard to get out of bed

3.1.1.6 Zombified

3.1.1.7 Conflict between wanting to be off meds cos of side effects but not wanting voices back

3.1.2 Meds don’t work

3.1.2.1 Tried numerous types of meds

3.1.2.2 Likes Clotiapine cos of lack of side effects, not cos it helps with symptoms

3.1.2.3 Olanzapine is calming cos makes you sleepy - sleep better

3.1.2.4 Tranquilisers didn't work, but GP kept prescribing different ones

3.1.2.5 Higher dose for episode - not real resolution

3.1.3 SU didn’t argue with former GP about meds even though "they didn’t help"

3.1.4 GP didn’t tell SU about med side effects

3.1.5 GP emphasis/insistence on meds

3.1.5.1 Don’t understand whole person

3.1.6 GP changed meds when SU asked

3.1.7 SU non compliance

3.1.7.1 Finds minimum med level herself, doesn't tell GP

3.2 **PHYSICAL HEALTH**

3.2.1 Diabetes

3.2.1.1 Check up every 3 months

3.2.2 Foot pain, Broken Leg

3.2.3 Physical and Mental Interact
3.2.3.1 Amyltriptamine for Diabetes led to depression and paranoia as side-effects
3.2.4  Prescribes meds for physical problems

3.3  MENTAL HEALTH
3.3.1  Lack of mental health training
3.3.1.1 GP couldn't help SU personally
3.3.1.2 GPs deal with depression, Psychiatrists – psychosis

NOTE: Negative Coding – lack of GP psychosocial roles mentioned by SU’s.

4.  Role of other professionals and voluntary services
4.1  Day Centre/Drop-In
4.1.1 Voluntary Work
4.1.2 Social outlet
4.1.3 No place to go on Sundays - depressed
4.1.4 Provides information

4.2  Psychiatrist
4.2.1 Diagnosed him with Paranoid Schizophrenia
4.2.2 Lack of access
4.2.2.1 Only 6 month reviews
4.2.2.2 Annual check up
4.2.2.3 Go to GP instead
4.2.2.4 Wait 3 months to see psychiatrist - too long
4.2.3 Prescribes Medication
4.2.3.1 Focus on medication, not therapy or why you're ill
4.2.4 Deals with psychosis (not GP)
4.2.5 Invalidates voices - in your head, not your neighbours
4.2.6 GP-Psychiatrist communication
4.2.6.1 GP doesn’t contact Psychiatrist

331
4.2.6.2 Psychiatrist sometimes sends letters to GP

4.2.7 Lack of continuity

4.2.8 Have control over decisions, not GPs
  4.2.8.1 Too much power
  4.2.8.2 Shared role is preferable - GP and psychiatrist

4.3 CPN
  4.3.1 If unwell, CPN arranges meeting with psychiatrist
  4.3.2 Sees CPN once every 2 weeks at home, not allowed more access
  4.3.3 Access to CPN not as good as access to key worker
  4.3.4 Asked CPN to get meds reduced, CPN had "power" to get it reduced by psychiatrist, unlike GP
  4.3.5 Social worker type role
  4.3.6 Check blood, kidneys, liver, medication levels

4.4 Key Worker/Support Worker
  4.4.1 Access is easy: Could see Key Worker any time
  4.4.2 Look into why you're ill, unlike psychiatrist
  4.4.3 Doesn't understand what hearing voices is about

4.6 Therapist
  4.6.1 Look into why you're ill, unlike psychiatrist
  4.6.2 Waiting list 6-12 months

5. **Conceptualisations of Recovery**
  5.1 Social Functioning
    5.1.1 Have friends, Socialising
    5.1.2 Have partner
    5.1.3 Job/Training Course
    5.1.3.1 Feels like I'm doing something useful
5.1.3.2 Job is something to talk about
5.1.3.3 Asked on to training course to work in mental health
5.1.4 Children/family
5.1.5 Have a house
5.1.6 Up in morning
5.1.7 Walk down street
5.1.8 Make breakfast
5.1.9 Taste food

5.2 Off medication
5.3 Self-direction, "in control"

5.4 Symptomatic Recovery
5.4.1 Less paranoia
5.4.2 Less voices
5.4.3 Not depressed
5.4.4 Ability to tell what's real or not
5.4.5 Laughing/Posture ("spring in my step")

5.5 Housing
5.5.1 Council
5.5.2 Private
5.5.3 Supervised Lodgings/Supported housing
5.5.4 Lives Alone
5.5.5 Lives with another mental health SU

5.6 Pessimistic Outlook for recovery
5.6.1 Has psychosis for years - no longer believes in recovery
5.6.2 Partial symptom reduction - "There might be a time when I hear less voices"
5.6.3 Pessimism not a bad thing - Too much emphasis on recovery as cure - Idealistic

5.6.3.1 Cope, Adapt life to it, Deal with symptoms, Not fear it
5.6.3.1.1 Like diabetes - Chronic, Adapt to it

5.7. Insight
5.7.1 "Cars can't swear at you"

5.8 Work
5.8.1 No paid work for 10/14 years

5.9 Recovery in Primary Care

6. Role of Family
6.1 Family helpful
6.1.1 Dad understands problem
6.1.2 Family recommended socialising more to stop voices
6.2 Family unhelpful
6.2.1 Mum says SUs are lazy and should get jobs

7. Role of Friends, Peers
7.1 All friends are mental health peers and staff
7.2 Many supportive friends
7.2.1 Peers helped each other find supported accommodation
7.3 Lost some friends who backed off due to mental health

8. Obstacles/Hindrances
8.1 General Obstacles
8.1.1 Racism
8.1.2 Harassment from neighbours
8.1.3 Problems at work
8.1.3.1 Offensive comments
8.1.3.2 Lost job
8.1.4 Bad living conditions
8.1.4.1 Living alone, spending most of time alone - depression
8.1.4.2 Loud neighbours, shouting, loud music - paranoia
8.1.5 Fear of violent attacks
8.1.6 Hearing voices
8.1.6.1 Prevents her from going outside
8.1.6.2 Causes relationship problems
8.1.7 Side-effects of Meds, especially tranquilisers
8.1.8 Services shut at weekends: GP, psychiatrists, support workers, day centres
8.1.9 Hospital is dangerous environment/bad atmosphere
8.1.9.1 Violent unstable patients
8.1.9.2 Liquid Cosh
8.1.9.3 ECT: brain damage, memory loss
8.1.10 Difficult to explain psychosis to others
8.1.11 Stigma
8.1.11.1 Newspapers usage: "psychotic serial killer"
8.1.12 Illegal drugs

8.2 Obstacles in Primary Care

9. What helps SUs/ Factors Promoting Recovery/ Recovery Program
9.1 Safe places (drop-ins) to go during the day cos SUs generally don't work
9.1.1 Group Therapy, Self-help groups
9.1.1.1 Social
9.1.1.2 Felt better
9.1.1.3 Got job afterwards
9.1.1.4 Voices went away
9.11.5 Realise there are other people like you
9.1.2 Workshops
9.1.2.1 Express yourself through art
9.1.2.2 Writing helps - not paid, but is like work
9.2 Good diet
9.3 Safe place to live
9.3.1 Housing needs repairs
9.3.2 Housing is in bad area
9.4 People who understand
9.4.1 Allow you to talk, listen to you
9.4.2 Don't say you can't talk about something
9.4.3 Give guidance
9.5 Accepting that you have psychosis
9.5.1 Coping strategies: "Learn your own symptoms so that you can deal with them"
9.6 Had insight into regression
9.7 Avoids TV, radio, books, conversation
9.8 Smokes loads, eventually pulls out
9.9 As health progresses, and you get used to meds and services - start to realise people there to help
9.10 Need to be constructive, productive
9.11 Goes to library daily
9.12 Self-management
9.12.1 Does her own medical research to argue with GP, and avoid "same mess as before"
9.12.2 Avoids GP, "tried to help myself"
9.13 Counselling - helped with coping
9.14 Hospital admission
9.14.1 Good food
9.14.2 Sociable - talk with other patients, not lonely
9.15 Sleeping helps
10. **Structure of Primary Care**

10.1 Frequency of seeing GP for mental health

10.1.1 Don't present to GP with mental health problems

10.1.2 Don't tell anyone in case they tell professionals (Fear of doctors)

10.1.3 Once per month for med prescription

10.2 GP lack of continuity

10.2.1 Moved location - different GP

10.2.1.1 Bad - explain everything again

10.2.1.2 No care or meds for 2 weeks after moving

10.2.2 Different GP each time - large practice, lack of continuity

10.2.2.1 Locums: never see again, know nothing about you

10.2.3 Put in hospital - different GP

10.2.4 Never asked for new GP

10.2.5 To see same GP - must wait 3/4 weeks - may become worse and end in hospital

10.3 GP arranges/co-ordinates services

10.3.1 Arranges meetings with psychiatrist

10.3.2 Arranges for a CPN when SU asked for one

10.3.3 Put on waiting list for Psychotherapist

10.4 GPs don't deal with/make decisions regarding mental health

10.4.1 GPs refer psychosis patients to psychiatrists/hospital

10.4.2 Psychiatrists have control

10.4.3 GPs cant prescribe by law, just psychiatrists

10.5 GP accessible

10.5.1 Go to GP not psychiatrist if ill, cos more accessible

10.6 GP lack of power
10.6.1 Have to do what bosses tell them

10.7 GPs overworked

11. Consultation interaction with GP

11.1 General Evaluation of GP

11.1.1 Positive

11.1.1.1 Understanding

11.1.1.2 Helpful

11.1.1.3 Sympathetic

11.1.1.4 One GP talked to patient, asked about voices: "What are voices saying?" "How many voices?"

11.1.1.5 Responsive: change meds

11.1.2 Negative

11.1.2.1 Unhelpful

11.1.2.2 Didn't listen

11.1.2.3 Told her she was hypochondriac

11.1.2.4 Fobbed off

11.2 GP gives advice

11.2.1 SU told to ignore people angering him

11.3 GP - less threatening

11.3.1 Less threatening than psychiatrist

11.3.1.1 Stigma of hospital

11.3.1.2 Psychiatrists have power to section, not GPs
## APPENDIX 9

**DEMOGRAPHIC DETAILS OF GP PARTICIPANTS**

<table>
<thead>
<tr>
<th></th>
<th>Gender</th>
<th>Ethnicity</th>
<th>Years worked as a GP</th>
<th>Special Interest in Mental Health</th>
</tr>
</thead>
<tbody>
<tr>
<td>GPwSI 1</td>
<td>F</td>
<td>Asian</td>
<td>24</td>
<td>Y</td>
</tr>
<tr>
<td>GPwSI 2</td>
<td>F</td>
<td>White British</td>
<td>14</td>
<td>Y</td>
</tr>
<tr>
<td>GPwSI 3</td>
<td>M</td>
<td>White British</td>
<td>32</td>
<td>Y</td>
</tr>
<tr>
<td>GPwSI 4</td>
<td>F</td>
<td>White British</td>
<td>5</td>
<td>Y</td>
</tr>
<tr>
<td>GPwSI 5</td>
<td>F</td>
<td>White British</td>
<td>20</td>
<td>Y</td>
</tr>
<tr>
<td>GPwSI 6</td>
<td>F</td>
<td>White British</td>
<td>18</td>
<td>Y</td>
</tr>
<tr>
<td>GPwSI 7</td>
<td>F</td>
<td>White British</td>
<td>24</td>
<td>Y</td>
</tr>
<tr>
<td>GPwSI 8</td>
<td>M</td>
<td>White British</td>
<td>12</td>
<td>Y</td>
</tr>
<tr>
<td>GPwSI 9</td>
<td>M</td>
<td>White British</td>
<td>7</td>
<td>Y</td>
</tr>
<tr>
<td>GPwSI 10</td>
<td>M</td>
<td>White British</td>
<td>19</td>
<td>Y</td>
</tr>
<tr>
<td>GPwSI 11</td>
<td>F</td>
<td>White British</td>
<td>25</td>
<td>Y</td>
</tr>
<tr>
<td>GPwSI 12</td>
<td>F</td>
<td>White British</td>
<td>17</td>
<td>Y</td>
</tr>
<tr>
<td>GPwSI 13</td>
<td>M</td>
<td>White British</td>
<td>23</td>
<td>Y</td>
</tr>
<tr>
<td>GPwSI 14</td>
<td>M</td>
<td>Asian</td>
<td>28</td>
<td>Y</td>
</tr>
<tr>
<td>GPwSI 15</td>
<td>M</td>
<td>White British</td>
<td>23</td>
<td>Y</td>
</tr>
<tr>
<td>GPwSI 16</td>
<td>F</td>
<td>White British</td>
<td>13</td>
<td>Y</td>
</tr>
<tr>
<td>GPwSI 17</td>
<td>M</td>
<td>White British</td>
<td>17</td>
<td>Y</td>
</tr>
<tr>
<td>GPS 1</td>
<td>M</td>
<td>Asian</td>
<td>N/A</td>
<td>N</td>
</tr>
<tr>
<td>GPS 2</td>
<td>F</td>
<td>White British</td>
<td>25</td>
<td>N</td>
</tr>
<tr>
<td>GPS 3</td>
<td>M</td>
<td>White British</td>
<td>18</td>
<td>N</td>
</tr>
<tr>
<td>GPS 4</td>
<td>M</td>
<td>White British</td>
<td>4</td>
<td>N</td>
</tr>
<tr>
<td>GPS 5</td>
<td>F</td>
<td>White British</td>
<td>13</td>
<td>N</td>
</tr>
<tr>
<td>GPS 6</td>
<td>M</td>
<td>White British</td>
<td>23</td>
<td>N</td>
</tr>
<tr>
<td>GPS 7</td>
<td>M</td>
<td>White British</td>
<td>24</td>
<td>N</td>
</tr>
</tbody>
</table>
### APPENDIX 10

**DEMOGRAPHIC DETAILS OF SU PARTICIPANTS**

<table>
<thead>
<tr>
<th></th>
<th>Gender</th>
<th>Ethnicity</th>
<th>Age (Birth Year)</th>
<th>Self diagnosis</th>
<th>Diagnosis given by health professionals</th>
<th>Age at first episode of psychosis</th>
<th>Housing Status</th>
<th>Accessing secondary care?</th>
</tr>
</thead>
<tbody>
<tr>
<td>SU 1</td>
<td>M</td>
<td>Asian</td>
<td>48 yrs (1962)</td>
<td>Schizophrenia</td>
<td>Paranoid Schizophrenia</td>
<td>20</td>
<td>Independent</td>
<td>Yes</td>
</tr>
<tr>
<td>SU 2</td>
<td>M</td>
<td>White British</td>
<td>30 yrs (1980)</td>
<td>Voice Hearer</td>
<td>Schizophrenia</td>
<td>26</td>
<td>Independent</td>
<td>Yes</td>
</tr>
<tr>
<td>SU 4</td>
<td>F</td>
<td>White British</td>
<td>24 yrs (1986)</td>
<td>Psychosis, Clinical Depression</td>
<td>Psychosis, Clinical Depression</td>
<td>16</td>
<td>Independent</td>
<td>Yes</td>
</tr>
<tr>
<td>SU 5</td>
<td>M</td>
<td>White British</td>
<td>38 yrs (1972)</td>
<td>Mild Schizophrenia</td>
<td>Personality Disorder</td>
<td>Teens</td>
<td>Independent</td>
<td>No</td>
</tr>
<tr>
<td>SU 6</td>
<td>M</td>
<td>Black</td>
<td>38 yrs (1972)</td>
<td>Depression</td>
<td>Schizophrenia</td>
<td>28</td>
<td>Supervised</td>
<td>No</td>
</tr>
<tr>
<td>SU 7</td>
<td>M</td>
<td>White British</td>
<td>41 yrs (1969)</td>
<td>Bipolar Disorder</td>
<td>Borderline Personality Disorder</td>
<td>31</td>
<td>Supervised</td>
<td>Yes</td>
</tr>
<tr>
<td>SU 8</td>
<td>F</td>
<td>White British</td>
<td>42 yrs (1968)</td>
<td>Paranoid</td>
<td>Paranoid Schizophrenia</td>
<td>4</td>
<td>Independent</td>
<td>Yes</td>
</tr>
<tr>
<td>SU 9</td>
<td>M</td>
<td>White British</td>
<td>74 yrs (1936)</td>
<td>N/A</td>
<td>N/A (Psychosis diagnosis an accommodation requirement)</td>
<td>N/A</td>
<td>Supervised</td>
<td>Yes</td>
</tr>
<tr>
<td>SU 10</td>
<td>F</td>
<td>Black</td>
<td>37 yrs (1973)</td>
<td>Hearing Voices</td>
<td>Schizophrenia</td>
<td>25</td>
<td>Independent</td>
<td>No</td>
</tr>
<tr>
<td>SU 11</td>
<td>M</td>
<td>Asian</td>
<td>26 yrs (1984)</td>
<td>N/A</td>
<td>N/A (Psychosis diagnosis an accommodation requirement)</td>
<td>N/A</td>
<td>Supervised</td>
<td>N/A</td>
</tr>
<tr>
<td>SU</td>
<td>Gender</td>
<td>Race</td>
<td>Age (Year)</td>
<td>Diagnosis</td>
<td>Treatment</td>
<td>Supervised?</td>
<td>Notes</td>
<td></td>
</tr>
<tr>
<td>----</td>
<td>--------</td>
<td>------</td>
<td>------------</td>
<td>-----------</td>
<td>-----------</td>
<td>-------------</td>
<td>-------</td>
<td></td>
</tr>
<tr>
<td>SU 12</td>
<td>M</td>
<td>White British</td>
<td>61 yrs (1949)</td>
<td>Driven Schizophrenia, Manic Depression, Alcoholism</td>
<td>28</td>
<td>Supervised</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>SU 13</td>
<td>F</td>
<td>Asian</td>
<td>40 yrs (1970)</td>
<td>Many considered, Unknown Schizoaffective, Eating Disorder</td>
<td>19</td>
<td>Independent</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>SU 14</td>
<td>F</td>
<td>Black</td>
<td>46 yrs (1964)</td>
<td>Schizophrenia, Clinical Depression Schizophrenia, Clinical Depression</td>
<td>13</td>
<td>Supervised</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>SU 15</td>
<td>F</td>
<td>Black</td>
<td>39 yrs (1971)</td>
<td>Voice Hearing Schizoaffective disorder, PTSD, Anxiety, Depression</td>
<td>24</td>
<td>Independent</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>SU 16</td>
<td>M</td>
<td>White British</td>
<td>N/A</td>
<td>Schizophrenia Schizophrenia</td>
<td>N/A</td>
<td>Independent</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>SU 17</td>
<td>M</td>
<td>White British</td>
<td>40 yrs (1970)</td>
<td>Regression, Depression, Agoraphobia Depression with significant psychotic symptoms</td>
<td>28</td>
<td>Supervised</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>SU 18</td>
<td>M</td>
<td>White British</td>
<td>35 yrs (1975)</td>
<td>Social anxiety with “stressed times around people” Psychosis, Schizophrenia</td>
<td>21</td>
<td>Independent</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>SU 19</td>
<td>M</td>
<td>White British</td>
<td>55 yrs (1955)</td>
<td>Following Buddhism, with associated periods of hypomania Schizoaffective Psychosis</td>
<td>21</td>
<td>Supervised</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>SU 20</td>
<td>M</td>
<td>White British</td>
<td>N/A</td>
<td>Hearing noises that others don’t, Stress</td>
<td>N/A</td>
<td>Independent</td>
<td>No</td>
<td></td>
</tr>
<tr>
<td>21 (excluded)</td>
<td>F</td>
<td>White British</td>
<td>26 yrs (1984)</td>
<td>Mental health problems, Communicating problems, Hearing Moderate Learning Difficulties</td>
<td>N/A</td>
<td>Independent</td>
<td>No</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Sex</td>
<td>Race</td>
<td>Age at Interview</td>
<td>Diagnosis</td>
<td>Age of Onset</td>
<td>Employment Status</td>
<td>Employment Status Comment</td>
<td></td>
</tr>
<tr>
<td>----</td>
<td>-----</td>
<td>------</td>
<td>------------------</td>
<td>-------------------------------</td>
<td>--------------</td>
<td>-------------------</td>
<td>--------------------------</td>
<td></td>
</tr>
<tr>
<td>22 (excluded)</td>
<td>M</td>
<td>White British</td>
<td>36 yrs (1974)</td>
<td>Social anxiety with intrusive thoughts</td>
<td>N/A</td>
<td>21</td>
<td>Independent</td>
<td>No</td>
</tr>
<tr>
<td>23 (excluded)</td>
<td>F</td>
<td>White British</td>
<td>N/A</td>
<td>Unstable</td>
<td>Depression, Anxiety, Social Phobia, OCD</td>
<td>20’s</td>
<td>Independent</td>
<td>Pending</td>
</tr>
</tbody>
</table>